Supportive Oncology Toolkit

equal hope
# Intended Use
This toolkit contains the work product of the Coleman Supportive Oncology Collaborative and represents input from over 200 professionals. A list of participants who contributed can be viewed at [www.supportiveoncologycollaborative.org](http://www.supportiveoncologycollaborative.org). This toolkit is to be used as a guide to oncology teams to assist in delivering supportive oncology services to improve cancer care. Any clinician seeking to apply or consult this content is expected to use independent medical judgement in the context of individual clinical circumstances to determine any patient’s care or treatment. The Coleman Supportive Oncology Collaborate and the Coleman Foundation make no warranties regarding content, use or application, and disclaims any responsibility for its application or use in any way.
The Coleman Supportive Oncology Collaborative (CSOC)

For decades, the Coleman Foundation has funded cancer programs directed at improving quality of life for cancer patients and survivors in the Chicagoland area. Motivated by the Institute of Medicine (IOM) 2013 Report - Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis, the Coleman Foundation conducted an exploration of supportive oncology with local healthcare providers. Supportive Oncology focuses on improving the quality of life for patients and their families affected by cancer from diagnosis to survivorship and end-of-life. The goal of supportive oncology is to reduce the physical and emotional burdens of illness through pain and symptom management, psychosocial support and integration of complementary therapies.

With assistance by the Center for Business Models in Healthcare, the exploration sought input from leadership and supportive oncology professionals from over 35 organizations: 13 cancer treatment sites, 14 cancer support centers, and 8 hospice organizations. The exploration generated dozens of project ideas. While most Chicago cancer centers had implemented or started implementation of some aspects of supportive oncology, no cancer centers in Chicago have achieved the level of quality and service delivery demanded by the IOM 2013 Report or cancer accreditation bodies. Cancer centers are wrestling with how to implement effective changes in supportive oncology that address recommendations and requirements, while adapting to local/regional requirements, resources and patient needs.

The Coleman Foundation Goals for Supportive Oncology

Cancer patients are:

• regularly screened for psychosocial/distress support and palliative care needs; and
• receive all services as identified by psychosocial/distress and palliative care screenings (from diagnosis through survivorship and end-of-life) from a collaboration of multiple, high quality community service providers that have core competencies in delivering cancer care.

The Coleman Foundation supported three Cycles of the Collaborative, which served to produce and pilot elements of the CSOC Toolkit and implemented process improvements in their cancer program or clinic.

CSOC Cycle 1 had interconnected components: 1) Process Design Teams led by Northwestern and NorthShore and 2) Process Improvement Sites: Sinai Health System, Mercy Hospital and Medical Center, John H. Stroger, Jr. Hospital of Cook County, University of Illinois Health, University of Chicago Medicine and Rush University Medical Center. Both components focused on supportive oncology processes for Distress, Survivorship, Palliative Care and Hospice referral.

CSOC Cycle 2 added four additional process sites: Jesse Brown VA Medical Center, Northwestern Medicine, Loyola University Medical Center and UnityPoint Health Peoria. The Process Design teams revised their focus to: Emotional/Distress; Geriatric Oncology, Advanced Disease, and Process/Administration.

CSOC Cycle 3 includes four sites: Sinai Health System, Jesse Brown VA Medical Center, Loyola University Medical Center and UnityPoint Health Peoria.
The Evolution of Supportive Oncology

- Supportive Oncology scope expanded to all aspects of quality of life
- Guidelines & certifications expanded to require Supportive Oncology Care
- IOM 2013 report “High Quality Cancer Care: Charting a New Course for a System in Crisis”
  - Identified components of Supportive Oncology as crucial to quality cancer care and addressing the crisis

NCCN guidelines for Supportive Care include:

- Distress Management
- Palliative Care
- Survivorship
- Cancer-Related Fatigue
- Adult Cancer Pain
- Antiemesis
- Cancer- and Chemotherapy-Induced Anemia
- Myeloid Growth Factors
- Prevention and Treatment of Cancer-Related Infections
- Smoking Cessation

Challenge:
Guidelines and recommendations are often non-specific and leave ample room for variation of processes for care delivery, e.g. distress screening at pivotal points in care.
Continuum of Cancer Care
According to the IOM report, supportive care for cancer patients and their families should start at diagnosis and continue through the entire care continuum.

Patients who have supportive care concerns are more likely to have a high rate of anxiety or distress. Providing cancer patients access to supportive care services that address their individual needs helps patients optimize their quality of life.

Care teams with access to supportive care services are able to connect their patients with services that improve patient’s overall quality of life. The ENABLE trials have found that early use of palliative/supportive care services for Metastatic Non-Small Cell Lung Cancer patients extended their life.

Administrators have found that more holistic supportive care aligns with Commission on Cancer Accreditation standards and supports high quality care that is guideline recommended. Some sites have found increases in patient satisfaction. Many sites have used implementations of supportive care screening as a quality improvement project to support accreditation requirements.
Current State of Supportive Oncology in Your Program

Before starting any quality improvement projects, it is important to understand the current state of the supportive oncology practices at your site. Going through a current state review provides an opportunity to identify areas of quality improvement and identify processes that are working well and should be optimized.

Supportive oncology care practices should be defined and outlined prior to implementing a current state review. The following three lists provide considerations developed by the CSOC experts:

**Supportive care event components**

- Communicate diagnosis and with patient
- Explore patient’s understanding of illness and their expectations
- Share prognosis with patient using a timeframe
- Review and document name of health care agent
- Complete advance directive documentation: POLST or code status
- Supportive Oncology Screening
  - Supportive Oncology care referrals based on patient specific needs
    - Distress, psychosocial, emotional
    - Physical function and/or fatigue related care
    - Symptom, side effect and other physical problems
    - Pain
    - Practical needs and/or family needs
    - Financial
    - Spiritual, existential and or religious
    - Nutrition / dietetics
    - Care Event - Cancer treatment summary and survivorship care plan
    - Referral to palliative care specialist and/or palliative care team
    - Specialized palliative care
- Hospice referral
- Hospice enrollment
Questions to answer regarding care event implementation and responsibility:

- Is this care event handled in a standard way in your program?
- Who is responsible for this care?
- How much time is typically spent on this care event per patient / per encounter?
- Is this care event delayed for a patient based on lack of resources available to provide it? If yes, please describe common situations
- Is this care event billed to a payer? What codes are used (e.g. CPT, specific ICD9/10 ranges to support billing, other)
- If billed, is it reimbursed? Please indicate if reimbursement is different by different payers
  - Is there a set reimbursement amount from Tricare for this care event?
  - Is there a set reimbursement amount from Medicare for this care event?
  - Is there a set reimbursement amount from Medicaid for this care event?
  - What is the approximate reimbursement amount you receive from private payers (this information will only be shared in a summarized, de-identified manner)
- Itemize the above by provider level if needed (e.g. physician vs. NP time)
- If this is not billed, how are you funding it?
- Are patient co-pays a challenge or barrier to this care event?
- Please answer these three questions if you don’t always provide this care event to your patients:
  - What are the reasons for not providing this care event?
  - Is reimbursement a partial or sole reason for not providing this care event? Please elaborate.
  - What role patient copays play in your inability to deliver this care event?
- Please share any other information pertinent to reimbursement, funding or patient copays, related to this care event, especially barriers and challenges

Overarching Questions:

- Your overall perspective of your Supportive Oncology Processes
- What is working well at your site?
- Where do you see opportunities for improvement at your site?
- What do patients and/or caregivers say about Supportive Oncology at your site?
- What do patients like about supportive oncology at your site?
- Where do patient’s experience challenges?
Supportive Oncology Screening and Defining the Care Process and Work Flow in Your Program

The template below provides a way to document your organization’s current supportive oncology, including distress screening and how the results are used and/or to identify where there are gaps in work flow. This template provides a holistic way to ensure the supportive care screening and resulting care are addressed.

<table>
<thead>
<tr>
<th>Aspect</th>
<th>Current state</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient population</td>
<td>Fill in your target population: cancer types, stages, other patient characteristics</td>
</tr>
<tr>
<td>Patient touchpoint</td>
<td>Which appointment(s)? E.g. at the first or second patient appointment after diagnosis delivery. Before, at or after the appointment? Is screening tool self-administered by the patient, or administered by a provider?</td>
</tr>
<tr>
<td>Event target timing</td>
<td>CSOC recommendation: at least one supportive oncology screening within 30 days of diagnosis date Fill in your target timing</td>
</tr>
<tr>
<td>Individual(s) responsible</td>
<td>List specialties and levels (e.g. surgical nurse, oncologist, general social worker) Could be multiple responsibilities to capture all relevant patients For each type of provider, briefly describe their specific role in this care event</td>
</tr>
<tr>
<td>Conduct Initial Supportive Oncology (including distress) Screening</td>
<td></td>
</tr>
<tr>
<td>---------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>Aspect</td>
<td>Current state</td>
</tr>
<tr>
<td>Event description / scope (what happens)</td>
<td>Describe what happens during this event, e.g. patient comes in for an appointment; receptionist hands him/her the screening tool on paper; asks to fill in with other forms.</td>
</tr>
<tr>
<td>Content to use</td>
<td>CSOC Supportive Oncology Tool</td>
</tr>
</tbody>
</table>
| Event output / documentation | CSOC recommendation: document results of screening in medical record  
*Fill in: who will document? Where (EMR, paper, other?)  
How are results of screening shared with the patient?  |
| Event hand-off | Who and how will route results of screening for evaluation, further assessment and care referrals?  
*PHQ Results (Distress / Anxiety):  
Health Literacy:  
Practical Concerns:  
Self Care Concerns:  
Family/Caregiver Concerns: |
<table>
<thead>
<tr>
<th>Aspect</th>
<th>Current state</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nutrition Concerns:</td>
<td></td>
</tr>
<tr>
<td>Physical Concerns:</td>
<td></td>
</tr>
<tr>
<td>Spiritual / Faith / Religious Concerns:</td>
<td></td>
</tr>
<tr>
<td>Pain:</td>
<td></td>
</tr>
<tr>
<td>Fatigue / Low Energy:</td>
<td></td>
</tr>
<tr>
<td>Physical Activity / Function:</td>
<td></td>
</tr>
<tr>
<td>Falls:</td>
<td></td>
</tr>
<tr>
<td>Treatment or Care concerns (including advance care planning):</td>
<td></td>
</tr>
</tbody>
</table>

**What Resources are available to patients within your program:**

Is a Cancer Support Center on site?

Do you have information about Community Cancer Centers available for patients?

Are the physicians, nurses, physician assistants, advance practice clinicians, medical assistants, and staff aware of supportive care resources available for cancer patients?
CSOC compared pre-existing screening tools and supportive oncology guidelines and found that no tool addressed all indicated and necessary components of supportive care screening. The effort was re-directed to identify the “best of” screening tools for each element of supportive care for cancer patients. Those tools and some supplemental content were combined to create a new, holistic supportive oncology screening tool, the CSOC screening tool.

The collaboration used the NCCN Problem List for Patients and the ASCO distress guideline, which supported the use of the PHQ4 for distress and anxiety as the foundation of the CSOC screening tool. The NCCN Distress Problem List for Patients was adapted to “concerns” rather than “problems”, and added content needed to support guideline indicated needs. The team adapted the Mini-Nutrition Assessment for nutritional needs screening incorporated PROMIS short forms for Pain, Fatigue and Physical Function. To further the identification of patient needs, a new section “Treatment and Care Concerns” was developed for the tool; the questions in this section are informed by palliative care guidelines and models.

A similar approach was carried out for the development of the CSOC Questions for Your Survivorship screening tool with focus on the ASCO survivorship guidelines.

Sites participating in the Coleman Supportive Oncology Collaborative have adapted the use of the CSOC screening tool to best fit their workflow or patient population. In some cases, the clinician uses the tool to screen for the patient’s needs. In other cases, the patient completes the screening tool and reveals their needs. In addition, the screening tool has helped guide conversation during the appointment.

For access to the suite of CSOC Screening tools:

**Supportive Oncology Screening Tools**

<table>
<thead>
<tr>
<th>Language</th>
<th>Pages</th>
<th>Download</th>
</tr>
</thead>
<tbody>
<tr>
<td>English</td>
<td>see page 12 – 13</td>
<td>Download HERE</td>
</tr>
<tr>
<td>Spanish</td>
<td>see page 14 – 15</td>
<td>Download HERE</td>
</tr>
</tbody>
</table>

**Supportive Oncology Screening Tool Linked to Patient Handouts**

<table>
<thead>
<tr>
<th>Language</th>
<th>Pages</th>
<th>Download</th>
</tr>
</thead>
<tbody>
<tr>
<td>English</td>
<td>see page 16 - 17</td>
<td>Download HERE</td>
</tr>
</tbody>
</table>

**Survivorship Screening Tools**

<table>
<thead>
<tr>
<th>Language</th>
<th>Pages</th>
<th>Download</th>
</tr>
</thead>
<tbody>
<tr>
<td>English</td>
<td>see page 18</td>
<td>Download HERE</td>
</tr>
</tbody>
</table>
Patient Screening Questions for Supportive Care

- All patients are asked to complete this questionnaire as part of their standard of care.
- Please take a few minutes to answer the following questions to help us better address your needs.

<table>
<thead>
<tr>
<th>Over the last 14 days, how often have you been bothered by the following problems?</th>
<th>Not at all</th>
<th>Severa l days</th>
<th>More than half the days</th>
<th>Nearly every day</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feeling nervous, anxious or on edge</td>
<td>YES</td>
<td>NO</td>
<td>YES</td>
<td>NO</td>
</tr>
<tr>
<td>Not being able to stop or control worrying</td>
<td>YES</td>
<td>NO</td>
<td>YES</td>
<td>NO</td>
</tr>
<tr>
<td>Little interest or pleasure in doing things</td>
<td>YES</td>
<td>NO</td>
<td>YES</td>
<td>NO</td>
</tr>
<tr>
<td>Feeling down, depressed, or hopeless</td>
<td>YES</td>
<td>NO</td>
<td>YES</td>
<td>NO</td>
</tr>
</tbody>
</table>

Do you need someone like a family member, friend or clinic worker to help you read hospital materials? YES NO

Do you need help when filing out medical forms by yourself?

Indicate if any of the below has been a concern for you in the past 7 days, please check YES or NO for each.

### Practical Concerns

**YES NO**
- Child care issues
- Issues paying for food
- Issues paying for housing
- Issues with transportation to/from treatment
- Work / school issues
- Insurance coverage issues or no health insurance
- Paying for medication or medical care
- I live alone

**Self Care Concerns**

Are you concerned about having someone available to help if:

**YES NO**
- You cannot get out of bed?
- You feel sick and cannot do daily chores?
- You cannot run errands?

**Family/Caregiver Concerns**

**YES NO**
- Concerns about my children
- Concerns about my partner
- Concerns about caregivers
- Ability to have children
- Concerns about other family members

**Spiritual / Faith / Religious Concerns**

**YES NO**
- Do you struggle with the loss of meaning and joy in your life?
- Do you have religious or spiritual struggles?

I would like to talk to someone about my “yes” checks above from Practical, Self Care, Family/Caregiver or Spiritual Concerns

**YES NO**

### Physical and Other Concerns

**YES NO**
- Breathing
- Constipation
- Diarrhea
- Fevers
- Nausea or vomiting
- Sleep
- Changes in urination
- Difficulty chewing or swallowing
- Mouth sores
- Dry mouth
- Dental/teeth issues
- Cough
- Swollen arms or legs
- Feeling full quickly or swollen abdomen
- Sexual intimacy or function
- Skin dry/itchy, blister/pain
- Tingling in hands/feet
- Appearance
- Use of tobacco/cigarettes/vaping
- Use of alcohol/drugs
- Difficulty concentrating
- Difficulty remembering things
- Difficulty finding the words I want to say

### Nutrition Concerns

**YES NO**
- Weight loss or lack of appetite
- Weight gain
- Issues with taste
- Concerns about nutrition and food

See other side to complete
Please answer these questions to help us address what you need. - continued

**Pain**

*In the past 7 days, have you been in pain?*

- NO
- YES

If YES, please mark one box per row below

<table>
<thead>
<tr>
<th>No pain</th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
<th>Very Severe</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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<td></td>
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<td></td>
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</table>

<table>
<thead>
<tr>
<th>In the past 7 days how intense was your pain at its worst?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</table>

<table>
<thead>
<tr>
<th>In the past 7 days how intense was your average pain?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

What is your level of pain right now?

**Fatigue/Low Energy**

*Please mark one box per row

<table>
<thead>
<tr>
<th>Not at all</th>
<th>A little bit</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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<td></td>
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</table>

<table>
<thead>
<tr>
<th>During the past 7 days I feel fatigued (low energy)</th>
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<tbody>
<tr>
<td></td>
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</table>

<table>
<thead>
<tr>
<th>During the past 7 days I have trouble starting things because I am tired</th>
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<tbody>
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</table>

<table>
<thead>
<tr>
<th>In the past 7 days how run-down did you feel on average?</th>
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<tbody>
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<td></td>
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</table>

<table>
<thead>
<tr>
<th>In the past 7 days how fatigued were you on average?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tbody>
</table>

**Physical Activity**

*Please mark one box per row

<table>
<thead>
<tr>
<th>Without any difficulty</th>
<th>With a little difficulty</th>
<th>With some difficulty</th>
<th>With much difficulty</th>
<th>Unable to do</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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</table>

<table>
<thead>
<tr>
<th>Are you able to do chores such as vacuuming or yard work?</th>
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<tbody>
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</table>

<table>
<thead>
<tr>
<th>Are you able to go up and down stairs at a normal pace?</th>
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</table>

<table>
<thead>
<tr>
<th>Are you able to run errands and shop?</th>
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<tbody>
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<table>
<thead>
<tr>
<th>Are you able to be out of bed most of the day?</th>
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</table>

<table>
<thead>
<tr>
<th>Are you able to take care of your personal needs (dress, comb hair, toilet, eat, bathe)?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</table>

**Falls**

<table>
<thead>
<tr>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
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</table>

<table>
<thead>
<tr>
<th>Have you had 2 or more falls in the past 6 months?</th>
</tr>
</thead>
<tbody>
<tr>
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</table>

<table>
<thead>
<tr>
<th>Have you been injured by a fall that required medical attention in the last 6 months?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</table>

<table>
<thead>
<tr>
<th>Do you feel unsteady when walking?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

**Treatment or Care Concerns**

*Please please check Yes or No for each

<table>
<thead>
<tr>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
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</table>

<table>
<thead>
<tr>
<th>I want to better understand my cancer diagnosis or stage.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</table>

<table>
<thead>
<tr>
<th>I want to better understand my prognosis or long term outcome.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</table>

<table>
<thead>
<tr>
<th>I have concerns or questions about my treatment options, medication, or my plan of care.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>I want help discussing, with my family and friends, my treatment options and what is important to me.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Do you have a Health Care Power of Attorney?</th>
</tr>
</thead>
<tbody>
<tr>
<td>YES</td>
</tr>
<tr>
<td>NO</td>
</tr>
<tr>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>I want help discussing and deciding on the kinds of medical care I want or don’t want with my family, friends or doctor.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Do you have an Advance Medical Directive/Living Will/POLST?</th>
</tr>
</thead>
<tbody>
<tr>
<td>YES</td>
</tr>
<tr>
<td>NO</td>
</tr>
<tr>
<td></td>
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</tbody>
</table>

**Other problems or concerns**


The development of this tool was supported by The Coleman Foundation

CSOC-C3-v.020.10082018
Preguntas de atención médica para pacientes

A todos los pacientes se les pregunta que completen este cuestionario como parte de su estándar de atención (médica). Por favor tome unos minutos para responder las siguientes preguntas para ayudarnos a atender mejor sus necesidades.

<table>
<thead>
<tr>
<th>Durante las últimas 2 semanas, ¿qué tan seguido ha tenido molestias debido a los siguientes problemas? 1</th>
<th>Ningún día</th>
<th>Varios días</th>
<th>Más de la mitad de los días</th>
<th>Casi todos los días</th>
</tr>
</thead>
<tbody>
<tr>
<td>Se ha sentido nervioso(a), ansioso(a) o con los nervios de punta</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>No ha sido capaz de parar o controlar su preocupación</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Poco interés o placer en hacer cosas</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Se ha sentido decaído (a), deprimido (a) o sin esperanzas</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

¿Necesita a alguien como un familiar, amigo, empleado de hospital/clinica o un medico para que le ayude a leer los materiales del hospital? ☐ ☐

¿Necesita ayuda llenando los formularios médicos? ☐ ☐

Por favor indique "Sí" o "No" si alguno de los siguientes ha sido una preocupación para usted en los últimos 7 días.

**Preocupaciones Practicas** 2,9

<table>
<thead>
<tr>
<th>SÍ</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐</td>
<td>☐</td>
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**Preocupaciones de Cuidarse Usted Mismo** 10

Le preocupa tener a alguien disponible para ayudarle si:

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<th>SÍ</th>
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**Preocupaciones Familiares/Cuidadores** 2

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**Preocupaciones Espirituales/Religiosas/Fe** 5

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<th>SÍ</th>
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Me gustaría hablar con alguien de los "SÍ" indicados arriba sobre mis Preocupaciones, Espirituales, Prácticas, Cuidado Personal, o de Familia /Cuidador. ☐ ☐

**Preocupaciones Físicas** 2

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<th>SÍ</th>
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</table>

**Preocupaciones de Nutrición** 2,3

<table>
<thead>
<tr>
<th>SÍ</th>
<th>NO</th>
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</thead>
<tbody>
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</tbody>
</table>

[Vea al reverso para completar]
### Dolor 6

<table>
<thead>
<tr>
<th>NO</th>
<th>Si no tiene dolor, omita esta sección y vaya a “Fatiga/Poca Energía”</th>
</tr>
</thead>
<tbody>
<tr>
<td>SI</td>
<td>Si marcó “SI”, ha estado con dolor, por favor marque “X” en las casillas de abajo</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>En los últimos 7 días que intenso fue el dolor en su peor momento?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sin dolor</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>En los últimos 7 días que intenso fue el dolor promedio?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sin dolor</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Cual es su nivel de dolor en este momento?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sin dolor</td>
</tr>
</tbody>
</table>

### Fatiga/Poca Energía 7

**Marque con una “X” para indicar su respuesta**

<table>
<thead>
<tr>
<th>Nada</th>
<th>Un Poco</th>
<th>Algo</th>
<th>Bastante</th>
<th>Mucho</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Durante los últimos 7 días me siento fatigado (poca energía)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sin</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Durante los últimos 7 días tengo problemas para iniciar cosas porque me siento cansado</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sin</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>¿En los últimos 7 días en promedio que debilitado/a se sintió?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sin</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>¿En los últimos 7 días en promedio que fatigado/a se sintió?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sin</td>
</tr>
</tbody>
</table>

### Actividad Física 8

**Marque con una “X” para indicar su respuesta**

<table>
<thead>
<tr>
<th>Sin dificultad</th>
<th>Con poca dificultad</th>
<th>Con alguna dificultad</th>
<th>Con mucha dificultad</th>
<th>Incapaz de hacer</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>¿Puede realizar tareas tales como pasar la aspiradora o trabajar en el jardín?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sin</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>¿Puede subir y bajar las escaleras a un ritmo normal?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sin</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>¿Puede hacer los mandados o ir a las tiendas?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sin</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>¿Es capaz de estar fuera de la cama la mayor parte del día?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sin</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>¿Es capaz de cuidar de sus necesidades personales (vestirse, peinarse, aseo higiénico, comer, bañarse)?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sin</td>
</tr>
</tbody>
</table>

### Caidas 12

<table>
<thead>
<tr>
<th>SI</th>
<th>NO</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>¿Ha tenido 2 o más caídas en los últimos 6 meses?</th>
</tr>
</thead>
<tbody>
<tr>
<td>SI</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>¿Se ha lastimado por una caída en los últimos 6 meses que haya requerido atención médica?</th>
</tr>
</thead>
<tbody>
<tr>
<td>SI</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>¿Se siente inestable al caminar?</th>
</tr>
</thead>
<tbody>
<tr>
<td>SI</td>
</tr>
</tbody>
</table>

### Tratamientos o Preocupaciones de atención 4

<table>
<thead>
<tr>
<th>SI</th>
<th>NO</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Quiero entender mejor mi diagnóstico de cáncer o la etapa</th>
</tr>
</thead>
<tbody>
<tr>
<td>SI</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Quiero entender mejor mi pronóstico o resultado a largo plazo</th>
</tr>
</thead>
<tbody>
<tr>
<td>SI</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Tengo inquietudes o preguntas sobre mis opciones de tratamiento, medicamento o plan de cuidado.</th>
</tr>
</thead>
<tbody>
<tr>
<td>SI</td>
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</table>

<table>
<thead>
<tr>
<th>Necesito ayuda para charlar con mi familia y amigos mis opciones de tratamiento y lo que es importante para mi.</th>
</tr>
</thead>
<tbody>
<tr>
<td>• ¿Tiene un poder notarial de atención de salud?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Quiero ayuda discutiendo y decidendo lo que quiero o no quiero con respecto a los procedimientos y cuidados médicos con mi familia, amigos o médico.</th>
</tr>
</thead>
<tbody>
<tr>
<td>• ¿Tiene una directiva médica anticipada / Testamento en vida / POLST?</td>
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</table>

### Otros problemas o preocupaciones 2:

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<th>Office Use Only:</th>
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<tr>
<td>SI</td>
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</table>

<table>
<thead>
<tr>
<th>Quiero entender mejor mi diagnóstico de cáncer o la etapa</th>
</tr>
</thead>
<tbody>
<tr>
<td>SI</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Quiero entender mejor mi pronóstico o resultado a largo plazo</th>
</tr>
</thead>
<tbody>
<tr>
<td>SI</td>
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</table>

<table>
<thead>
<tr>
<th>Tengo inquietudes o preguntas sobre mis opciones de tratamiento, medicamento o plan de cuidado.</th>
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<tbody>
<tr>
<td>SI</td>
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</tbody>
</table>


*The development of this tool was supported by The Coleman Foundation*
Patient Screening Questions for Supportive Care

- All patients are asked to complete this questionnaire as part of their standard of care.
- Please take a few minutes to answer the following questions to help us better address your needs.

### Practical Concerns

<table>
<thead>
<tr>
<th>YES</th>
<th>NO</th>
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### Self Care Concerns

**Are you concerned about having someone available to help if:**

<table>
<thead>
<tr>
<th>YES</th>
<th>NO</th>
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### Family/Caregiver Concerns

<table>
<thead>
<tr>
<th>YES</th>
<th>NO</th>
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### Spiritual / Faith / Religious Concerns

<table>
<thead>
<tr>
<th>YES</th>
<th>NO</th>
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I would like to talk to someone about my “yes” checks above from Practical, Self Care, Family/Caregiver or Spiritual Concerns

YES: ☐ NO: ☐

---

### Physical and Other Concerns

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<tr>
<th>YES</th>
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</tbody>
</table>

### Nutrition Concerns

<table>
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<tr>
<th>YES</th>
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</tbody>
</table>

See other side to complete
**Pain**

In the past 7 days, have you been in pain?

- **NO**  [ ]  If NO, skip to “Fatigue/Low Energy”
- **YES**  [ ]  If YES, please mark one box per row below

<table>
<thead>
<tr>
<th>Pain</th>
<th>No pain</th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
<th>Very Severe</th>
</tr>
</thead>
<tbody>
<tr>
<td>In the past 7 days how intense was your pain at its worst?</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>In the past 7 days how intense was your pain?</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>What is your level of pain right now?</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
</tbody>
</table>

**Fatigue/Low Energy**

Please mark one box per row

During the past 7 days I feel fatigued (low energy)

- [ ] Not at all
- [ ] A little bit
- [ ] Somewhat
- [ ] Quite a bit
- [ ] Very much

During the past 7 days I have trouble **starting** things because I am tired

In the past 7 days how run-down did you feel on average?

In the past 7 days how fatigued were you on average?

**Physical Activity**

Please mark one box per row

Are you able to do chores such as vacuuming or yard work?

Are you able to go up and down stairs at a normal pace?

Are you able to run errands and shop?

Are you able to be out of bed most of the day?

Are you able to take care of your personal needs (dress, comb hair, toilet, eat, bathe)?

**Falls**

Have you had 2 or more falls in the past 6 months?

Have you been injured by a fall that required medical attention in the last 6 months?

Do you feel unsteady when walking?

**Treatment or Care Concerns**

Please please check Yes or No for each

- **YES**  [ ]
- **NO**  [ ]

I want to better understand my cancer diagnosis or stage.

I want better to understand my prognosis or long term outcome.

I have concerns or questions about my treatment options, medication, or my plan of care.

I want help discussing, with my family and friends, my treatment options and what is important to me.

- Do you have a Health Care Power of Attorney?  [ ]  **YES**  [ ] **NO**

I want help discussing and deciding on the kinds of medical care I want or don’t want with my family, friends or doctor.

- Do you have an Advance Medical Directive/Living Will/POLST?  [ ]  **YES**  [ ] **NO**

Other problems or concerns?

**Office Use Only:**

- Pt alone
- Pt with family
- Pt with clinician/staff

---


*The development of this tool was supported by The Coleman Foundation*
**Questions for your Survivorship Appointment**

All patients are asked to complete this questionnaire as part of their standard of care. Please take a few minutes to answer the following questions to help us better address your needs.

Over the **last 14 days**, how often have you been bothered by the following problems?

<table>
<thead>
<tr>
<th>Please mark one box per row</th>
<th>Not At All</th>
<th>Several Days</th>
<th>More Than Half The Days</th>
<th>Nearly Every Day</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feeling nervous, anxious or on edge</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Not being able to stop or control worrying</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Little interest or pleasure in doing things</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Feeling down, depressed, or hopeless</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Fear of developing another cancer or a recurrence</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

Please indicate if you developed any of the below concerns as a result of your cancer treatment by checking Yes or No for each.

<table>
<thead>
<tr>
<th>YES</th>
<th>NO</th>
<th>Physical Concerns</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐</td>
<td>☐</td>
<td>Ability to have children</td>
</tr>
<tr>
<td>☐</td>
<td>☐</td>
<td>Appearance</td>
</tr>
<tr>
<td>☐</td>
<td>☐</td>
<td>Breathing</td>
</tr>
<tr>
<td>☐</td>
<td>☐</td>
<td>Constipation or Diarrhea</td>
</tr>
<tr>
<td>☐</td>
<td>☐</td>
<td>Hot flashes and/or vaginal dryness</td>
</tr>
<tr>
<td>☐</td>
<td>☐</td>
<td>Nausea or Vomiting</td>
</tr>
<tr>
<td>☐</td>
<td>☐</td>
<td>Difficulty with chewing or swallowing due to cancer therapy</td>
</tr>
<tr>
<td>☐</td>
<td>☐</td>
<td>Pain</td>
</tr>
<tr>
<td>☐</td>
<td>☐</td>
<td>Sexual intimacy or function</td>
</tr>
<tr>
<td>☐</td>
<td>☐</td>
<td>Dry skin</td>
</tr>
<tr>
<td>☐</td>
<td>☐</td>
<td>Sleep</td>
</tr>
<tr>
<td>☐</td>
<td>☐</td>
<td>Decreased range of motion or loss of strength</td>
</tr>
<tr>
<td>☐</td>
<td>☐</td>
<td>Lower energy level</td>
</tr>
<tr>
<td>☐</td>
<td>☐</td>
<td>Swollen arms/legs</td>
</tr>
<tr>
<td>☐</td>
<td>☐</td>
<td>Tingling in my hands/feet</td>
</tr>
<tr>
<td>☐</td>
<td>☐</td>
<td>Trouble remembering, concentrating</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>YES</th>
<th>NO</th>
<th>Financial Concerns</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐</td>
<td>☐</td>
<td>Paying for food and/or housing</td>
</tr>
<tr>
<td>☐</td>
<td>☐</td>
<td>Paying for my medication or medical care</td>
</tr>
<tr>
<td>☐</td>
<td>☐</td>
<td>Insurance coverage or no health insurance</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>YES</th>
<th>NO</th>
<th>Social Concerns</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐</td>
<td>☐</td>
<td>Concerns about my children</td>
</tr>
<tr>
<td>☐</td>
<td>☐</td>
<td>Concerns about my partner</td>
</tr>
<tr>
<td>☐</td>
<td>☐</td>
<td>Issues with work or school</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>YES</th>
<th>NO</th>
<th>Spiritual / Faith / Religious Concerns</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐</td>
<td>☐</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>YES</th>
<th>NO</th>
<th>Treatment or Care Concerns</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐</td>
<td>☐</td>
<td>Lack understanding about my cancer diagnosis or stage</td>
</tr>
<tr>
<td>☐</td>
<td>☐</td>
<td>Have questions about potential long term complications from my treatment</td>
</tr>
<tr>
<td>☐</td>
<td>☐</td>
<td>Developed other illnesses as a result of my cancer treatment</td>
</tr>
<tr>
<td>☐</td>
<td>☐</td>
<td>Issues with transportation to/from appointments</td>
</tr>
<tr>
<td>☐</td>
<td>☐</td>
<td>Need help coordinating my care</td>
</tr>
<tr>
<td>☐</td>
<td>☐</td>
<td>Need cancer screening</td>
</tr>
</tbody>
</table>

**Other problems or concerns:**

---

*This tool is adapted from: (1) The National Comprehensive Cancer Network, NCCN Guidelines* for Distress Management, Problem List, Version 3.2015; (2) the PHQ-4 developed by Kroenke K, Spitzer RL, Williams JB, Löwe B.; (3) American Society of Clinical Oncology, Providing High Quality Survivorship Care in Practice: An ASCO Guide, (2014) Any clinician seeking to apply or consult the Coleman Supportive Oncology Initiative Follow Up Reference is expected to use independent medical judgement in the context of individual clinical circumstances to determine any patient’s care or treatment. The Coleman Foundation makes no representations or warranties of any kind regarding their content, use or application and disclaims any responsibility for their application or use in any way.
Preguntas para cita de sobrevivencia

A todos los pacientes se les pregunta que completen este cuestionario como parte de su estándar de atención (médica). Por favor tome unos minutos para responder las siguientes preguntas para ayudarnos a atender mejor sus necesidades.

Durante las últimas 2 semanas, ¿qué tan seguido ha tenido molestias debido a los siguientes problemas?

<table>
<thead>
<tr>
<th>Marque con una “X” para indicar su respuesta</th>
<th>Ningún día</th>
<th>Varios días</th>
<th>Más de la mitad de los días</th>
<th>Casi todos los días</th>
</tr>
</thead>
<tbody>
<tr>
<td>Se ha sentido nervioso(a), ansioso(a) o con los nervios de punta</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No ha sido capaz de parar o controlar su preocupación</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poco interés o placer en hacer cosas</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Se ha sentido decaído (a), deprimido (a) o sin esperanzas</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Temor de desarrollar otro cáncer o una reaparición</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Por favor indique “Sí” o “No” si ha desarrollado alguna de las siguientes preocupaciones como resultado de su tratamiento contra el cáncer.

<table>
<thead>
<tr>
<th>SI</th>
<th>NO</th>
<th>Preocupaciones Practicas</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Problema pagando por comida o vivienda</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Problema pagando por medicamentos o su cuidado médico</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Problemas con la cobertura médica o no tiene seguro médico</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>SI</th>
<th>NO</th>
<th>Preocupaciones Sociales</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Preocupaciones sobre sus hijos</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Preocupaciones sobre su pareja</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Preocupaciones sobre su trabajo o escuela</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>SI</th>
<th>NO</th>
<th>Preocupaciones Espirituales/Religiosas/Fe</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>SI</th>
<th>NO</th>
<th>Preocupaciones de Nutrición</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Preocupaciones sobre su peso</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Preocupaciones sobre su dieta (comida) y riesgo de cáncer / incidencia</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Preocupaciones sobre los suplementos alternativos/medicinas naturales</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>SI</th>
<th>NO</th>
<th>Tratamientos o Preocupaciones de atención</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Falta de conocimiento sobre su diagnóstico de cáncer o la etapa</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Preguntas sobre complicaciones a largo plazo debido a su tratamiento de cáncer</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Preocupaciones de haber desarrollado otras enfermedades como resultado de su tratamiento de cáncer</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Problemas con el transporte hacia/desde su tratamiento</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Necesito ayuda coordinado mi cuidado</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Necesito ayuda con exámenes de detección de cáncer</td>
</tr>
</tbody>
</table>

Por favor indique qué factores pueden ser relevantes para su estilo de vida marcando “Sí” o “No”.

<table>
<thead>
<tr>
<th>SI</th>
<th>NO</th>
<th>Factores de estilo de vida</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Uso cámaras bronceadoras</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Estoy frecuentemente afuera en el sol</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Uso tabaco</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Uso medicamento prescrito para dolor por razones ajenas al dolor</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Hago ejercicio regularmente</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Bebo Alcohol</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Uso drogas recreacionales</td>
</tr>
</tbody>
</table>

*This tool is adapted from: (1) The National Comprehensive Cancer Network, NCCN Guidelines® for Distress Management, Problem List, Version 3.2015; (2) the PHQ-4 developed by Kroenke K, Spitzer RL, Williams JB, LöweB.; (3) American Society of Clinical Oncology, Providing High Quality Survivorship Care in Practice: An ASCO Guide, (2014)

CSOC-Survivorship-v.005.09182017
Supportive Oncology Execution
Follow Up Reference Documents

To address identified supportive oncology concerns, the CSOC created one-page “Follow Up Reference Documents” based on nationally recognized guidelines. These documents provide steps for further assessment and align with each item on the CSOC screening tool. The follow up reference also provides approaches that may address the concern and who to refer the patient to. Any clinician seeking to apply or consult these documented is expected to use independent medical judgement in the context of the individual clinical circumstances to determine any patient’s care or treatment. Clinician and patient resources/links are included at the bottom of each document.

List of Clinician Follow Up References available both online and on subsequent pages:

1. PHQ4
2. Health Literacy
3. Child Care
4. Paying for Food
5. Paying for Housing
6. Transportation
7. Work/School Issues
8. Insurance
9. Paying for Medicine
10. Living Alone
11. Self-Care – Someone available to help
12. Concerns for Children
13. Concerns for Partners
14. Concerns for Caregivers
15. Help with Family
16. Ability to have Children
17. Spiritual
18. Breathing Issues
19. Constipation
20. Diarrhea
21. Fevers
22. Nausea/Vomiting
23. Sleep
24. Urination
25. Chewing/Swallowing
26. Cough

27. Mouth Sores
28. Dry Mouth
29. Swollen Appendages
30. Swollen Abdomen
31. Sexual Concerns
32. Skin Dry/Itchy/Blister/Pain
33. Tingling Hand/Feet
34. Appearance
35. Alcohol/Drugs
36. Cognitive
37. Weight Loss
38. Weight Gain
39. Taste Issues
40. Nutrition
41. Pain Mild/Moderate
42. Pain Severe
43. Fatigue
44. Physical Activity Mild
45. Physical Activity Moderate/Severe
46. Falls
47. Understanding Diagnosis
48. Understanding Prognosis
49. Understanding Treatment Options
50. Help Discussing
51. Help Discussing and Deciding Options

Complete Set of Follow Up References for downloading HERE
PHQ-4 – Anxiety/Depression:
MILD/MODERATE/SEVERE SCORE

Start With adding answer scores to get Total Score

PHQ-4 Anxiety
screening tool inquiries are:
- Feeling nervous, anxious or on edge
- Not being able to stop or control worrying

PHQ-4 Depression
screening tool inquiries are:
- Little interest or pleasure in doing things
- Feeling down, depressed, or hopeless

Answer of:
- Not at all (+0)
- Several Days (+1)
- More than half the days (+2)
- Nearly every day (+3)

Total score is determined by adding together the scores for each of the 4 inquires. Scores are rated as normal (0-2), mild (3-5), moderate (6-8), and severe (9-12).

Total Score 0-2 = Normal
- Patients scoring within the category of “Normal”
- Does not need to be assessed further, No follow-up referral
- Inform patient about future routine screenings

Total Score 3-5 = Mild Category
Total Score 6-8 = Moderate
Total Score 9-12 = Severe Category
- Recommended that anyone with this category score be screened further for anxiety/depression
- A score of 3 or greater in either the Anxiety or Depression screening inquires is considered positive for screening purposes.

Share with all patients that anxiety and depression symptoms are common reactions and can be managed.
- Provide support and validation
- Encourage pleasant activity, relaxation, and exercise if appropriate
- Follow your institution’s internal risk assessment protocol or suicidal/homicidal ideation protocol to further assess SI/HI risk.

Approach

Next Step
Refer to Physician/APC or SW
- Assess for SI/HI risk if needed
- Inform patient about supportive care in the communityclinical setting
- Inform patient of follow-up screenings
- Mid level provider, in consultation with treating physician, can further determine referral for patient if needed

See link in References for CSOC Palliative Training Modules
Impact of Distress on Patient Care, How to Address Patient Distress: Mild, Moderate and Severe, Using the Example of PHQ-4 Results

Provide education on supportive care in the communityclinical setting.
- Share Patient Links and Handouts
- See Reference links below for additional information

Timing

Sub Acute
1-3 days for those with Mild and Moderate and able to function

Same Day
For those with any score not able to function

Urgent - immediate referral to a physician or to the ER is recommend

for those with suicide ideation risk

Notes
Thoughts of death, self-harm, and suicide may be common among patients with cancer, with increased risk among pain, emotional distress, and functional limitations. Therefore, assessment of psychosocial distress must be placed in context of other supportive care needs. Risk of suicide is heightened in the year following cancer diagnosis, but patients may also consider self-harm, suicide, or euthanasia throughout the cancer continuum including the end of life. Thoughts of death without suicidal intent may also occur.

Stage I-IV: Patients with a mild or moderate screen could be provided with education and resource information, and re-screened at a later visit as appropriate. Any patient with a positive screen (mild, moderate or severe) should be assessed for suicidal ideation. The PHQ-4 can be administered by health care personnel or it can be self-administered. (Kroenke et al., 2009)

Stage IV: High-Quality Management of Physical and Depressive Symptoms May Reduce Severe Anxiety at End of Life for Patients with Cancer, Study Finds (see link in References below)

Patient Links and Handouts:
- American Cancer Society, Anxiety, Fear, and Depression
- NIH, Adjustment to Cancer: Anxiety and Distress (PDQ®)
- NIH, Depression (PDQ®)
- Cancer Net, Anxiety
- Cancer Net, Depression

CSOC Patient Handout can be accessed at:
http://cancer-help.me/phq-anx-depression
http://cancer-help.me/depression

References:
- NCCN Continuing Education, Coleman Supportive Oncology Training Modules
  Several modules are helpful, specifically:
- Distress: Impact on Care, Screening for Distress, and Addressing Distress
- NIH, Adjustment to Cancer: Anxiety and Distress (PDQ®)
- Screening, Assessment, and Care of Anxiety and Depressive Symptoms in Adults With Cancer: An American Society of Clinical Oncology Guideline Adaptation
- An ultra-brief screening scale for anxiety and depression: the PHQ-4.
- Longitudinal Analysis of Severe Anxiety Symptoms in the Last Year of Life Among Patients With Advanced Cancer: Relationships With Proximity to Death, Burden, and Social Support
### Health Literacy –

**“YES” to either “Do you need someone like a family member, friend, hospital/clinic worker, or caregiver to help you read hospital materials? Or “Do you need help when filling out medical forms by yourself?”**

<table>
<thead>
<tr>
<th>Start With</th>
<th>If Yes</th>
<th>Next Step</th>
<th>Timing</th>
</tr>
</thead>
</table>
| Asking the patient the below question | Further inquiry:  
- if the questions were read to them, would they themselves be comfortable/able to answer them?  
- Would pt like a family member or someone else to help them complete the form?  
If proceeding with the screening being read aloud, patient should check answers if able or wants to.  
Further questions may be needed to determine what language might be better.  
- Screening Tool in English, Spanish, Polish or Traditional Chinese  
- Obtain translators, either institution provided or family members | Discontinue screening if patient requests or exhibits signs of distress.  
Use teach-back method or ask patient “what did we cover today?” to reinforce important information the patient should know and understand.  
Document patients preferences for future screens and means of communication when possible to reduce patient frustration of repeating possible inabilities and to improve upon patient understanding of their disease and treatment. | At time of screening |  
| | If left blank |  
Would you like a family member or someone else to help you complete this form? Or “Do you need help to read this form or other medical paperwork?” |  |  
| | If No |  
Ask what type of assistance would they like |  |  

### Notes

Purpose of the Health Literacy questions is to help in the broader sense cancer care when pt has literacy issues. Discovering this issue early should lead to different means of communication and support resulting in better care.

Depending on when/where patient is receiving tool:
- If given in the waiting room by front desk staff, they cannot offer help to patient but if the patient indicates they cannot complete the tool, front desk staff can suggest they hold on to the screening tool and discuss once roomed.
- If given once roomed, when handing to the patient, create a script to tease out right away any literacy issues.
  - For a quick assessment you could ask, “How far did you go in school?” and “How do you feel about reading?” (Coleman Palliative Medicine Conference January 17th, 2019)

Creating resources with picture icons for visual understanding may be helpful. May be useful for non-native English patients, patients with health literacy issues or both. Example: Pill Card would help pt who cannot read or understand their medication dosing.

### Patient Links and Handouts:

- **Ask Me 3**
- CSOC Patient Handout can be accessed at: [http://cancer-help.me/reading-understanding](http://cancer-help.me/reading-understanding)

### References:

- AMA Foundation, Helath literacy and patient safety: Help patients understand
- NIH, Clear Communication
- NIH, Health Literacy, Professional Development
- Assessing and Addressing Health Literacy
- How to Create a Pill Card

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Practical Concerns – “YES” to Childcare issues

**Start With**
Asking the patient the below questions

- Will this be a barrier to your medical treatment?
- Do you feel you need support to address the childcare concern today?
- What stands in the way now of you (or your family) getting childcare now? Financial? Other?
- Do you have friends or family in the community?
- Are you affiliated with a local spiritual/faith community or other community organization?

**Approach**
Encourage patient to share this concern with family, friends, community groups or faith community as a way to seek support.

If applicable:
- Suggest patient discuss this concern with a representative from the school/daycare for assistance.
- Suggest patient investigate possible options within their Employee Assistance Program through the employer.
- Determine what worked in the past and/or what the patient has already tried. Who usually takes care of them when you have a childcare need?

Document all responses and include in medical record and/or referral if referring to another medical professional

**Next Steps**
Have a discussion/share relative options.

Refer to a social worker, child life specialist, patient advocate, patient navigator, or nurse if no social worker is available for further guidance and additional support

See “Journey Connections” link below for information and assistance with childcare.

Follow institution standards for mandated reporting.

Share Patient Links and Handouts as appropriate

**Timing**
- Discuss same day if there is no tentative plan and children are being left alone for extended period of time or if abuse or neglect is a concern.
- Acute – within 24 hours if interfering with care or there is no tentative plan
- Routine - within 1 week if not interfering with care.

---

**Notes**

**Any Stage**
- Local Faith Communities/Social Service Agencies – vary by community.
- Determine availability of afterschool programs
- Childcare Assistance Program (CCAP) – State of Illinois childcare referral/linkage program for economically distressed families (see link below)

**Stage IV**
- Address longer term issues such as guardianship, estate planning
- Involve family, church, etc.

**Patient Links and Handouts:**

- [American Cancer Society, Financial issues for families: Getting help with living expenses](#)
- [CancerCare.org – financial assistance: funding available for childcare, transportation, home assistance; program availability varies based on funding levels](#)
- [Illinois Department of Human Services, Child Care Assistance Program (CCAP)](#)
- [Illinois Department of Human Services, Temporary Services for Needy Families (TANF)](#)
- [Illinois Department of Human Services, Cash](#)

- Child Care options with cost:
  - [Care.com](#)
  - [SitterCity](#)
  - [MoniCare](#)

CSOC Patient Handout can be accessed at: [http://cancer-help.me/childcare](http://cancer-help.me/childcare)

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Practical Concerns –
“YES” to Issues paying for food

<table>
<thead>
<tr>
<th>Start With</th>
<th>Approach</th>
<th>Next Steps</th>
<th>Timing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asking the patient the below questions</td>
<td>Determine what worked in the past and/or what the patient has already tried.</td>
<td>Refer to financial social worker/counselor (if none available, refer to social worker, patient advocate, or patient navigator) if additional help is needed. Additional option refer to a cancer support center’s financial navigator.</td>
<td>Discuss same day if possible</td>
</tr>
<tr>
<td>Have you had concerns in the past paying for food?</td>
<td>See Food Resources below.</td>
<td>Have a discussion/share relative options with the patient.</td>
<td>Acute – within 24 hours if interfering with care.</td>
</tr>
<tr>
<td>Have you already tried to resolve this concern?</td>
<td></td>
<td>• See “Patient Links and Handouts” section below for guidance, if needed</td>
<td>Routine - within 1 week if not interfering with care.</td>
</tr>
<tr>
<td>Have you shared this concern with others – members of your family, friends, community groups or your spiritual community?</td>
<td>Encourage patient to share this concern with family, friends, community groups or faith community as a way to seek support.</td>
<td>• Provide list of resources to the patient. If possible and wanted, help connect patient with the resource(s)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Share Patient Links and Handouts as appropriate.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>See “Food Resources”</td>
<td></td>
</tr>
</tbody>
</table>

Notes
Stage IV: Patient’s may be eligible for Social Security Disability.

Patient Links and Handouts:
- Supplemental Nutrition Assistance Program (SNAP)
- Social Security Disability
- Cancer.Net, Financial Resources
- American Cancer Society, Financial issues for families: Getting help with living expenses
- Livestrong, Information Just For You
- Culinary Care
- Enter search words: food, paying for food, issues paying for food, financial assistance

Food Resources:
- Greater Chicago Food Depository https://www.chicagosfoodbank.org/news/
- Illinois Department of Human Services, Cash, SNAP & Medical Assistance http://www.dhs.state.il.us/page.aspx?item=33698
- City of Chicago, Community Service Center Location https://www.cityofchicago.org/city/en/depts/fss/providers/serv/svcs/community_servicecenterlocations.html

CSOC Patient Handout can be accessed at:
http://cancer-help.me/food

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The McKinney-Vento Act defines homeless children as "individuals who lack a fixed, regular, and adequate nighttime residence." This includes children who:

- Lacked consistent or fixed housing, such as with friends or relatives, or living in a shelter or временно убежище
- Reported being homeless at least once in the last 48 hours
- Are running away from home

Patient Links and Handouts have information and resources for a variety of housing or homelessness issues and can be used for guidance. Share with patients directly who have the ability to utilize. Assist patients as much as possible.

- Medicaid and have a need for skilled care can be housed at a nursing home under what is called 'custodial care'. State Medical Assistance office is the best source for information about if patient qualifies for long-term care services.
- Patients on the brink of defaulting on a mortgage or eviction should speak with a lawyer to understand their options and hopefully be able to get a new payment plan that they can afford: http://www.lcbh.org/ and https://www.ihda.org/my-community/foreclosure-programs/
- Social Security Disability may be of assistance, see link to Social Security Disability below.

**Notes**

The McKinney-Vento Act defines homeless children as "individuals who lack a fixed, regular, and adequate nighttime residence." This includes children who:

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- Are running away from home

Patient Links and Handouts have information and resources for a variety of housing or homelessness issues and can be used for guidance. Share with patients directly who have the ability to utilize. Assist patients as much as possible.

- Medicaid and have a need for skilled care can be housed at a nursing home under what is called 'custodial care'. State Medical Assistance office is the best source for information about if patient qualifies for long-term care services.
- Patients on the brink of defaulting on a mortgage or eviction should speak with a lawyer to understand their options and hopefully be able to get a new payment plan that they can afford: http://www.lcbh.org/ and https://www.ihda.org/my-community/foreclosure-programs/
- Social Security Disability may be of assistance, see link to Social Security Disability below.

**Patient Links and Handouts:**

- American Cancer Society, Financial issues for families: Getting help with living expenses
- Social Security Disability Benefits
- Livestrong, Free Personalized Cancer Support
- Illinois Medical District Guest House
- Joe’s House, Lodging Guide for Cancer Patients
- The Boulevard, Medical Respite for Chicago homeless
- Cancercare Financial Assistance Program
- Illinois Department of Human Services
- The Catholic Charities, Housing Services
- All Chicago, making homelessness history
- City of Chicago Emergency Rental Assistance
- Thresholds, for pts with co-occurring mental illness

CSOC Patient Handout can be accessed at: http://cancer-help.me/housing

**Follow Up Reference for Clinicians**

You can review information within Patient Links and Handouts with your patients.

**Start With**

- Will this concern be a barrier to your medical treatment?
- Have you dealt with housing instability or homelessness in the past?
- What specific steps have you taken already to resolve this concern?
- Do you feel you need support to address this concern?
- Have you shared this concern with others – members of your family, friends, community groups or your spiritual community?

**Approach**

- Tell me more about where you are currently living so that I can better understand how we might be able to help you.
  - Determine if the patient or family is homeless or experiencing chronic housing instability.
  - Or determine if patient has resolved homeless in the past and if this experience could be repeated.
    - See Notes section below.
- How would you feel about sharing this concern with your family, friends, community groups or faith community as a way to seek support?

**Next Step**

- Refer to financial specific social worker/counselor if available.
  - Or, social worker, patient advocate, case manager, or patient navigator.
  - Have a discussion/share options with the patient.
    - If the patient and/or family is homeless, assist with housing arrangements.
    - See/Share “Patient Links and Handouts” section below for guidance, if needed
    - Provide list of resources to the patient. If possible and wanted, help connect patient with the resource(s)

**Timing**

- Discuss same day if possible
- Acute – within 24 hours if interfering with care.
- Routine - within 1 week if not interfering with care.
### Practical Concerns – “YES” Issues with transportation to/from treatment

<table>
<thead>
<tr>
<th>Start With</th>
<th>Approach</th>
<th>Next Step</th>
<th>Timing</th>
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</thead>
<tbody>
<tr>
<td>Asking the patient the following: Is the reason for this issue any of the following: • financial difficulty • physical function issue • no means of transportation (e.g., having no car)</td>
<td>Financial issues: • Smaller grants may be available through small private foundations, municipalities, senior service organizations, hospital foundations and others. Physical function issue: • Clarify to what extent (e.g., uses ambulation device, cannot step into regular vehicle) • Document all responses and include in medical record and/or referral if referring to another medical professional • Need of handicap accessible vehicle, wheelchair van? No means of transportation: • Discover what is available to the patient and assist with planning if possible, including non-emergency medical transportation assistance through patient’s insurance (if applicable). Share patient vouchers for gas, taxis or other transportation assistance that may be available.</td>
<td>Have a discussion/share relative options. Share Patient Links and Handouts as appropriate. Journey Connections has specific transportation category with many resources available. Refer to social worker, patient advocate, patient navigator, or nurse if no social worker is available for further guidance (such as assistance with registering for PACE) and additional support for any of the reasons. Refer to Physical Therapy if appropriate</td>
<td>Discuss same day if possible or within 24 hours if there is no tentative plan and interfering with care. Routine - within 1 week if not interfering with care.</td>
</tr>
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</table>

#### Notes

Depending upon the patient’s age, government provided financial aid for transportation may be available (e.g., National Aging and Disability Transportation Center). Many not-for-profits specialize in specific age or veteran related assistance. Available assistance with transportation may be directly related to where patient lives. For example, municipalities may have a transportation service or public transportation may be readily available. Medicaid’s non-emergency transportation services may be eligible for rides to doctor’s appointments for Medicaid-approved care. Rides in your area may be offered by taxi, car, van, or a form of public transportation. Call your Medicaid caseworker for more information and to find out if you are eligible.

Private pay options are available for those who can afford it in terms of paratransit, taxi or public transportation.

#### Patient Links and Handouts:

- American Cancer Society, Road to Recovery
- LiveStrong, Transportation and Other Cancer Support Services
- Livestrong, Cancer Navigation
- Chicago Transit Authority
- Regional Transportation Authority
- US Department of Labor, Family and Medical Leave Act (FLMA)
- City of Chicago Senior Transportation Programs
- Susan Lang Pay-it-forward Patient Travel Assistance Program
- Medicaid Assurance of Transportation
- Pay Transportation: First Transit (private insurance may cover cost)
- Paratransit, taxi, Uber, Lyft, CTA, etc

CSOC Patient Handout can be accessed at: [http://cancer-help.me/transportation](http://cancer-help.me/transportation)

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Practical Concerns – “YES” to Work / School Issues

Start With
Asking the patient the below questions

Are you concerned about your job security?

Are you concerned your employer/workplace will not be/is not accommodating?

Do you need help filing for Social Security disability?

Are you a college student and concerned your school will not be/is not accommodating?

Are you a college student and need help financially?

Next Step
Suggest patient talk with:
• Employer’s Employee Assistance Program (EAP) if one exists
• Employer’s Human Resources (HR) department if one exists
• Patient’s manager
Possible referral to Social Worker who may have suggestions on how to have this discussion based on the patient’s concerns.
Share Patient Links and Handouts as appropriate.
See Reference Links below for additional information.

Timing
Sub Acute, 1-3 days to Routine, within 1 week depends on the level of distress the specific concern is causing the patient.

Notes
Stage IV or disease that qualifies under compassionate allowances on SSA.gov: Consider long term disability. Some patients may have long term disability insurance (self purchased or through employer). Also consider social security disability.

Patient Links and Handouts:
- CancerandCareers.org
- American Cancer Society, Working During and After Treatment
- LiveStrong, Employment Issues
- US Department of Labor, Family and Medical Leave Act (FMLA)
- Social Security Disability Benefits
- National Cancer Legal Services Network
- LAF, Free Legal Assistance for those living in poverty in Cook County Illinois
- Scholarships and Resources, National Collegiate Cancer Foundation
- Scholarships, Cancer for College

Legal Rights Links:
- Americans with Disabilities Act (ADA)
- US Equal Employment Opportunity Commission, Q&A about Cancer in the Workplace and the ADA
- Students with Hidden Disabilities Under Section 504 or the Rehabilitation Act of 1973
- Individuals with Disabilities Education Act (IDEA)

CSOC Patient Handout can be accessed at:
http://cancer-help.me/work and http://cancer-help.me/school

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Practical Concerns –
“YES” to Insurance coverage or no health insurance

Start With
Asking the patient the below question

Do you have health insurance?

If YES

Do you understand your Healthcare Insurance and Benefits?

Do you need help to pay for your care not covered by your health insurance?

Do you know what is covered by your health insurance? (Some insurances [County Care, Family Health Network] will cover medical expenses but will not reimburse for things like psychotherapy or complimentary-alternative treatments (like acupuncture or massage)

Do you need help to pay for your health insurance?

Next Step

Refer to a social worker, patient advocate or patient navigator. Refer to your institution’s financial (billing) counselor if one is available to assist with billing issues.

Social workers and caseworkers can help better understand insurance coverage as well as submit claims and paper work for Medicare or Medicaid, and may be able to refer pt to assistance programs from organizations that may help with the cost of remaining bill.

Make sure patient read and understand their policy to learn which services are covered and the portion of medical expenses they’ll be responsible for paying. If patient is being denied health coverage for specific treatments, meet with the hospital administrator or a patient advocate.

Journey Connections has specific “Financial Assistance” category, that contains resources to assist with paying for health insurance and care.

Share Patient Links and Handouts as appropriate. See ACA links below in References for additional information.

If NO

Do you need help getting health insurance?

Do you need to reinstate your insurance?

• Instruct patient to contact their insurer immediately if they have not done so to explain their situation.

Next Step

Patient may need social worker or patient navigator assistance.

If appropriate, connect patient to Affordable Care Act (ACA) health insurance website (link below). ACA agencies can help patients enroll, but patient may need social worker or patient navigator assistance connecting with best agency from which to acquire health insurance.

Next Step

Notes

Health care insurance can be acquired through several avenues based on income, age, employment, lack of employment, dependents, etc. Some options may include private health insurance, employer provided, Affordable Care Act Health Insurance Marketplace policies, Medicare or Medicaid. Undocumented immigrants might apply for coverage on behalf of documented individuals. Charity care may also be available through your institution.

Patient Links and Handouts:

➢ American Cancer Society, Understanding Health Insurance
➢ Affordable Care Act, (ACA) Health Insurance Marketplace
➢ ACA Premium Payments, Grace Periods & Termination Information
➢ American Cancer Society, Health Insurance and Financial Assistance for the Cancer Patient
➢ HealthCare.gov, Health coverage for immigrants
➢ LLS, Finances and Insurance Coverage
➢ HealthWell Foundation®,
➢ Patient Advocate Foundation, Co-pay relief
➢ Cancer Net, Managing the cost of Cancer Care
➢ Cancer Net, Financial Considerations
➢ Livestrong, Health and Disability Insurance
➢ Livestrong, Cancer Navigation
➢ PAF, Patient Advocate Foundation, Getting Care While Uninsured

CSOC Patient Handout can be accessed at: http://cancer-help.me/insurance

References:

➢ About the Affordable Care Act, Regulations & Guidance
➢ ACA in Action at CMS

➢ Social Security Disability
➢ Medicaid
➢ Medicare

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### Practical Concerns – 
**“YES” to Paying for medications or medical care**

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<tr>
<th>Start With</th>
<th>Next Step</th>
<th>Timing</th>
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<tbody>
<tr>
<td><strong>Do you have health insurance?</strong></td>
<td><strong>If NO</strong></td>
<td><strong>Sub Acute: 1-3 days to Routine within 1 week</strong></td>
</tr>
<tr>
<td></td>
<td>Do you need help getting health insurance?</td>
<td>if not interfering with care or at next scheduled physician visit</td>
</tr>
<tr>
<td></td>
<td><strong>If YES</strong></td>
<td></td>
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<tr>
<td></td>
<td>Is your insurance adequately covering your medical bills?</td>
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<td></td>
<td>Have you contacted your insurance provider for help?</td>
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<tr>
<td></td>
<td>Have you applied for financial assistance in the past?</td>
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<td></td>
<td>Have you spoken with a financial counselor at the hospital?</td>
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<td></td>
<td>Are you enrolled in any compassionate use or expanded access (EAPs) programs?</td>
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<tr>
<td></td>
<td><strong>If YES</strong></td>
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<tr>
<td></td>
<td>Share Patient Links and Handouts as appropriate</td>
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<tr>
<td></td>
<td><strong>Notes</strong></td>
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<td><strong>Stage IV:</strong> Explore use of medication relative to patient goals; consider quality of life as an alternative to treatment.</td>
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<td></td>
<td>Patients need to understand the intent of any treatment or medications. Determine if patients acknowledges their prognosis and how medications and treatment how they will affect their quality of life.</td>
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</table>

### Patient Links and Handouts:
- HealthCare.gov, US Government Health Insurance Exchange
- NeedyMeds, Find help with the cost of medicine
- PAN Foundation, help for underinsured
- Partnership for Prescription Assistance®
- Patient Advocate Foundation, Co-pay relief
- HealthWell Foundation®, copay assistance for medication/therapy
- American Cancer Society, Finding and Paying for Treatment
- American Cancer Society, Compassionate Drug Use
- American Cancer Society, Help paying for Prescription Drugs
- Social Security, Benefits for People with Disabilities
- Coleman Foundation Follow Up Reference Document: ‘Practical Concerns – “YES” to insurance coverage issues or no health insurance’
- CSOC Patient Handout can be accessed at: http://cancer-help.me/insurance

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Practical Concerns – “YES” to “I live alone”

Start With
Asking the patient the below questions

[Sometimes people need help with basic care needs.]

Do you have someone you can depend on to help with basic care needs such as bathing and dressing?

If Yes

Further inquire, document in referral:
• Ask who the help is and when available
• Does pt need more help or support?
• Inquire if patient currently has any home services (i.e. homemaker, hired caregiver, visiting nurse) and if not, does pt need help getting them?
• Inquire if there is an understanding of how their cancer diagnosis or treatment may affect their abilities
• Conduct an ADL/IADL assessment
• If there is any question about the patient’s cognitive condition, make note on referral

Patient with ADL/IADL inability:
Refer to Physician/APC or Nurse
• Assess for patient frailty or physical function. Physical difficulties may be partially or fully reversible, consider referral to PT/OT
• Discuss progression and treatment if there is a lack of understanding
• Screen for cognitive issues if indicated

As a clinician do you have concerns about this patient living alone currently or in the near future? Ability to live alone should be based on:
• Physical Function Status
• Emotional Status
• Cognitive Status
Refer to Social Worker for assistance with home services

Patient with no ADL/IADL abilities:
Refer to Social Worker for assistance with home services

If No

Further inquire, document in referral:
• Encourage patient to seek out any help they have used in the past (Family, friends, faith community, neighbors)
• Inquire if patient has ever used home services (i.e. homemaker, hired caregiver, visiting nurse) and if not, does pt need help getting them?
• Conduct an ADL/IADL assessment
• If there is any question about the patient’s cognitive condition, make note on referral

NOTE: If patient reports living alone, has no services, and has difficulty with ADLs/IADLs—should prompt an urgent referral to social work and PT

Next Step

Patient Links and Handouts:

- Coping With Cancer When You’re On Your Own: How to Get the Support You Need
- American Cancer Society, Support Programs and Services in Your Area
- Cancer Support Community
- Little Brothers, Friends of the Elderly

CSOC Patient Handout can be accessed at: http://cancer-help.me/self-help

Follow Up Reference for Clinicians

Notes

Any Stage – Patients at any stage may need services if living alone. Conducting a ADL/IADL assessment will help indicate if there is enough help or a need of help. Medication adherence or transportation (See Follow Up Reference to “Transportation” concerns for guidance) issues may need addressing. May have financial issues paying for services if low income or getting services from Department of Aging.

Stage IV – Several stage IV cancers qualify under compassionate allowances for quickly obtaining Social Security Disability Insurance or Supplemental Security Income programs, which could have pay for home care services.

Geriatric - Geriatric sub-team discussing clinician guidance for physical frailty and function assessment, info to follow.

References:


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Self Care Concerns –
“YES” to any having someone available to help if...

Start With
asking patient the below question

Have you had help in the past when feeling sick or not being able to run errands?

If Yes
Conduct an ADL/IADL assessment
• Encourage patient to seek out any help they have used in the past
• Family, friends, faith community, neighbors
• Home services (i.e. homemaker, hired caregiver, visiting nurse)
• Do you need help paying for home services?
Inquire if there is an understanding of how their cancer diagnosis or treatment may affect their ability to live at home alone.
Document patient’s responses and note in referral.

If No
Conduct an ADL/IADL assessment
• Do you need assistance getting home services (i.e. homemaker, hired caregiver, visiting nurse)?
• Do you need help paying for home services?
• Inquire if they have family, friends, neighbors, or a Faith community from whom they would be comfortable asking for help.
Inquire if there is an understanding of how their cancer diagnosis or treatment may affect their abilities.
Document patient’s responses and note in referral.

Follow Up Reference for Clinicians

Notes
Any Stage – Patients at any stage may need help. Needing assistance may arise as a result of treatment. Financial issues may be a barrier to getting services, offer any assistance available i.e., low income or already getting services from Department of Aging. Patients may need guidance asking for help. “Do you need help asking for help?” Provide prompts to educate the pt on how to ask for help “you’ve offered to help, could you ________? Role play as a possible tool to help.

Stage IV – Several stage IV cancers qualify under compassionate allowances for quickly obtaining Social Security Disability Insurance or Supplemental Security Income programs which could help pay for home care services.

Geriatric - Geriatric sub-team discussing clinician guidance for screening, info to follow. Local Senior Citizen’s Centers may have social workers who could have helpful resources.

Patient Links and Handouts:

- CancerCare, Coping With Cancer When You’re On Your Own
- American Cancer Society, Support Programs and Services in Your Area
- Cancer Support Community
- Family Caregiver Alliance®
- Ill Dept of Human Services, Home Services
- The Catholic Charities
- Culinary Care
- Care.com

CSOC Patient Handout can be accessed at: http://cancer-help.me/self-help

References:


Websites for communicating, help and support:

- My Cancer Circle
- CaringBridge
- CaringBridge (Spanish)
- Lotsa Helping Hands
- MyLifeLine
- Take them a meal
- Meal train
- PostHope
- MyLifeLine

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31
SOC Toolkit
Version 02.2022
Family/Caregiver Concerns –
“YES” to Concerns about my children

Start With
Asking the patient the below questions

What are your specific concerns about your children?

How old are your children?
• If young, who is their primary caregiver?

Do they know about your illness? If so, what do they know?

Are you too sick to care for your children?

Approach

If the children are not aware of the illness:
• discuss the concerns about disclosing
• If wanted, develop or share a plan how to discuss with children, how their lives are being impacted and/or will be impacted. (See links below)

Is there an increase in problematic behaviors since learning about the illness?
For example:
• not enjoying what they typically have enjoyed prior to diagnosis?
• asking for repeated reassurances?
• clingier than before?
• changes in their sleep & appetite?
• Has their performance in school changed?

If exhibiting, document in patient EMR that states children are not coping well/displaying problematic behavior.

If patient feels that they are too sick to care for their children, ask the patient if they need help with caregiving arrangements for their children.
• How would you feel about sharing this concern with your family, friends, community groups or faith community as a way to seek support?

If there is a negative effect on the children’s schooling, suggest patient have a discussion with the teacher and/or school social worker.

Next Step

Refer as applicable to:
Child life specialist, counselor, social worker, cancer resource/support center resources or chaplains.
• Can assist with family discussions
• May be able to assist with temporary caretaking resources
• Can offer additional help and support
• Can schedule an appointment for assessment with counselor or social worker if children are not coping well/displaying problematic behaviors

If the children are displaying problematic behaviors, a referral to family/child specific psychosocial services may be considered.

Share Patient Links and Handouts as appropriate
See Reference Link Below

Timing

Discuss same day if possible

Acute – within 24 hours if interfering with care

Routine - within 1 week if not interfering with care

Notes

Stages I-III: Cancer Support Centers often have programs and services to help families. See Reference links below for information on how to talk to children about a loved one’s cancer.

Stage IV: For single parents proper legal paperwork is need to determine custody plans for children under the age of 18 for when a parent is no longer able to care for the children. Patients may need help in securing legal assistance.

Patient Links and Handouts:

- American Cancer Society, Helping Children When a Family Member Has Cancer
- Cancer.Net, Talking With Your Children
- Cancer.Net, Talking With Family and Friends
- NIH, Talking to Children about Your Cancer
- CancerCare, Helping Children Understand Cancer: Talking to Your Kids About Your Diagnosis

CSOC Patient Handout can be accessed at:
http://cancer-help.me/children

References:

- The ASCO Post, Helping Patients Talk to Their Children About Cancer, Paula K. Rauch, MD
- CANCERCare* Online Support Groups, share with patient/family/caregiver if clinician considers appropriate

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### Start With

**Asking the patient the below questions**

Do you have serious concerns about how your partner is handling your cancer diagnosis or in need of additional physical or emotional support?

Are you able to openly communicate with your partner about your illness?

Is your partner supportive of you as you manage this illness?

Has your relationship changed between your partner?

Have you completed written documentation as to who would make healthcare decisions if you cannot?

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<thead>
<tr>
<th><strong>IF YES</strong></th>
<th><strong>Next Step</strong></th>
<th><strong>Timing</strong></th>
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</table>
| If not significant:  
- help to normalize this experience noting that it is not uncommon for partners to have difficulties with their loved one’s cancer.  
- Share Patient Links and Handouts as appropriate | Refer to social worker or mental health counselors if there is significant concern.  
Refer to appropriate support group in person or online, cancer resource or cancer support center and if possible, schedule an appointment with the service.  
Share Patient Links and Handouts | Depending on level of distress, can be discussion same day or within 1-3 days |
| If significant:  
- suggest a referral to counseling or medical professional for the partner.  
- Share Patient Links and Handouts | | |

### Notes

**Stages I-III:** It is important that the patient and partner’s goals of care align or are understood (see link in References for CSOC Palliative Training Module Goals of Care). Patients or partners may be in need of more information or education. Encourage partner to attend all medical appointments, not attending medical appointments with patient can bring about communication issues.

**Stage IV:** Additional caregiver support, caregiver respite or end-of-life support may be needed at this stage.

### Patient Links and Handouts:

- ACS, For spouses, families, and friends
- LIVESTRONG, Communicating With Your Partner
- CancerCare, Online Caregiver Support Group – Spouses/Partners
- Well Spouse Organization, Support, Sharing, and Social Community
- NIH, Family Caregivers in Cancer
- NIH, Facing Cancer with Your Spouse or Partner
- Cancer.Net, Talking With Your Spouse or Partner

[CSOC Patient Handout can be accessed at: http://cancer-help.me/partner](http://cancer-help.me/partner)

### References:

- NIH Family Care Givers in Cancer: Roles and Challenges (PDQ®)
- NCCN Continuing Education, Coleman Supportive Oncology Training Modules
  
Several modules are helpful, specifically:
  
- How to Discuss Practical and Family Concerns
- Goals of Care and Advanced Care Planning Over Time
- POLST Paradigm – Physician Orders for Life-Sustaining Treatment

- CANCERCare® Online Support Groups, share with patient/family/caregiver if clinician considers appropriate

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Family/Caregiver Concerns – “YES” to Concerns about caregivers

**Start With**
Asking the patient the below questions

What do your caregivers do to assist you in your care?

Do you feel like your caregivers need additional help right now?

Are you concerned about your caregiver’s physical or emotional health?

How informed are your caregivers about your current health status?

Have you completed written documentation as to who would make healthcare decisions if you cannot?

**Approach**
Have a discussion/share relative options with the patient

- Provide contact information for physician and/or patient navigator that the patient can share with caregivers if they become concerned and need assistance

- Assure patient that there are support resources for caregivers and many caregivers use this support

**Next Step**
Refer to a social worker, cancer center or support center for additional resources

If there is a serious concern about the patient’s caregiver:
- Refer to psychologist or social worker to meet with caregiver(s) and patient to address concerns
- If needed plan around re-establishing a support team to assist the patient if caregiver is not able

Share Patient Links and Handouts as appropriate

See Reference links below for additional information

If the patient and/or family is homeless or having housing issues, see “Follow Up Reference for Issues paying for food or housing – HOUSING ONLY”

Refer to Palliative Care or Social Worker or whomever in your institution assists with legal documentation

Instruct patient to keep copies of completed forms with them at all times

See link in References for CSOC Palliative Training Module POLST Paradigm – Physician Orders for Life-Sustaining Treatment and Advance Care Planning Over Time

**Timing**
Routine – within 1 week if not interfering with care

Acute – within 24 hours if interfering with care or for advanced directives completion IF the patient has a poor prognosis. Otherwise, within 30 days

**Notes**
Stages I-IV: Caregivers can show symptoms of anticipatory grief, exhaustion, burnout, burden of multiple care giving roles, having medical or financial issues themselves. It is strongly suggested that caretakers attend appointments with patient. Sometimes issues can arise when goals of care are different between patient and caretaker. All caretakers, to extent authorized by patient, need to be aware of patient’s Goals of Care and should have copies of POLST (advanced stage) and POA for Healthcare.

**Patient Links and Handouts:**
- NCCN, Patient and Caregiver Resources
- American Cancer Society, Caregivers and Family
- NIH, Support for Caregivers of Cancer Patients
- NCI, Support for Caregivers, Advanced Cancer
- Cancer.Net, Caring for a Loved One
- LIVESTRONG, Caregiver Support
- Caregiver Action Network

CSOC Patient Handout can be accessed at: http://cancer-help.me/caregiver

**References:**
- National Alliance for Caregiving (NAFC)
- NAFC/AARP, Caregiving in the US, 2015
- NCCN Continuing Education, Coleman Supportive Oncology Training Modules
  - Several modules are helpful, specifically:
    - How to Discuss Practical and Family Concerns
    - Addressing Symptoms that Impact Quality of Life:
      - Nausea/Vomiting, Constipation, Dyspnea & Shortness of Breath
- CANCERCare® Online Support Groups, share with patient/family/caregiver if clinician considers appropriate

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**Family/Caregiver Concerns – “YES” to Ability to have children**

*It is vitally important that a patient who is interested in reproductive options/fertility meets with an onco-fertility clinic as soon as possible. Fertility diminishes with many onco-therapies/treatments and the process of fertility must happen before onco therapy. If a patient is an advanced stage, this may not be feasible.*

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<tr>
<th>Start With</th>
<th>Approach</th>
<th>Next Step</th>
<th>Timing</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Asking the patient the below questions</strong></td>
<td><strong>Has the doctor spoken to you about if or how cancer treatment may affect your ability to have children?</strong></td>
<td><strong>If patient has not started drug treatment, provide contact information for fertility preservation and encourage patient to have appointment as soon as possible and before treatment.</strong></td>
<td><strong>Fertility Hotline</strong> 312-503-3378 312-503-3378 312-926-2000 312-355-2634</td>
</tr>
<tr>
<td><strong>Would you or your partner like further information on ability to have children?</strong></td>
<td><strong>If drug treatment has started, encourage the patient to discuss with their physician how the treatment may affect fertility.</strong></td>
<td><strong>Even if patient does not want further information, inform them that there are available resources that can be provided to them and/or their partner in the event they decide they would like additional information and that the options change after drug treatment is started.</strong></td>
<td><strong>Same Day if possible</strong> if there are concerns about fertility being preserved and drug treatment has not started or if the patient and/or partner are experiencing significant emotional distress, this will require immediate attention</td>
</tr>
<tr>
<td></td>
<td><strong>If there is a partner, determine if the partner needs any supports.</strong></td>
<td><strong>If there is a partner, determine if the partner needs any supports.</strong></td>
<td><strong>Routine - within 1 week:</strong> If there is no immediate treatment planned and/or no significant emotional distress</td>
</tr>
</tbody>
</table>

**Local Resources**
- Northwestern Medicine Fertility and Reproductive Medicine
- Northwestern Patient Navigator for Fertility Preservation
- Ann & Robert H. Lurie Children's Hospital of Chicago, Fertility & Hormone Preservation & Restoration Program
- UI Health, Fertility Preservation Program

**Patient Links and Handouts:**
- NCCN, Cancer and Fertility
- American Cancer Society, Fertility and Women With Cancer
- American Cancer Society, Fertility and Men With Cancer
- LIVESTRONG, Becoming a parent after cancer
- Cancer.Net, Fertility Concerns and Preservation for Women
- Cancer.Net, Fertility Concerns and Preservation for Men
- NIH, Sexual and Fertility Problems (Women)
- NIH, Sexual and Fertility Problems (Men)

CSOC Patient Handout can be accessed at: http://cancer-help.me/have-children

**References:**
- NCCN Guidelines, Adolescent and Young Adult Oncology, Fertility/Endocrine Considerations
- ASCO, Fertility Preservation
- Oncofertility: A New Medical Specialty Helping Young Cancer Patients Have Children
- The Oncofertility Consortium

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Family/Caregiver Concerns – 
“YES” to Concerns about other family members

Start With
Asking the patient the below questions

Are you able to disclose your illness to your family members?
Do your family members need additional information about your illness that you need help to provide?
Are your family members supportive of you?
Do you family members need help to cope with your illness?
In what ways has your family relationships changed?
Do your family members have their own illnesses or challenges?

If patient or family members are in need of assistance or additional information:
- see Patient links and Handouts for information and assistance with concerns
- Have a discussion/share relative options with the patient or family member
- Provide list of resources to the patient.
- If possible and wanted, help connect family member with resources

Document all responses and include in medical record and/or referral if referring to another medical professional

Next Step
If additional help is wanted, refer patient to social worker or physician/APN appropriately based on the specific concern. Referral may include family members to discuss patient concerns, assuming patient is requesting this intervention.

Refer patient or family members to a cancer wellness community for information and support if available and wanted.

If family members are not coping well with the diagnosis, make appropriate referral to social worker, counselor, spiritual advisor based on family member’s needs to provide the family member with support.

If family member is the caregiver, refer to social worker, counselor, or other appropriate mental health specialist to ensure that he/she is aware of the needs of this role and supports available if needed.

Share Patient Links and Handouts as appropriate.

Timing
Routine - within 1 week if not interfering with care or unless there is an immediate concern to the safety of the patient or family member.
Routine - within 1 week if not of immediate concern

Notes
Stages I-IV: When a patient does not have family member support, always document in medical record. This will be necessary in the event that this becomes a limiting factor to mental and physical care. Caregiver wellness is often critical to patient’s ability to access medical treatment and wellbeing and safety at home; key is to determine their ability to meet the demand of this role and to be supported when needed. Caregivers should be told that there are support groups, in person/online/by phone, available to them if they begin to feel overwhelmed or isolated.

Patient Links and Handouts:
- NCCN, Patient and Caregiver Resources, Advocacy and Support Groups
- ASCO, Talking with Family and Friends
- American Cancer Society, After Diagnosis: A Guide for Patients and Families
- American Cancer Society, Helping Children when a Family Member Has Cancer
- Cancer.Net, Family Life
- NIH, Changes for the Family

CSOC Patient Handout can be accessed at: http://cancer-help.me/family

References:
- CANCERCare® Online Support Groups, share with patient/family/caregiver if clinician considers appropriate

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**Spiritual/Faith/Religious Concerns – “YES” to Do you struggle with the loss of meaning and joy in your life? or Do you have religious or spiritual struggles?**

<table>
<thead>
<tr>
<th>Start With</th>
<th>If YES</th>
<th>Next Step</th>
<th>Timing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Share/ask the patient the below.</td>
<td>Encourage patient to seek out any help they have used in the past that helped with their struggles.</td>
<td>Based on the patient’s answers to the clarifying questions, consider:</td>
<td>If this is an area that is causing an existential crisis, depression or anxiety, discuss same day.</td>
</tr>
<tr>
<td>If they have no resource, see the below clarifying questions and refer accordingly.</td>
<td>• Referral to a chaplain/spiritual leader</td>
<td>• Referral for mindfulness/meditation</td>
<td>If the distress in this area is mild to moderate, the timing can be routine, within 1 week.</td>
</tr>
<tr>
<td>If NO</td>
<td>Clarify what the physical, mental, emotional and/or spiritual manifestations of the patient’s concerns are. Is the patient:</td>
<td>• Referral to a support group</td>
<td></td>
</tr>
<tr>
<td>• Experiencing anxiety or depression?</td>
<td>• Referral for religious counseling</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Unable to sleep, eating too much or too little?</td>
<td>• Referral for psychological referral</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Feeling alone, without a support system?</td>
<td>• Referral for medication/treatment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Feeling helpless/hopeless?</td>
<td>• Referral for mindfulness/meditation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Feeling disconnected from sources that used to offer solace, e.g. Religion/Spirituality or want a connection to Religion/Spirituality</td>
<td>See Reference links below for additional information</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Follow up by asking:</td>
<td>Share Patient Links and Handouts as appropriate</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Did you feel this way before your diagnosis?</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Notes**

It is helpful for providers to understand how broad the definition of Spirituality is. When helping to address these concerns not only focus on strictly religious issues, but also on important concepts like making sense out of the cancer diagnosis, isolation, loneliness, etc.

Spirituality can be defined as the aspect of humanity that refers to the way individuals seek and express meaning and purpose, and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred.1

Spiritual well-being in cancer patients reduces depression, decreases despair near end of life, decreases a desire for a hastened death, lowers levels of distress and improves quality of life across life expectancy. Spirituality helps patients adjust to and cope with the cancer experience, find meaning and purpose and find a sense of health in the midst of disease.2

**Patient Links and Handouts:**

- NCCN, Finding Comfort in Spirituality
- NIH, Spirituality in Cancer Care (PDQ®)
- NCI Support for People with Cancer, Taking Time
- HealthCare Chaplancy Network™, Can’t Believe I Have Cancer

CSOC Patient Handout can be accessed at: http://cancer-help.me/spiritual

**References:**

- Improving the Quality of Spiritual Care...Consensus Conference:
- National Consensus Project, Domain 5, Spiritual, Religious and Existential Aspects of Care
- NIH, PDQ®, Spirituality in Cancer Care SpringerLink, Spirituality and meaning....abstract
- Spirituality and meaning in supportive care: spirituality-and meaning-centered group psychotherapy interventions in advanced cancer....abstract
Physical Concerns – “YES” to Breathing

Start With
Asking the patient the below questions

Are you having trouble breathing normally just sitting here in this room?

If YES
A “yes” answer should trigger immediate attention by a nurse, APC or physician in clinic if available, or emergency room who should obtain:
Objective, clinical data including history, physical examination
- Physician examination should include O2 saturation at rest and with exertion.

Next Step
Primary treating medical team is first-line to address. This team could include a primary care provider or emergency room physician depending on what location or provider the patient seeks.

Refer to Physician/APC
Primary treating team decide whether to send for additional evaluation and testing for cause of dyspnea (CXR, CT scan perhaps pulmonary embolism protocol, echo, cardiac rule-out, hemoglobin, etc.)

If Severe:
Acute - WITHIN 24 hours

If not Severe:
Sub Acute 1-3 days

Timing
Urgent – See APC, Physician before leaving or send to EMERGENCY ROOM

Notes
Stages I-II: Assess for disease recurrence or comorbid condition to manage (for example a new effusion, heart failure, volume overload, pulmonary embolism, anemia). May need palliative care for symptom management (primary palliative care). May be a role for physical medicine, pulmonary rehab, or physical therapy referral at this point if the patient is feeling short of breath and there is no clear cause.

Stage IV: Assess for acute reversible conditions, co-morbidities. Typically the oncologist would handle if reversible, causes not related to an underlying co-morbidity which might be treated by a different subspecialist. If symptoms are due to late stage disease progression, for example breathlessness due to progression, please consider:
- Thoracentesis if moderate to large pleural effusion; or placement of indwelling pleurex catheter if repetitive thoracentesis expected
- Fan for relief of dyspnea - discuss whether NIPPV indicated, wanted, helpful or able to be delivered
- Medications like opioids or decadron for shortness of breath
Consider palliative referral (see NCCN guidelines for Dyspnea) if shortness of breath is not relieved by standard opioids or if the patient has another complex end of life (EDL) need.

Geriatric: Similar process of care for all ages

Patient Links and Handouts:
- American Cancer Society, Shortness of Breath
- Cancer.Net, Shortness of Breath or Dyspnea
- NIH, Home Oxygen Safety
CSOC Patient Handout can be accessed at: http://cancer-help.me/breathing

References:
- NCCN Palliative Care, Dyspnea, PAL-11
- NCCN Palliative Care, Venous Thromboembolic Disease

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Physical Concerns – “YES” to Constipation

Start With

Asking the patient the below question

Did your constipation start with a new medication or treatment?

If YES

Options/Recourse

MA or higher level screener: communicate answer of yes to constipation starting with a new medication or treatment to Physician/APC and referral or notes for Next Step

APC or higher screener:

• Assess for cause and severity
• Rule out impaction, especially if diarrhea accompanies constipation (overflow around impaction)
• Rule out obstruction (history, physical exam and abdominal x-ray. Consider GI consult if stenting is feasible for obstruction)

If NO

Options/Recourse

MA or higher level screener: communicate this answer of no to recent onset of diarrhea to Physician/APC in referral or notes for Next Step.

APC or higher screener:

• Assess for cause and severity of constipation, whether impaction present
• Potential other causes (e.g., hypercalcemia, hypokalemia, hypothyroidism, diabetes mellitus, medications)

Constipation Preventive Measures

• Increase fluids
• Increase dietary fiber if patient has adequate fluid intake and physical activity. With opioid induced constipation – Never recommend over the counter fiber supplements (e.g.; Metamucil, Citrucel) for first line treatment.
• Exercise, if appropriate
• Laxative, stool softeners, suppository may be needed if difficulty evacuating stool
• Colace does not work well for opioid induced constipation – patients usually need a daily laxative (sometimes colace is used in conjunction with senna)
• Frail patients may benefit from step stool to raise legs while sitting on toilet – helps with evacuation in setting of weak abdominal muscles

Next Step

Refer to Physician/APC

Nurse can assess for:

• Impaction, use algorithm for management
• Difficulty evacuating and recommend suppositories
• Make sure to screen for difficulty evacuating stool

If obstruction – send to ER.

If no BM in more than two days: Sub Acute 1-3 days

Follow Up Reference for Clinicians

Notes

Stages I-II: Refer to NCCN guidelines. Make sure to take a careful history. Is issue with straining or more of an issue with evacuation of stool? Review medications carefully. If constipation mild, can try dietary modification and increased fluid intake first. If patient not on opioids and ambulatory, can try fiber supplement. Avoid fiber supplements if constipation is opioid induced. If constipation moderate to severe, may need assessment for stool impaction.

Stage IV: Refer to NCCN guidelines. Very preventable if from opioids, try to prevent constipation that is medication induced. Make sure a bowel regimen is prescribed for all patients receiving an opioid prescription. Avoid fiber supplements if constipation is opioid induced. If constipation moderate to severe, may need assessment for stool impaction.

Geriatric: Constipation is very common. With age there is less water in body, easily dehydrated, narcotics effects are stronger and can happen quicker. Co-morbidities and polypharmacy should both be considered as reasons for constipation in this population.

Patient Links and Handouts:

- American Cancer Society Constipation Information
- Cancer.Net, Constipation
- NIH, Gastrointestinal Complications (PDQ®)
- NIH, Constipation

CSOC Patient Handout can be accessed at: http://cancer-help.me/constipation

References:

- NCCN Guidelines® Palliative Care Constipation, PAL-17
- NIH (PDQ®), Gastrointestinal Complications—Overview
- NCCN Continuing Education, Coleman Supportive Oncology Training Modules

Several modules are helpful, specifically: Constipation

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Physical Concerns – “YES” to Diarrhea

Start With
Asking the patient the below questions

Did your diarrhea start with a new medication or treatment?

If YES

Options/Recourse
MA or higher level screener:
communicate yes, that diarrhea started with a new medication or treatment to Physician/APN and referral or notes for Next Step.

APN or higher screener:
Assess for Possible Etiologies
• Recent antibiotic use
• Chemotherapy regimen side effects
• Medications that frequently induce diarrhea

Next Step
Refer to Physician/APN or Nurse
• If no contraindications, consider immediate antidiarrheal therapy indicated by grade.
• If chemotherapy induced, consider decreasing or delaying the next dose of chemotherapy based on severity of the diarrhea

Timing
Routine - within 1 week
- or -
If unable to keep hydrated: Urgent – See Physician/APN or Nurse before leaving or send to EMERGENCY ROOM

If NO

Options/Recourse
MA or higher level screener:
communicate this answer of no to recent onset of diarrhea to Physician/APN and referral or notes for Next Step.

APN or higher screener:
• Look for signs of infectious diarrhea
• Evaluate whether diarrhea arose from an aggressive bowel regimen
• Evaluate whether diarrhea is a symptom of an evolving bowel obstruction
• Dietary changes
• Is there a history of inflammatory bowel disease or irritable bowel disease
• Malabsorption
• Screen for C. diff if indicated

Next Step
Refer to Physician/APN or Nurse
• If fecal impaction is suspected, confirm with rectal exam, or x-ray
• If fecal impaction:
  ➢ Premedicate patient with opioids or anxiolytics
  ➢ Treat with digital disimpaction
  ➢ Enemas until clear
• Consider antidiarrheal therapy if no contraindications
  (Usually loperamid)
• Consider GI referral
• Consider Colonoscopy in some patients

Timing
Routine - within 1 week
- or -
If unable to keep hydrated: Urgent – See Physician/APN or Nurse before leaving or send to EMERGENCY ROOM

Notes
Stages I-IV: Make sure to take a careful history regarding stool frequency and assess for dehydration. Review chemotherapy regimen side effects and other medication side effects. Could diarrhea be infectious? If possibility of infection, avoid antidiarrheal therapy. Assess for hydration status. Especially for frail patients, patient may have diarrhea due to fecal impaction causing stool overflow.

Geriatric: Diarrhea in this population can cause dehydration quickly. Antibiotics can cause diarrhea sooner than in younger patients. Make sure to educate the patient on the danger of dehydration and when to call if diarrhea is not controlled.

Patient Links and Handouts:
➢ American Cancer Society Diarrhea Information
➢ Cancer.Net, Diarrhea
➢ NIH, Diarrhea
➢ ASCO answers, Diarrhea

CSOC Patient Handout can be accessed at: http://cancer-help.me/diarrhea

References:
➢ NCCN Guidelines Palliative Care Diarrhea, PAL-18
➢ Senior Adult Oncology
➢ NCCN Continuing Education, Coleman Supportive Oncology Training Modules
Several modules are helpful, specifically: Diarrhea

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## Physical Concerns – “YES” to Fevers

### Start With
Asking the patient the below questions

<table>
<thead>
<tr>
<th>Have you have a fever of 100.5 or greater in the past 24 hours?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have you taken any medication to reduce the fever in the past 8 hours?</td>
</tr>
</tbody>
</table>

### If YES or NO

- Check patient’s current temperature
- Further inquiry as appropriate:
  - Are you receiving chemotherapy?
    - A “yes” answer should trigger immediate attention by a nurse, APC or physician in clinic if available, or emergency room
    - If “no”, further inquire about other symptoms e.g., chills, cough, sore throat, body aches, urinary burning. Communicate these answers in referral or notes for Next Step

- Refer to Physician/APC
  - Physician/APC to rule out febrile neutropenia
  - If fever of unknown origin in the later stages of illness, may consider referral to palliative care
  - See Reference links below for additional information
  - Share Patient Links and Handouts as appropriate

### Next Step
Refer to Physician/APC

### Timing
Urgent – See Physician/APC before leaving or send to EMERGENCY ROOM

### Acute – within 24 hours

### Notes

**Stages I-III:** If patient is undergoing chemotherapy, fever >100.5 may be a sign of a serious life threatening infection. These patients need prompt medical attention to rule out febrile neutropenia. Patients will need a physical examination, blood work (CBC, blood cultures), chest x-ray, urine studies performed. Would not treat fever until after proper evaluation.

**Stage IV:** Same as above. If determined that persistent fevers are “tumor fevers” due to the cancer itself, patient may receive antipyretics around the clock with acetaminophen, NSAIDS or hi-dose steroids.

**Geriatric:** Temperature of 101 or greater should be immediate/urgent care or if not available, to the ER for evaluation. Older adults have a harder time generating a fever response. Ask about chills and sweats. Fevers in this population should be taken very seriously and need aggressive care. Family and care takers need to be education on the danger of fever in an older person and when to seek medical care. Both flu and pneumonia vaccines are usually recommended, especially with a cancer diagnosis.

### Patient Links and Handouts:
- [American Cancer Society, Fever](#)
- [CDC, Prepare: Watch out for Fever](#)
- [NIH, NCI Infection and Neutropenia](#)
- CSOC Patient Handout can be accessed at: [http://cancer-help.me/fever](http://cancer-help.me/fever)

### References:
- [NCCN Prevention and Treatment of Cancer-Related Infections](#)

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Physical Concerns – “YES” to Nausea or Vomiting

Start With

Did your symptoms start with chemotherapy or another new medication?

IF YES

MA level screen: communicate this answer of yes to symptoms starting with chemotherapy or new medication directly to Physician/APC and in referral or notes for Next Step

APC or higher screen:

Access for possible etiologies

- Chemotherapy related
- Review ALL medications as possible cause
- Opioid related
  - could be opioid induced nausea, usually a temporary symptom that abates as patient grows accustomed to the medication
  - Could be result of opioid induced constipation

IF NO

MA level screen: communicate this answer of no to symptoms starting with chemotherapy or new medication directly to Physician/APC and in referral or notes for Next Step

APC or higher screen:

Access for possible Etiologies

- Review ALL medications as possible cause
- Due to partial or complete bowel obstruction
- Is patient constipated
- Does the patient have any neurologic symptoms that would raise the concern of CNS involvement
- Is there progression of cancer
- Is it anticipatory nausea
- Is it due to pain

Next Step

Refer to Physician/APC or Nurse

Consider Antiemetics

If due to chemotherapy consider:
- 5HT3 antagonist (i.e. ondansetron)
- NK-1 Receptor antagonist (i.e. aprepitant)
- Dexamethasone
- Metoclopramide
- Prochlorperazine

If anticipatory nausea/vomiting consider Lorazepam

If due to increased intracranial pressure, consider dexamethasone

See Reference links below for additional information

Share Patient Links and Handouts as appropriate

Timing

If dehydration present: Acute - WITHIN 24 hours

If no dehydration present: Sub-Acute 1-3 days

Notes

Stages I-III: Oncologist should be aware of concerning symptoms because may be related to cancer progression. A good history is key. Nursing staff can also be trained to fully assess symptoms.

Stage IV: Oncologist should be aware of concerning symptoms because may be related to cancer progression. A good history is key. Nursing staff can also be trained to fully assess symptoms. See NCCN algorithms for management of nausea and vomiting related to chemotherapy.

Geriatric: This population may have issues with fluids and keeping hydrated which can exacerbate dehydration concerns. Dangerous dehydration issues can happen quickly, within a day. Especially with opioid use.

Patient Links and Handouts:

- American Cancer Society Nausea and Vomiting
- ASCO answers, Nausea and Vomiting
- Cancer.Net, Nausea and Vomiting
- NIH, NCI Nausea and Vomiting Related to Cancer Treatment (PDQ®)
- CancerCare, Chemotherapy-Induced Nausea and Vomiting
- CancerCare, Tips for Managing Nausea

CSOC Patient Handout can be accessed at:
http://cancer-help.me/nausea-vomiting

References:

- NCCN Guidelines Palliative Care Nausea and vomiting Interventions, PAL-15
- NCCN Guidelines Antiemesis
- NIH, NCI Treatment-Related Nausea and Vomiting (PDQ®) – Health Professional Version
- NCCN Continuing Education, Coleman Supportive Oncology Training Modules
  - Several modules are helpful, specifically: Nausea/Vomiting

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Physical Concerns – “YES” to Sleep

Start With

Asking the patient the below questions

Did your sleep issues start with diagnosis?

Did your sleep issues start with a new treatment?

If YES

Options/Recourse

MA level screener: communicate these answers to Physician/APC in referral or notes for Next Step

APC or higher screener:
Assess for cause

- Optimal management of pain and other symptoms
- Addressing psychological spiritual and existential concerns adequately
- Offer basic sleep hygiene education
- Relaxation training/Cognitive behavioral therapy
- Encourage exercise if appropriate
- Review new or recent medications that may be the cause
- Were steroids given as premeds for chemotherapy

If NO

Options/Recourse

Assess for cause

- Ask if the sleep disturbance is a chronic condition present before diagnosis/treatment
- What if anything improved the condition in the past
- Offer basic sleep hygiene education
- Relaxation training/Cognitive behavioral therapy
- Encourage exercise

Next Step

Refer to Physician/APC or Psychosocial

Any primary care team member who inquires about sleep

• Consider medication to treat, may need to be more cautious in geriatric patient population
• Alter medications if medications are the underlying cause
• Discuss with oncologist possible steroid dose reduction
• Address the psychosocial domain which may contribute

Share Patient Links and Handouts as appropriate

See Reference links below for additional information

Timing

Routine - within 1 week

Acute - WITHIN 24 hours: if insomnia > 3 nights/days

Notes

Stages I-III: Consider whether it is fear of recurrence or due to other life stressors like return to work, relationship issues. Does patient have history of sleep APCEa? Try and avoid hypnotics except for very short term use. Older patients should especially use hypnotics with caution, as they can increase risk of confusion and falls. Review medications that may impact sleep such as steroids, diuretics etc. Thorough sleep history is important.

Stage IV: Be sure to address existential concerns or fear of progression. Review medications that may impact sleep such as steroids, diuretics etc. Thorough sleep history is important. Hypnotics or anxiolytics may be useful to help with sleep if other interventions are not possible or unhelpful. For older or frail patients, assess for fall risk and caregiver support at night before prescribing medication for sleep.

Geriatric: Cognitive issues can be a cause of sleep disturbances. Sleep/wake reversal can happen to older adults. Sundowners is an early sign of cognitive issues and a trigger for a cognitive assessment. Needs aggressive sleep hygiene treatment.

Patient Links and Handouts:

- American Cancer Society, Sleep Problems
- Cancer.Net, Sleeping Problems: Insomnia
- NIH, Sleep Problems
- NIH Sleep Disorders (PDQ®) – Patient Version
- CSOC Patient Handout can be accessed at: http://cancer-help.me/pfh-sleep

References:

- NCCN, Palliative Care, Sleep/Wake Disturbances (PAL-22)
- NCCN, Survivorship, Sleep Disorders (SSD-1)

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### Physical Concerns – “YES” to Changes in urination

#### Start With
**Asking the patient the below questions**

- Are you having too little urine output?
- Are you having too much urine output?
- Is your urine a different color or look different?
- Do you have pain or burning with urination, fever, chills?

#### If YES

**MA level screener:** communicate these answers to Physician/APC in referral or notes for Next Step.

**APC or higher screener: Options/Recourse**

**Further inquiry as appropriate:**
- How long has this been an issue?
- Is there urine leakage or bladder control problems?
- Is patient on furosemide (Lasix)?
- Is patient on any medication or discontinued medication for benign prostatic hyperplasia (BPH) medication?

**Assess for cause**
- Evaluate for reversible condition:
  - Obstruction
  - Infection
- Consider medications as the underlining cause (e.g., opioids, diuretics or anticholinergics)
- Recent addition or increase of IV fluids or oral fluids?

#### If NO

**Options/Recourse**

Ask what the concern is, refer to physician as appropriate

#### Next Step

Refer to Physician/APC
- If infection: obtain urinalysis, urine culture and treat empirically with antibiotics.
- Consider Urogynocology referral if indicated

Refer to urologist or ER if obstruction is suspected.

Share Patient Links and Handouts as appropriate

See Reference links below for additional information

#### Timing

For obstruction:
- Urgent consideration with medical evaluation. May indicate urologic evaluation.

For other concerns:
- Acute- WITHIN 24 hours

#### Notes

**Stages I-III:** If symptoms of possible urinary retention, consider checking post void residual. May treat benign prostatic hyperplasia through primary team or send to urologist for further evaluation. If symptoms are worrisome for obstruction, consider urologic evaluation. Review medications carefully that could impact urination (anticholinergics, diuretics, opioids etc.) See Fast Fact link in References below.

**Stage IV:** If symptoms of possible urinary retention, consider checking post void residual. May treat benign prostatic hyperplasia through primary team or send to urologist for further evaluation. Urinary retention can be quite common in patients with terminal illness. Given patient condition, consider Foley catheter. Review medications carefully that could impact urination (anticholinergics, diuretics, opioids etc.) See Fast Fact link in References below.

**Geriatric:** Incontinence is a prevalent issue, both being and becoming in this population. Patients on chemo can produce large amounts of urine which may be challenging to control. This may then result in conscious reduced fluid intake by patient with dehydration being the repercussion.

#### Patient Links and Handouts:
- [American Cancer Society, Managing Urinary Incontinence for Men with Cancer](http://cancer-help.me/urination)
- [Livestrong, Effects Chemotherapy Has on Urinary Systems](http://cancer-help.me/urination)
- [NIH, NCi, Urinary and Bladder Problems](http://cancer-help.me/urination)
- [Cancer.Net, Urinary Incontinence](http://cancer-help.me/urination)
- [Cancer.Net, Infection](http://cancer-help.me/urination)

CSOC Patient Handout can be accessed at: [http://cancer-help.me/urination](http://cancer-help.me/urination)

#### References:
- NCCN, Abdominal Pain, Perirectal Pain, Diarrhea, and Urinary Tract Symptoms (FEV-7)
- Palliative Care Network of Wisconsin, Fast Fact and Concepts #287, Drug-Induced Acute Urinary Retention
### Physical Concerns —

**“YES” to Difficulty chewing or swallowing**

<table>
<thead>
<tr>
<th>Start With</th>
<th>MA or higher level screener: communicate these answers to Physician/APC in referral or notes for Next Step</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asking the patient the below questions</td>
<td><strong>APC or higher screener:</strong></td>
</tr>
<tr>
<td>Is swallowing difficult?</td>
<td><strong>If YES</strong></td>
</tr>
<tr>
<td>Options/Recourse</td>
<td><strong>Nurse - In the outpatient setting can teach patients to perform oral assessment daily and when to report findings to the clinician</strong></td>
</tr>
<tr>
<td>• Assess imaging for esophageal or other thoracic tumor involvement; role for radiation/stenting in these cases</td>
<td><strong>Physician/APC - should be made aware, especially if this is indicator of overall decline/poor prognosis</strong></td>
</tr>
<tr>
<td>• Assess and treat esophagitis (PPI or H2 blocker, motility agents)</td>
<td>• 0 = none</td>
</tr>
<tr>
<td>• Evaluate for thrush</td>
<td>• 1 = erythema of the mucosa;</td>
</tr>
<tr>
<td>• If dental problems are discovered, refer to dentist</td>
<td>• 2 = patchy ulcerations or pseudomembranes;</td>
</tr>
<tr>
<td></td>
<td>• 3 = confluent ulcerations or pseudomembranes, bleeding with minor trauma</td>
</tr>
<tr>
<td></td>
<td>• 4 = tissue necrosis, significant spontaneous bleeding, and life-threatening consequences</td>
</tr>
<tr>
<td></td>
<td>(National Cancer Institute Common Toxicity Criteria, NCI-CTC)</td>
</tr>
<tr>
<td>Do you have your own teeth?</td>
<td><strong>Registered Dietitian (RD) – refer to if a reversible condition and if available, if not available on site, refer to RD at outside cancer center if possible</strong></td>
</tr>
<tr>
<td>Are you brushing or flossing your teeth?</td>
<td><strong>Share Patient Links and Handouts as appropriate</strong></td>
</tr>
<tr>
<td></td>
<td><strong>See Reference links below for additional information</strong></td>
</tr>
<tr>
<td>Do you currently have any infections that you know of?</td>
<td><strong>If NO</strong></td>
</tr>
<tr>
<td>Options/Recourse</td>
<td><strong>Sub Acute 1-3 Days</strong></td>
</tr>
<tr>
<td>• Provide written instruction and education to patients regarding oral care</td>
<td><strong>Nurse - In the outpatient setting can teach patients to perform oral assessment daily and when to report findings to the clinician</strong></td>
</tr>
<tr>
<td>• Verify understanding with return explanation and demonstration</td>
<td><strong>Physician/APC - should be made aware, especially if this is indicator of overall decline/poor prognosis</strong></td>
</tr>
<tr>
<td>Does your mouth feel dry?</td>
<td><strong>If YES</strong></td>
</tr>
<tr>
<td>Do you have pain in your mouth or sores?</td>
<td><strong>Options/Recourse</strong></td>
</tr>
<tr>
<td></td>
<td><strong>Access for reversibility, identify if any:</strong></td>
</tr>
<tr>
<td></td>
<td>• Ulcerative lesions</td>
</tr>
<tr>
<td></td>
<td>• Bleeding and pain</td>
</tr>
<tr>
<td></td>
<td>• Thrush</td>
</tr>
<tr>
<td>Is taste affected?</td>
<td><strong>If YES</strong></td>
</tr>
<tr>
<td></td>
<td><strong>Refer to Follow Up Guidance for:</strong></td>
</tr>
<tr>
<td></td>
<td>• Mouth Sores</td>
</tr>
<tr>
<td></td>
<td>• Issues with Taste</td>
</tr>
<tr>
<td></td>
<td>• Dry Mouth</td>
</tr>
</tbody>
</table>

**Notes**

**Stages I-III:** Refer to speech pathologist if a swallowing issue. Refer to dentist if having difficulty chewing due to dental issues.

**Stage IV:** For late stage swallowing issues, medications can be changed from pill to liquid. Consider life expectancy and accompanying comfort measures. Educate regarding normal dying process. Refer to GI for stenting if anatomic. For oral candidiasis, use systemic antifungal agents (level of evidence 1, Recommendation Grade A) For oral and perioral viral infections, both acyclovir and valacyclovir are recommended for the prevention of HSV infection (Grade of recommendation A, level of evidence I) Review role of tube feeding with swallowing difficulty. May be appropriate if issue is related to mechanical blockage rather than overall decline (i.e. esophageal mass, head and neck cancer). If not, may be a trigger for a palliative care referral as a sign of overall decline/poor prognosis.

**Geriatric:** This population may have dental/denture issues that may make chewing and swallowing difficult. Make sure to address any teeth issues that could be resolved with proper mouth care or dental referral.

### Patient Links and Handouts:

- American Cancer Society, Swallowing Problems
- NCCN, Understanding the Oral Complications - From Cancer Treatment

CSOC Patient Handout can be accessed at: [http://cancer-help.me/chewingandswallowing](http://cancer-help.me/chewingandswallowing)

### References:

- NCCN Guidelines, Head and Neck Cancers
- Cancer.Net, Difficulty Chewing
- Cancer.Net, Difficulty Swallowing or Dysphagia
- NIH, Chemotherapy and Your Mouth
- NIH, Oncology Team, Oral Complications of Cancer Therapy

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Start With

Asking the patient the below questions

Do you have pain in your mouth, any sores or sore spots?
Do you have an infection that you know of?
Are you brushing or flossing your teeth?

MA level screener:
communicate these answers to Physician/APC in referral or notes for Next Step

IF YES

APC or higher screener:

Options/Recourse
Assess for cause
• Examine oral cavity and look for lesions and/or thrush
• Treatment related stomatitis
• Head Neck guidelines, other guidelines

Oral Care:
• Use gentle toothpaste (children’s toothpaste)
• Use soft toothbrush
• Rinse mouth with water after eating or drinking

IF YES

For additional information see Follow Up Reference for:
• Dry Mouth
• Issues with Taste

Next Step

Refer to Physician/APC or Nurse
Share Patient Links and Handouts as appropriate
See Reference links below for additional information

For stomatitis:
Assess for risk factors, medications that worsen dry mouth (anticholinergics, certain chemotherapies, opioids, antihypertensives, antidepressants)

Treatment in step-wise approach:
• Coating agents such as bismuth salicylate, sucralfat, or other antacids
• Water-soluble lubricants for mouth and lips
• Topical analgesics, such as benzydamine hydrochloride
• Topical anesthetics, such as lidocaine viscous (might impair gag reflex for a short period)
• Oral or parenteral analgesics, including opioids if needed, for pain not controlled with above

(From NIH nursing guidelines of stomatitis management)

Assess and discuss risk for osteonecrosis (bisphosphonate therapy)

Timing

Sub Acute
1-3 days

Notes

Stages I-III: Consider the possibility of thrush or stomatitis.
Stage IV: Consider dose reduction of chemotherapy if chemotherapy is the offending agent and symptom support is not effective.
Geriatric: This is a very common symptom in older adults. Be sure to remove any dentures or partials and assess the gums underneath.

Patient Links and Handouts:
• American Cancer Society, Mouth Sores
• Cancer.Net, Mouth Sores or Mucositis
• NIH, Head and Neck Radiation Treatment and Your Mouth
• NIH, Chemotherapy and Your Mouth
• NIH, Oral Complications of Chemotherapy and Head/Neck Radiation (PDQ®)
• NIH, Mouth and Throat Problems
• ASCO answers, Dental and Oral Health

CSOC Patient Handout can be accessed at:
http://cancer-help.me/mouthsores

References:
• NCCN Guidelines, Head and Neck Cancers
• NIH, Oral Complication of Chemotherapy and Head/Neck Radiation (PDQ®) Professional Version
• NIH, Cancer Treatment and Oral Health
• NIH, Oncology Team, Oral Complications of Cancer Treatment
• NIH, Oncology Team, Oral Complications of Cancer Treatment, pocket guide

Follow Up Reference for Clinicians

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Physical Concerns – “YES” to Dry Mouth

Start With
Asking the patient the below questions

Do you have an infection that you know of?
Are you brushing and flossing your teeth?
Do you have sores or pain in your mouth?

MA level screener: communicate these answers to Physician/APC in referral or notes for Next Step

APC or higher screener:

If YES

Options/Recourse
Assess for cause
• Screen for medications that cause xerostomia—are all medications necessary (consider changing meds)
• Suggest over the counter salivary/mouth care agents
• Add humidifier to oxygen (if applicable)

Oral Care:
• Encourage to sip water often
• Suggest using liquids to soften or thin foods
• Use gentle toothpaste (children’s toothpaste)
• Use soft toothbrush
• Recommend using sugarless gum or sugar-free hard candies to help stimulate saliva flow

If YES

Refer to Follow Up Guidance for:
• Mouth Sores
• Issues with Taste

Next Step

Refer to Physician/APC, Nurse, or Registered Dietitian

Nurse assess significance, then dietician involved, as dry mouth impacts eating. A nurse or pharmacist could perform patient education.

Utilize members of interdisciplinary team to provide patient education: anatomic, infectious, mouth sores.

Share Patient Links and Handouts as appropriate

See Reference links below for additional information

Timing

Routine - within 1 week

Notes

Stages I-III: Suggest dietary and educational counseling for the prevention of dysgeusia. The Oral Care Study Group of the Multinational Association of Supportive Care in Cancer and International Society of Oral Oncology (MASCC/ISOO) recommends the use of oral pilocarpine (Level of evidence II, Grade B) or oral mucosal lubricants/saliva substitutes for short-term improvement of xerostomia following radiation therapy in head and neck cancer patients. (Level of evidence II, Grade B). They also suggest the use of acupuncture to stimulate salivary gland secretion and to alleviate xerostomia. (Level of evidence II, Grade C)

Stage IV: Recommendations as above (soft toothbrush, over the counter salivary/mouth care agents; sugar-free gum or hard candies).

Geriatric: Dry mouth is very common in this population. Dental/denture insurance coverage may not be adequate, important to address this symptom in this population to help circumvent any issues or out of pocket costs. (e.g., Dentures may become ill fitting and need adjustments, hospital responsibility to keep track of dentures when patient is admitted to hospital and all personal belongings, keep near patient at all times and inventoried in EMR to prevent loss). Oral health is very important. Dry mouths are more prone to infections.

Patient Links and Handouts:
- American Cancer Society, Mouth Dryness or thick saliva
- Cancer.Net, Dry Mouth or Xerostomia
- NIH, Oral Complications of Chemotherapy and Head/Neck Radiation (PDQ®)
- NIH, Chemotherapy and Your Mouth
- NIH, Head and Neck Radiation Treatment and Your Mouth
- NIH, Dry Mouth
- ASCO answers, Dental and Oral Health

CSOC Patient Handout can be accessed at: http://cancer-help.me/drymouth

References:
- American Dental Association, Xerostomia
- NIH, Oral Complication of Chemotherapy and Head/Neck Radiation (PDQ®) Professional Version
- NIH, Cancer Treatment and Oral Health
- NIH, Oncology Team, Oral Complications of Cancer Treatment
- NIH, Oncology Team, Oral Complications of Cancer Treatment, pocket guide

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SOC Toolkit
Version 02.2022
Physical Concerns – “YES” to Cough

Start With
Asking the patient the below questions

- How long have you had a cough?
- Have you had any fevers?
- Is your cough producing any phlegm? If so, what color?
- Is your cough dry, meaning not phlegm producing?
- At what time of the day are you coughing?
- Do you cough more when you eat or drink?

If Yes

Document all answers in patient record.
These answers help determine etiology of cough.

Next Step

Refer to Physician/APC

Access for infectious etiologies such as acute bronchitis or pneumonia if indicated.

If no infectious indication, determine if cough could be from:
- Pleural disease-effusion, tumor
- Lung parenchyma infiltration
- Major airway or endobronchial tumor
- Cough after radiation or after chemotherapy
- COPD; chronic bronchitis
- Bronchiectasis
- Pericardial effusion
- Upper airway cough syndrome due to a variety of rhinosinus conditions
- Gastroesophageal reflux disease
- Asthma
- Lymphangitis carcinomatosis
- Chest infection
- Microembolism
- Tracheoesophageal fistula
- Vocal cord paralysis
- Congestive heart failure
- Postinfectious cough Eosinophilic bronchitis
- Angiotensin-converting enzyme inhibitor

Early empiric treatment:
- Reduce/eliminating possible causative agents (cigarette smoker, ACE inhibitors)
- Treat underlying cause (medications for bacterial URI, bronchodilators for asthma/COPD, chemo and/or radiation cancer related cough, etc.)
- Rx for cough: guaifenesin, dextromethorphan, codeine, etc. (can move up from weaker to stronger depending on the severity of the cough)
- Pts with ILD (interstitial lung disease) and cancer, bronchial dilators and steroids may be needed
- If cough does not improve in 3-5 days, revaluate.

Timing

Sub-
Acute,
1-3 days

Share Patient Links and Handouts as appropriate

See Reference links below for additional information

Patient Links and Handouts:
- NIH, Cough
- Cancer.Net, When to Call the Doctor During Cancer Treatment
CSOC Patient Handout can be accessed at: http://cancer-help.me/cough

References:
- Palliative Medicine Doctors Meeting, Cough in Cancer Patients
- Palliative care: Overview of cough, stridor, and hemoptysis

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### Physical Concerns – “YES” to Swollen arms or legs

**Start With**

**Asking the patient the below questions**

<table>
<thead>
<tr>
<th>Question</th>
<th>Action</th>
<th>Timing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is this a medication side effect?</td>
<td>If YES, Refer to Physician/APN</td>
<td>Sub Acute 1-3 days</td>
</tr>
<tr>
<td>Is this because of low albumin?</td>
<td>If YES, Refer to Dietary Counselor</td>
<td>Sub Acute 1-3 days</td>
</tr>
<tr>
<td>Is it lymphedema?</td>
<td>If YES, Consider Occupational/Physical Therapy referral</td>
<td></td>
</tr>
<tr>
<td>Could this be a blood clot?</td>
<td>Options/Recourse</td>
<td>Acute-WITHIN 24 hours</td>
</tr>
<tr>
<td>• Assess for deep vein thrombus</td>
<td>Refer to Physician/APN, Dietary Counselor or Nurse</td>
<td>Sub Acute 1-3 days</td>
</tr>
<tr>
<td>• Diuretic may help in the appropriate patient (taking into account electrolytes and blood pressure)</td>
<td>Have nurse discuss/share relative options with patient.</td>
<td></td>
</tr>
<tr>
<td>• Suggest wearing compression stockings</td>
<td>Share Patient Links and Handouts as appropriate</td>
<td></td>
</tr>
<tr>
<td>• Suggest elevating leg</td>
<td>See Reference links below for additional information</td>
<td></td>
</tr>
<tr>
<td>• Suggest reduction of salt and processed foods</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Review medications (sometimes medications can cause leg swelling such as calcium channel blockers)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Notes**

**Stages I-III:** Many frail patients are unable to wear traditional T.E.D.™ hose due to difficulty getting them on or the compression is too tight. For these patients recommend ACE wraps that caregivers can assist with or place. Can also try over the counter compression hose that provide less compression.

**Stage IV:** This is a very common problem for patients with stage IV cancer. Diuretic can be tried in appropriate patients. Patient and family often need counseling on why this is happening and that it is not reversible. Can be a very distressing symptom for patients and families.

**Geriatric:** If swollen appendages present in this population, consider a screen for malnutrition. Low albumen can cause edema.

**Patient Links and Handouts:**
- American Cancer Society, Understanding Lymphedema – For Cancers Other Than Breast Cancer
- American Cancer Society, Lymphedema – Breast Cancer
- NCCN, What You Should Know About Lymphedema
- NIH, NCI Lymphedema (PDQ®) Patient Version
- NIH, National Library of Medicine Compression Stockings

CSOC Patient Handout can be accessed at: [http://cancer-help.me/swollenarmsandlegs](http://cancer-help.me/swollenarmsandlegs)

**References:**
- NIH, Lymphedema (PDQ®) Health Professional Version
- NCCN Supportive Care, Cancer-Associated Venous Thromboembolic Disease
- National Lymphedema Network, The Diagnosis and Treatment of Lymphedema
- Cancer.Net, Lymphedema
- NCI Managing Chemotherapy Side Effects, Swelling
Physical Concerns – “YES” to Feeling full quickly or swollen abdomen

Start With
Asking the patient the below questions

Have you had progressive fullness?

Do you have any vomiting?

MA level screener: communicate these answers to Physician/APC in referral or notes for Next Step

APC or higher screener:

If YES

Options/Recourse

Inquire for duration of symptoms

• acute versus sub-acute

Assess for constipation

• For additional information see Follow Up Reference for Constipation

If patient not constipated, assess for other cause

• Gaseous distention

• Ascites

• Mass effect/organomegaly

• Gastric or esophageal problems

• Gastric outlet obstruction or small bowel evolving obstruction

• Peritoneal disease

• Malignant involvement of the GI tract causing a motility disorder

• Motility disorder

• Mood disorder

• Cachexia

Keep in mind if patient has diarrhea, may be overflow diarrhea due to an impaction.

If NO

Inquire if patient is constipated.

For additional information see Follow Up Reference for Constipation

Refer to Physician/APC

• Physical exam

• Consider imaging, either an obstructive series or abdominal CT

• Consider Ultrasound to evaluate for ascites

• Consider GI consult if a motility disorder

• Consider medications for gas/constipation

• Consider a nutrition consult

Share Patient Links and Handouts as appropriate

See Reference links below for additional information

Follow Up Reference for Clinicians

Notes

Stages I-III: Rule-out possibility of recurrent disease manifesting as ascites, organomegaly, bowel obstruction. Consider nonmalignant etiologies such as constipation, motility disorder. Consider medication related etiologies. Consider Nutrition consult for gaseous distension and food recommendations.

Stage IV: If surgery is not recommended for bowel obstruction, consider steroids, placement of decompressive G-tube. Consider pleurx catheters for recurrent ascites. Consider steroids for hepatic capsule distension. Consider nutrition consult for gaseous distension. Consider steroids for cachexia.

Geriatric: Similar process of care for all ages.

Patient Links and Handouts:

- American Cancer Society, Swelling
- Cancer.Net, Fluid Retention or Edema
- Cancer.Net, Fluid in the Abdomen or Ascites
- NIH, NCI, Edema

CSOC Patient Handout can be accessed at: http://cancer-help.me/feelingfull

References:

- Malignant ascites: A review of prognostic factors, pathophysiology and therapeutic measures

- Abstract - Management of ascites due to gastrointestinal malignancy

- NIH PDQ®, Nutrition in Cancer Care – for health professionals, Overview

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Physical Concerns –
“YES” to Sexual intimacy or function

Start With
Asking the patient the below questions

Is this a physical problem you are having?

MA or higher level screener:
communicate these answers
to Physician/APC in referral or
notes for Next Step

APC or higher level screener:

Options/Recourse
Assess for cause
• Vaginal dryness or
dyspareunia
• Erectile Dysfunction (ED)
• Other
• Review medications that
cause ED (opioids, some
antidepressants)
• Screen for comorbid risk
factors (DM, alcoholism,
CAD, smoking, obesity,
menopause)

If YES

Is this an emotional problem you are having?

Options/Recourse
desire/feeling attractive
If physical appearance changes
are involved, connection to
resources (i.e. support groups,
wig donation)

If YES

Refer to whomever patient feels comfortable
to share with in conjunction w/physician
(Nurse, Social Worker, Psychosocial)

Even if problems are physical, patients should
be asked if they want referral for
psychotherapist or social worker with
expertise in intimacy issues.

Refer to Physician/APC
• Should be addressed early on alongside
other side effect discussion
• The majority of patients feel the
importance of this is minimized by the
healthcare staff
• Gynecologist for women
• Urologist for men

Referring to Social Worker
• Individual intervention is preferable to
group intervention. Patients may be
uncomfortable with group discussions
about sexual topics. Individual
interventions also allow for a more
personal approach to addressing intimacy
issues.

Referral sexual counselor or psychologist who
specializes in sexual intimacy.

Referral to couples counseling, psychology as
appropriate.

Share Patient Links and Handouts as
appropriate

See Reference links below for additional
information

Follow Up Reference for Clinicians

Next Step
Timing

Notes

Stages I-III: Physical Therapist specializing in pelvic floor dysfunction as a resource – if pain during intercourse is an issue, they may
be able to help with it. Consider survivorship programming which addresses sexual issues.

Stage IV: Intimacy is still an important concern for stage IV patients and important to address for incurable cancer patients also.
Counseling on other safe ways to express love/intimacy if sex is no longer safe or possible.

Geriatric: This population can have issues with this and should not be dismissed as a possibility. Similar treatment across all ages.

Patient Links and Handouts:

- American Cancer Society, Cancer, Sex, and the Female Body
- American Cancer Society, Sex and the Man With Cancer
- Cancer.Net, Dating and Intimacy
- Cancer.Net, Sexuality and Cancer Treatment: Men
- Cancer.Net, Sexuality and Cancer Treatment: Women
- NIH, NCJ, Self-Image and Sexuality

CSOC Patient Handout can be accessed at: http://cancer-help.me/sexual

References:

- British Columbia Cancer Agency, Symptom Management Guidelines: Intimacy and Sexuality

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judgement in the context of individual clinical circumstances to determine any patient’s care or treatment. The Coleman Foundation makes no
representations or warranties of any kind regarding their content, use or application and disclaims any responsibility for their application or use in any way.
Physical Concerns –
“YES” to Skin dry/itchy, blister/pain

Start With
Asking the patient the below questions

Is this a problem that was present before being diagnosed with cancer?

MA or higher level screener: communicate these answers to Physician/APC in referral or notes for Next Step

APC or higher level screener:

If YES

Options/Recourse
Assess for cause
- Allergies
- Dermatologic diseases or sensitivity
- Diet-induced
- If poor functional status, consider pressure ulcers, edema, infectious causes like fungal rash
- Shingles
- Scabies or bedbugs

If NO
See Next Questions

Is this a new problem since starting a new treatment?

If YES

Options/Recourse
Assess for cause
- drug induced
  - Sometimes itching can be caused by opioids - consider opioid rotation and consider prescribing antihistamine. Usually opioid induced itching is not a true allergy and will not cause a rash - if rash present MD should be notified
  - Chemotherapy induced rash which may require medication management
  - EGFR inhibitors
  - Review with pharmacy those chemotherapies which typically cause rash and management algorithms. Sometimes, chemotherapy may need to be held or discontinued based on rash severity
    - Shingles
    - Radiation induced skin injury or radiation recall
    - Consider contact dermatitis from dressings and adhesives

Is this a new problem since ending a treatment?

If YES

Refer to Physician/APC or Nurse
Consider Dermatology referral
Consider reviewing published algorithms for treatment of chemotherapy induced rashes, i.e. rashes from EGFR inhibitors
Physical exam will be essential – this trigger has a broad differential
Share Patient Links and Handouts as appropriate
See Reference links below for additional information

If NO

Physical Concerns
- Stages I-III: Physical exam important to help determine cause. Often rashes stem from chemotherapy. Consider guidelines to treat chemotherapy induced rashes. If no visible rash or skin lesion, may be due to opioid induced itching.
- Stage IV: Often rashes stem from chemotherapy. Consider guidelines to treat chemotherapy induced rashes. However, other conditions may not be amenable to cure; focus on ameliorating symptoms (for example topical lidocaine or morphine creams may help) or other symptom control (for example, Benadryl for itchiness), prevention of worsening condition (for example, proper emollients, proper beds or caregivers to help bed sores), and prevention of infection. Some patients may need wound care team support or procedures like a Foley catheter to protect peroneal/sacral wounds.
- Geriatric: Geriatric skin is baseline dryer. Assess whether this concern is this new or ongoing. If ongoing, ask how patient has treated this issues before and if not successful, offer different treatment options.

Patient Links and Handouts:
- American Cancer Society, Dry Skin
- American Cancer Society, Side Effects of Targeted Cancer Therapy Drugs
- Cancer.Net, Skin Conditions
- NCCN, Skin Rashes
- PubMed Health, PDQ® Patient Version, Pruritus
- NIH, NCI, Skin and Nail Changes

C SOC Patient Handout can be accessed at: http://cancer-help.me/skin

References:
- NIH, Pruritus (PDQ®)
- EGFR Rash - Clinical practice guidelines for the prevention and treatment of EGFR inhibitor-associated dermatologic toxicities
- MSK, Skin Care Guidelines, Radiation Therapy

Notes
- Stages I-III: Physical exam important to help determine cause. Often rashes stem from chemotherapy. Consider guidelines to treat chemotherapy induced rashes. If no visible rash or skin lesion, may be due to opioid induced itching.

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**Physical Concerns** –

**“YES” to Tingling in hands/feet**

**Start With**

Asking the patient the below question

<table>
<thead>
<tr>
<th>MA or higher level screener: communicate these answers to Physician/APC in referral or notes for Next Step</th>
</tr>
</thead>
<tbody>
<tr>
<td>APC or higher level screener:</td>
</tr>
</tbody>
</table>
| **IF YES**

**Options/Recourse**
A good history is essential
Assess for cause
- Medication induced
- Chemotherapy induced
- Is the tingling unilateral and is any weakness present to raise concern of a neurologic event?

**IF NO**

**Options/Recourse**
A good history is essential
Assess for cause
- Diet/alcohol related, other neurologic condition (like nerve impingement)
- Tailor evaluation to the severity of the symptoms and how it impacts function and quality of life (physical/neurologic exam, consider blood tests, nerve conduction tests, MRIs or other tests, consider Neurology referral especially if uncertain etiology)

If late stage disease or obvious cause would treat with medication for neuropathic pain i.e. gabapentin or tricyclic; sometimes methadone

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**Notes**

**Stages I-III:** Focus on cause and removing inciting agents; if tingling is related to chemotherapy, assess the grade and decide on whether dose modification is warranted. In the adjuvant setting, maintaining dose intensity is important. However, if the tingling becomes grade 3 or 4, consider holding chemotherapy, reassessing at next cycle, and dose modification if necessary.

**Stage IV:** Focus on quality of life besides reducing/stopping the inciting agent; treatment is complex and varied – highly consider palliative care or pain specialty referral if uncontrolled and/or debilitating.

If tingling is related in time to chemotherapy administration, evaluate severity and consider dose modification if it is grade 3 or 4.

Share Patient Links and Handouts as appropriate
See Reference links below for additional information

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**Patient Links and Handouts:**
- American Cancer Society, Peripheral Neuropathy Caused By Chemotherapy
- Cancer.Net, Peripheral Neuropathy
- NCCN, What is Peripheral Neuropathy
- NIH, Chemotherapy-Induced Peripheral Neuropathy
- NCI, NIH, Nerve Problems (Peripheral Neuropathy)

CSOC Patient Handout can be accessed at:
http://cancer-help.me/tingling

---

**References:**
- NCCN Guidelines, Survivorship
- NCCN Task Force Report: Management of Neuropathy in Cancer
- Prevention and Management of Chemotherapy-Induced Peripheral Neuropathy in Survivors of Adult Cancers: American Society of Clinical Oncology Clinical Practice Guideline
- Fast Fact, #197 Chemotherapy induced Peripheral Neuropathy

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Follow Up Reference for Clinicians

Next Step
Timing

Acute-

WITHIN 24 hours
Would you like resources to address your concerns about your appearance or body image?

**MA or higher level screener:**
Communicate these answers to Physician/APC in referral or notes for Next Step

**APC or higher level screener:**

- **IF YES**
  - **Options/Recourse**
  - Refer to Social Worker for resources
  - Refer to Journey Connections Tool

- **IF NO**
  - **Options/Recourse**
  - If it is important for oncologist/nurse to address this. Patients often don’t express their body image concerns with the healthcare team because they are concerned that it will be seen as trivial or shallow. Having the team address it up front, not only allows the distress to be addressed, but also validates that this is a normal experience for patients.

**Options/Recourse**
- Refer to Psychosocial or Social Worker
- Share Patient Links and Handouts as appropriate
- See Reference links below for additional information

**Routine**
- Within 1 week

---

**Notes**

*Stages I-III:* Refer to a clinical social worker within healthcare system. If there are no social workers on staff, than refer to a cancer support center for treatment related to body image distress. Can refer to Look Good Feel Better by the American Cancer Society when appropriate.

*Stage IV:* Refer to a clinical social worker within healthcare system. If there are no social workers on staff, than refer to a cancer support center for treatment related to body image distress. Can refer to Look Good Feel Better by the American Cancer Society when appropriate.

*Geriatric:* This population CAN have issues with this and should not be dismissed. Disheveled look can be a sign of having cognitive issues.

---

**Patient Links and Handouts:**
- American Cancer Society, Look Good Feel Better
- Cancer.Net, Self-Image and Cancer
- Cancer.Net, Teens, Coping with Changes to Your Body
- Cancer.Net, Young Adults, Cancer and Your Body
- NIH, NCI, Self-Image and Sexuality

CSOC Patient Handout can be accessed at: http://cancer-help.me/appearance

---

**References:**
- Managing Body Image difficulties of adult cancer patients: Lessons from available research
Physical Concerns – “YES” to Use of alcohol/drugs

Start With

Asking the patient the below question

Do you or others close to you have any concerns about your use of alcohol or drugs?

MA or higher level screener: communicate these answers to Physician/APC in referral or notes for Next Step

APC or higher level screener:

If YES

Options/Recourse

CAGE AID - simple and short screening tool for drug and alcohol abuse
Assess for suicidality (older men – especially older white men, are at increased risk for suicide) If suicidal ideation currently or in past, recommend assessing for firearms.
Assess for risk factors prior to prescription of risky medications (opioids, benzodiazepines, etc...).
Risk factors include:
• History of sexual abuse
• History of psychiatric disorder
• History of alcohol/drug abuse
Sign contract with patient and set limits up front for prescribing (single pharmacy, single provider, no early refills, regular urine screening).
• Most patients minimize/under report substance use so it is important to tie screening to a discussion of how substance use will impact their treatment/disease process
• Patients will be more likely to honestly report use if they understand that it will interfere with their treatment
• Patients are typically more motivated to seek substance treatment if they understand that use worsens their treatment/disease outcomes

If NO

Options/Recourse
• It is important for clinician/nurse to have knowledge of the use and address appropriately.

Next Step

Refer to Physician/APC or Nurse
• Education about worsening pain due to metastatic disease, verses drug use for abusive purposes
• Address existential distress (Chaplain, Social Worker).
• If patient on methadone maintenance for abuse, have communication with maintenance program about using methadone for maintenance versus pain.
• Close monitoring (via prescription monitoring plan) for appropriate refilling of medications, single provider; urine toxicity screening periodically if patient still receiving treatment.
• Limit setting from prescribing physician and clear restrictions about refills of opioids.
• Referral to substance abuse treatment if appropriate
Share Patient Links and Handouts as appropriate
See Reference links below for additional information

Timing

If active suicidal:
Urgent - See NP, Physician before leave or sent to EMERGENCY ROOM

Score of 1-4 on CAGE AID, or clinical significance on another assessment: Discuss same day

Patient or family verbal endorsement of concerns: Sub Acute 1-3 days

Notes

Stages I-III: Substance use concerns require referral to a therapist who specializes in addictions. This cannot be adequately addressed by oncology therapists who do not have an addiction specialty. Discuss taper plan and expectations up front if patient does require a risky medication. Utilize other analgesics/atypical analgesics, interventional pain management more readily.

Stage IV: For a patient on hospice/imminently dying, discuss realistic expectations with patient and family about ability to stop alcohol/drugs/tobacco. May not be the right time to detox from these things and may cause more harm (i.e. withdrawal in an imminently dying patient). In these cases, discuss safety measures (no O2 with smoking, falls with alcohol consumption), minimize polypharmacy. Treatment team needs the information on any alcohol/drug issues to allow for best approach in treating/monitoring patient.

Geriatric: This population CAN have issues with this and should not be dismissed as a possibility. Due to their age, tend to have a lower tolerance and should be assessed and treated accordingly.

Patient Links and Handouts:

- American Cancer Society, Alcohol use and Cancer
- American Cancer Society, Nutrition and Physical Activity During and After Cancer Treatment
- American Cancer Society, The Link Between Alcohol and Cancer

CSOC Patient Handout can be accessed at: http://cancer-help.me/alcohol and http://cancer-help.me/drugs

References:

- NIH, Medical & Health Professionals, DRUG ABUSE
- NIH, Medical & Health Professionals, ALCOHOL ABUSE
- CAGE-AID screen for substance (alcohol and drug) use disorders
- Fast Fact #127, Substance Use Disorders In The Palliative Care Patient
- Fast Fact #244, Screening For Opioid Misuse And Abuse
- SAMHSA Substance Abuse Treatment Facility Locator

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### Physical Concerns –

**“YES” to Difficulty concentrating/remembering things/finding the words**

Start With

- Asking the patient the below question

**Are these memory or concentration issues new for you?**

#### If Yes

**Important to clarify if this issue(s) is:**
1. New or a change from prior
2. A stable situation

**Further inquiry, document and note in referral:**
- Have you had any change in balance?
- Have you had any vision changes, dizziness or weakness recently?
- Have you started cancer therapy?

**Note:**
- Memory/concentration issues can be related to depression, give PHQ4 results with notes on memory/concentration with referral.
- Treatment can result in self perceived cognitive problems (trouble with information processing, attention, thinking, short-term memory)
  - sometimes referred to as “chemobrain”
  - can occur during any cancer treatment

**Next Step**

- Refer to Physician/APC
  - Assess for cognitive impairment
  - Patients that endorse symptoms for depression/anxiety can impact concentration and memory
  - Assess for neurologic side effects of anticancer therapy: visual changes, vertigo or new weaknesses
  - May consider CNS imaging if concern for brain metastasis. Decision to do imaging depends upon clinical assessment, likelihood of that type of cancer to go to brain, prior imaging.

**Timing**

- Acute - Within 24 hrs if Neuro exam is worrisome
- Within 4-6 weeks if Neuro exam is normal

#### If No

**Further inquiry, document and note in referral:**
- How long have you had memory/concentration issues?
- Are you currently being treated for them?

**Trained Clinician:**

- Proceed with Cognitive Screening Assessment:
- APC, in consultation with treating physician, can further determine referral for patient if needed
  - Low threshold for screening older adults for cognitive impairment
  - Recommend screening all patients that endorse symptoms for depression/anxiety which can impact concentration and memory give PHQ4 results with notes on memory/concentration with referral.

**Next Step**

- Refer to Physician/APC/Neuro-Psych
  - Assess cognitive impairment (patients that endorse symptoms for depression/anxiety can impact concentration and memory)
  - Assess for ability to maintain treatment plan
  - Consider involving PCP if has prior history of cognitive impairment or dementia for guidance or consider referral to geriatrician or geri-oncologist

**Timing**

- Acute - Within 24 hrs if Neuro exam is worrisome
- Within 4-6 weeks if Neuro exam is normal

**Notes**

- **Any Stage** - The word “cognition” can induce panic in some patients, use memory or ability to think instead.
- **Geriatric** - Will find delirium and dementia more often in this population. Additional info to follow, Geriatric team working on screening for pt meeting age and/or cognitive deficiencies

**Patient Links and Handouts:**

- American Cancer Society, Chemo Brain
- CancerCare, Chemo Brain: What You Need to Know
- Cancer.Net, Attention, Thinking, or Memory Problems
- ASCO answers, Chemobrain

CSOC Patient Handout can be accessed at: http://cancer-help.me/memory

**References:**

- Mini-Cog™
- NIH, Understanding “Chemobrain” and Cognitive Impairment after Cancer Treatment
- ASCO Post, How Cancer and It’s Treatments Affect Cognitive Function
- LINKS TO TRAINING will be added when Geriatric assessment is decided upon

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Nutrition Concerns –
“YES” to Weight loss or lack of appetite

Start With
Asking the patient the below questions

Are you eating regular sized meals?
Are you eating small meals throughout the day?
Does food taste normal?
Are you using oral nutrition supplements?
Do you have access to food or need assistance with meal preparation?
Are you having any issues with your teeth?

If NO
Options/Recourse
Appropriate to answers, encourage patient to:
• Eat small and more frequent meals
• Eat foods that are rich in calories and nutrients
• Avoid heavy meals, greasy or fried foods and foods that cause gas
• Eat what tastes good or feels good
• Eat flavorful food or try adding different seasonings to your foods
• Use plastic utensils for metallic taste
• Refer to Meal Assistance Program

Next Step
Refer to Registered Dietitian if available, if not, refer to Registered Dietitian at outside cancer center if possible
or
Refer to Physician/APC or Nurse
Have discussion/share relative options/recourse with patient
• Discuss adding oral nutrition supplements if appropriate
• Give Samples or coupons if available

Timing
Acute-
WITHIN
24 hours

If YES
Options
For additional information see Follow Up References for:
• Nausea
• Constipation
• PHQ4 (anxiety/depression)
• Mouth Sores

References:
• NCCN Palliative Care, Anorexia/Cachexia, PAL-13
• NIH, Nutrition in Cancer Care PDQ®, – for health professionals, Tumor-Induced Effects on Nutritional Status
• Protein calorie malnutrition, nutritional intervention and personalized cancer care

Notes
Stages I-III: Nutrition recommendations are based on individual labs, comorbidities, tolerances and preferences of the patient, not necessarily based on stage. May have larger emphasis on artificial nutrition if patient having significant weight loss due to reversible medical problems. Discussion on diet consisting of real food verses empty processed foods.

Stage IV: Anorexia/cachexia may be trigger for palliative care referral. Educating family and patient about normal loss of appetite during dying process (For additional information on Early Satiety, see page PAL-13 and PAL14 in Palliative NCCN Guidelines®). Be knowledgeable about cultural factors surrounding. Promote making food available and gentle encouragement to eat, but also setting manageable expectations for patient’s lowered nutrition needs when dying. Give family alternative ways to show love/care for patient. Have discussion about feeding tubes and artificial nutrition (may be appropriate for some patients, not for others). Focus on preparing patient/family on symptoms that may come up from lack of protein- i.e. decubitus ulcers, swollen lower extremities, fatigue. May further consider corticosteroid as method for short-term appetite stimulation. Any patients with dentures or partials check for ill fit (often occurs with weight loss) which can contribute to eating difficulties. Generally, if patient has a terminal illness, it is not recommended that dentures or partials be replaced because they are expensive, and continued weight loss will inhibit a proper fit. Recommendation is to eat soft, pureed foods without dentures or partials if fit is impaired. Coumadin food restrictions are not necessary when life limiting late stage disease is present or has comorbidities. Review medications (polypharma) for those that may no longer be needed.

Geriatric: May have issues with fluids and keeping hydrated which can affect taste. Reduced saliva production may be an issue. Sucking on lemon flavored candy can help increase saliva. Muscle mass loss/atrophy can also be triggered by memory loss (confusing to shop, cook or even forget to eat). Screen for physical and mental (Mini-Cog™) decline, possible referral to resources that can provide a safer living situation.

Patient Links and Handouts:
• American Cancer Society, Appetite Changes
• American Cancer Society, Weight Changes
• Cancer Net, Appetite Loss Handout
• Cancer Net, Weight Loss
• NIH, Nutrition in Cancer Care (PDQ®)
• ASCO Answers Fact Sheet, Appetite Loss
• Memorial Sloan Kettering Eating Well

CSOC Patient Handout can be accessed at: http://cancer-help.me/weightloss

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### Nutrition Concerns – “YES” to Weight gain

**Start With**
Asking the patient the below questions

<table>
<thead>
<tr>
<th>Did your weight gain start at diagnosis?</th>
<th>If NO</th>
<th>Next Step</th>
<th>Timing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did your weight gain start with treatment?</td>
<td>Are you eating more and/or exercising or moving less?</td>
<td>If YES</td>
<td>Refer to Physician/APC, Nurse or Registered Dietitian</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Immobility - Encourage exercise if appropriate</td>
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<td></td>
<td>• Limit portion sizes and caloric restriction</td>
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<td>• Reduce intake of sweets, such as desserts and juices</td>
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<td>• Avoid drinks, such as soda, that are high in sugar</td>
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<td></td>
<td>• Eat more fruits and vegetables, whole grain breads, cereals, nuts/seeds and legumes</td>
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<td></td>
<td>• If safe, increase physical activity (walking or exercising)</td>
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<td></td>
<td>• Choose lean meats and low-fat dairy products</td>
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<td></td>
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<td></td>
<td>• Limit fats such as margarine, mayonnaise, and high-fat-sauces or dressings</td>
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<tr>
<td></td>
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<td></td>
<td>• Avoid trans fats (anything made with partially hydrogenated oils or shortening)</td>
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<td></td>
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<td></td>
<td>• Try broiling or steaming foods rather than frying in oil or butter</td>
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<td></td>
<td>• Drink water, unless instructed to limit fluid intake</td>
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<td></td>
<td>Refer to Registered Dietitian if available – they will have relevant materials and resources to provide to the patient</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>See Reference links below for additional information</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Share Patient Links and Handouts as appropriate</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>If YES</th>
<th>Refer to Psychosocial or Registered Dietitian</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Refer to Physician/APC for differential diagnosis (see additional notes below)</td>
</tr>
<tr>
<td></td>
<td>Share Patient Links and Handouts as appropriate</td>
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<tr>
<td></td>
<td>See Reference links below for additional information</td>
</tr>
<tr>
<td></td>
<td>Share Patient Links and Handouts as appropriate</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>If NO</th>
<th>Refer to Physician/APC for differential diagnosis &amp; appropriate treatment</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>• Related to treatment</td>
</tr>
<tr>
<td></td>
<td>• Patient retaining fluid, diuretic needed</td>
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<tr>
<td></td>
<td>• Related to immobility</td>
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<tr>
<td></td>
<td>• Related to medications</td>
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<tr>
<td></td>
<td>See Reference links below for additional information</td>
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<tr>
<td></td>
<td>Share Patient Links and Handouts as appropriate</td>
</tr>
</tbody>
</table>

### Notes

**Stages I-III** - Nutrition recommendations are based on individual labs, comorbidities, tolerances and preferences of the patient, not necessarily based on stage. Review long-term issues with weight gain in survivorship (increased risk for recurrence for certain malignancies or other comorbidities) Discussion on a healthy diet with fruits and vegetables, nuts, beans whole grains and unprocessed meats.

**Stage IV** - Nutrition recommendations are based on individual labs, comorbidities, tolerances and preferences of the patient, not necessarily based on stage. Educate on balancing fluid, the risk of fluid overload in patients receiving IV fluids. Unless related to fluid retention, weight gain may be beneficial to most stage IV patients.

**Geriatric:** Consider fluid status, protein, malnutrition or edema. Men on hormone therapy for prostate cancer can gain weight. If losing strength along with weight gain, may need referral to resources that can provide a safe living situation.

### Patient Links and Handouts:
- American Cancer Society, Information on Weight Gain
- NCCN, Information on Diet and Weight Changes
- Cancer.Net, Weight Gain
- Cancer.Net, Obesity, Weight, and Cancer Risk
- NIH, Nutrition in Cancer Care (PDQ®)

CSOC Patient Handout can be accessed at: [http://cancer-help.me/weightgain](http://cancer-help.me/weightgain)

### References:
- NCCN Guidelines, Survivorship, Nutrition and Weight Management
- NIH, PDQ®, Nutrition in Cancer Care
- NIH, PDQ®, Nutrition in Cancer Care
- NIH, PDQ®, Nutrition Implications of Cancer Therapies

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### Nutrition Concerns – “YES” to Issues with Taste

#### Start With

Asking the patient the below questions

<table>
<thead>
<tr>
<th>Are you maintaining your weight?</th>
<th>Options/Recourse</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• Use plastic utensils for metallic taste</td>
</tr>
<tr>
<td></td>
<td>• Eat what tastes best</td>
</tr>
<tr>
<td></td>
<td>• Eat foods that are rich in calories and nutrients when possible</td>
</tr>
<tr>
<td></td>
<td>• Eat flavorful food or add different/additional seasonings</td>
</tr>
<tr>
<td></td>
<td>• Try oral nutrition supplements</td>
</tr>
<tr>
<td></td>
<td>• Encourage patient to explore different types of foods to find foods that may work</td>
</tr>
<tr>
<td></td>
<td>• Discuss good oral care</td>
</tr>
<tr>
<td>If NO</td>
<td>Next Step</td>
</tr>
<tr>
<td></td>
<td>Refer to Registered Dietitian if available, if not, refer to Registered Dietitian at outside cancer center if possible</td>
</tr>
<tr>
<td></td>
<td>Registered Dietitian or Nurse - Have discussion/share relative options with patient</td>
</tr>
<tr>
<td></td>
<td>May try zinc oxide, 25mg, 4 times a day (QID)</td>
</tr>
<tr>
<td></td>
<td>See Reference links below for additional information</td>
</tr>
<tr>
<td></td>
<td>Share Patient Links and Handouts as appropriate</td>
</tr>
</tbody>
</table>

#### Do you have any mouth sores or thrush?

Options/Recourse

- See above Options/Recourse
- See Weight loss Follow Up Reference for additional information

If YES

- Refer to Physician/APC
- Physician/APC - Have discussion/share relative options with patient
- See Reference links below for additional information
- Share Patient Links and Handouts as appropriate

If NO

- Refer to Registered Dietitian if available, if not, refer to Registered Dietitian at outside cancer center if possible
- Registered Dietitian or Nurse - Have discussion/share relative options with patient
- May try zinc oxide, 25mg, 4 times a day (QID)
- See Reference links below for additional information
- Share Patient Links and Handouts as appropriate

#### Timing

- Discuss same day
- Routine - within 1 week

### Notes

**Stages I-III:** Nutrition recommendations are based on individual labs, comorbidities, tolerances and preferences of the patient, not necessarily based on stage. Suggest cooking with additional spices or herbs, flavoring water with lemon, lime or cucumber, using plastic utensils verses metal, sucking on lemon flavored candy to rid mouth of metal taste. Discussion on healthy diet consisting of real food verses processed, fruits and vegetables, nuts, beans whole grains and unprocessed meats.

**Stage IV:** Nutrition recommendations are based on individual labs, comorbidities, tolerances and preferences of the patient, not necessarily based on stage. Similar to recommendations on weight loss, may be natural part of dying process. If patient closer to dying, discuss lowered appetite/nutritional needs. Encourage eating for pleasure and comfort. Review cultural implication of eating/drinking less.

**Geriatric:** Always check for proper fit with dentures. Several factors may contribute to loose fitting dentures such as weight loss or dehydration. This population may have issues with fluids and keeping hydrated which can affect taste. Reduced saliva production may be an issue. Sucking on lemon flavored candy can help increase saliva and in turn, reduce or mask bad taste.

### Patient Links and Handouts:

- American Cancer Society, Taste and Smell Changes
- Cancer.Net, Taste Changes
- American Institute for Cancer Research®, Heal Well, A Cancer Nutrition Guide
- NIH, Nutrition in Cancer Care (PDQ®)
- NCI, Eating Hints, Before, During and After Cancer Treatment
- CSOC Patient Handout can be accessed at: [http://cancer-help.me/taste](http://cancer-help.me/taste)

### References:

- NIH, PDQ®, Nutrition in Cancer Care, Nutrition Therapy, Alterations of taste and smell
- Meal context and food preferences in cancer patients: results from a French self-report survey

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### Nutrition Concerns – “YES” to Concerns about nutrition and food

#### Start With
Asking the patient the below questions

#### Options/Recourse
Differential diagnosis & appropriate treatment:
Offer reassurance that treatment and/or cancer affects nutritional state
- Reduce intake of sweets, such as desserts and juices
- Avoid drinking beverages that have sugar
- Eat more fruits and vegetables, whole grain breads, cereals and beans
- If safe, increase physical activity such as walking
- Choose lean meats and low-fat dairy products
- Limit fats such as margarine, mayonnaise and high-fat- sauces or dressings
- Avoid trans fats (anything made with partially hydrogenated oils or shortening)
- Try broiling or steaming foods rather than frying them in oil or butter
- Drink lots of water, unless instructed to limit fluid intake

#### Cachectic Patients
- Need high fat, high calorie nutrition
- Enjoyable food choices of any type in small portions may be of benefit to the patient

Refer to Registered Dietitian if available, if not, refer to Registered Dietitian at outside cancer center if possible

See Reference links below for additional information

Share Patient Links and Handouts as appropriate

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#### Notes

**Stages I-III:** Nutrition recommendations are based on individual labs, comorbidities, tolerances and preferences of the patient, not necessarily based on stage. Discussion on healthy diet consisting of real food verses processed, fruits and vegetables, nuts, beans whole grains and unprocessed meats.

**Stage IV:** Nutrition recommendations are based on individual labs, comorbidities, tolerances and preferences of the patient, not necessarily based on stage. If patient closer to dying, discuss lowered appetite/nutritional needs. Encourage eating for pleasure and comfort. Review cultural implication of eating/drinking less. Review medications (Polypharma) as some may no longer be needed.

**Geriatric:** This population may have issues with fluids and keeping hydrated which can affect taste. Reduced saliva production may be an issue. Sucking on lemon flavored candy can help increase saliva and in turn, reduce or mask bad taste. Coumadin food restrictions are not necessary when life limiting late stage disease is present or has comorbidities.

#### Patient Links and Handouts:
- [American Cancer Society Nutrition Information](#)
- [Cancer.Net, Food and Cancer Prevention](#)
- [NIH, NCI, Nutrition in Cancer Care (PDQ®)](#)
- [Journey Connections, Food and Nutrition category](#)
- [ASCO Answers, Food Safety & Cancer Treatment](#)

CSOC Patient Handout can be accessed at: [http://cancer-help.me/nutrition](http://cancer-help.me/nutrition)

#### References:
- [NCCN Guidelines, Survivorship, Nutrition and Weight Management](#)
- [NIH, PDQ®, Overview of Nutrition in Cancer Care](#)
- [NIH, PDQ®, Nutrition Therapy in Cancer Care](#)
- [NIH, PDQ®, Treatment of Symptoms](#)
- [NIH, PDQ®, Nutrition in Advanced Cancer](#)

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## Physical Concerns –
### Pain, Mild and Moderate Total Scores

<table>
<thead>
<tr>
<th>Total Score:</th>
<th>Approach</th>
</tr>
</thead>
</table>
| 9 – 11 = Mild | Refer to Physician/APC or Nurse  
- Pain assessment - quality, intensity, location(s), timing, and duration. Review imaging, consider further imaging or lab work to evaluate if disease progression is the cause, or correlate with other findings/history. Review chronic pain history (non-cancer causes of pain)  
- Overall effect of pain on quality of life (QOL)- assess cultural, spiritual, emotional considerations for patient  
- If pain opioid sensitive-  
  - Consider titrating short-acting opioid  
  - If on opioid, start patient on a laxative  
- Neuropathic pain-consider anticonvulsant or antidepressant as adjuvant  
- Chemotherapy-induced neuropathy, trial of steroids or may need dose-reduction in chemotherapy  
- Topical agents  
- Bone pain  
  - Nonsteroidal anti-inflammatory drugs (NSAID) therapy if tolerable, bisphosphonate, safety modifications for activity  
  - May need surgical consult if pathological or compression fractures present  
- Consider PT/OT, radiation, anesthesia pain, complementary and alternative medicine (CAM), non-pharmacologic methods  
- Patient/family education about expectations, opioid safety, pain management principles  

<table>
<thead>
<tr>
<th>12 – 14 = Moderate</th>
<th><strong>Next Step</strong></th>
</tr>
</thead>
</table>

### Notes

**Stages I-III:** Higher emphasis on adjuvant analgesic such as PT/OT, complementary and alternative medicine (CAM) (i.e. acupuncture/massage), ice/heat, local anesthetics.

**Stage IV:** Review overall effects of pain on quality of life (QOL) and benefits verses side effects of opioid therapy if it is being considered. Discuss implications for overall disease management (i.e. expectation for patient that pain will increase or get worse, involvement of palliative care team for ongoing management). Patient teaching that pain may not completely go away. Goal may be to make tolerable while weighing side effects of therapy. Continue to reassess/affirm that goals center on patient’s comfort, function and safety.

**Geriatric:** May be advantageous for patient if family or caregiver keeps a diary of the pain (how much and when) and have patient complete pain screen at home in a comfortable environment. When these are then brought to appointments, provides more useful information improving the strategy to address the pain.

### Patient Links and Handouts:

- American Cancer Society, Cancer Pain
- Cancer.Net, Side Effects, Pain
- NIH, Cancer Pain (PDQ®)
- NIH, Pain

CSOC Patient Handout can be accessed at: http://cancer-help.me/pain

### References:

- NCCN, Clinical Practice Guidelines in Oncology (NCCN Guidelines®) Adult Cancer Pain
- NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) Older Adult Oncology
- NCCN Continuing Education, Coleman Supportive Oncology Training Modules
- Livestrong, Pain Management
- ASCO Answers, Managing Pain
- NIH, Cancer Pain (PDQ®)
- Pain Assessment: The Basics and Pain Management: Beyond the Basics
- NIH, Cancer Pain (PDQ®)

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Physical Concerns –

**Pain, Severe Total Score**

### Start With

Adding answer scores to get Total Score

### Total Score:

- **No Pain (+1)**
- **Mild (+2)**
- **Moderate (+3)**
- **Severe (+4)**
- **Very Severe (+5)**

- **No Pain (+1)**
- **Mild (+2)**
- **Moderate (+3)**
- **Severe (+4)**
- **Very Severe (+5)**

### Options/Recourse

**Severe**

Uncontrolled pain is a medical emergency and should be addressed promptly.

A Severe Total Score should trigger immediate attention by a nurse, APC or physician preferably in clinic, if no clinicians available consider emergency room.

### Approach

Refer to Physician/APC or Nurse

- Consider if this is an oncologic, pain emergency. Should patient be admitted for inpatient pain control?
  - If yes - admission with palliative care consultation (stage IV)
  - If no - rapid titration of opioids (short acting)
- Pain assessment - quality, intensity (1-10 scale, visual analog scale, FACES scale for nonverbal or cultural differences), location(s), timing/duration. Review imaging, consider further imaging or lab work to evaluate if disease progression or correlate with other findings/history. Review chronic pain history (non-cancer causes of pain)
- Overall effect of pain on quality of life (QOL) - assess cultural, spiritual, emotional considerations for patient
  - If pain is opioid sensitive -
    - Rapidly titrate short-acting opioid
    - If on opioid, start patient on a laxative
  - Neuropathic pain - consider anticonvulsant or antidepressant as adjuvant
  - Chemo-induced neuropathy, trial of steroids or may need dose-reduction in chemo
  - Topical agents
  - Consider celiac plexus block or other types of interventional pain management strategies for the appropriate candidates
  - Bone pain
    - NSAID therapy if able to tolerate, bisphosphonate, safety modifications for activity
    - May need surgical consult if pathological or compression fractures present
  - Consider PT/OT, radiation, anesthesia pain, complementary and alternative medicine (CAM), non-pharmacologic methods
  - Patient/family education about expectations, opioid safety, pain management principles
- Share Patient Links and Handouts as appropriate
  - See Reference links below for additional information

### Next Step

Refer to Physician/APC or Nurse

- Consider if this is an oncologic, pain emergency. Should patient be admitted for inpatient pain control?
  - If yes - admission with palliative care consultation (stage IV)
  - If no - rapid titration of opioids (short acting)
- Pain assessment - quality, intensity (1-10 scale, visual analog scale, FACES scale for nonverbal or cultural differences), location(s), timing/duration. Review imaging, consider further imaging or lab work to evaluate if disease progression or correlate with other findings/history. Review chronic pain history (non-cancer causes of pain)
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  - Bone pain
    - NSAID therapy if able to tolerate, bisphosphonate, safety modifications for activity
    - May need surgical consult if pathological or compression fractures present
  - Consider PT/OT, radiation, anesthesia pain, complementary and alternative medicine (CAM), non-pharmacologic methods
  - Patient/family education about expectations, opioid safety, pain management principles
- Share Patient Links and Handouts as appropriate
  - See Reference links below for additional information

### Timing

**Urgent – See Physician/APC before leaving or send to ER Emergency Room**

### Notes

**Stages I-III:** Further increase social worker, chaplain support for coping with pain. Assess patients with moderate and severe pain for concurrent depression and anxiety which can contribute to a complex pain syndrome.

**Stage IV:** Reassess/affirm that goals are for patient’s comfort, function and safety. If prognosis is terminal and patient is in severe pain, clarify how much care to focus on comfort. Healthcare practitioner review prognosis and assess patient or health care surrogate’s goals of care. If primary focus is on patient’s comfort, that guides pain management and treatment plan. If primary focus is on life prolongation at all costs, this may change pain management strategy. If prognosis and goals of care are disparate, consider a palliative care consult. If patient has months-years prognosis, consider intrathecal pump therapy or other long-term anesthesia procedure. If patient has weeks-months, review burden of increase of opioids (i.e. if patient has event in immediate future, may fatigue from increased pain medications). If patient is imminently dying (hours-days), and has severe pain, inpatient hospice is recommended. Send home with hospice if dying at home is important. Assess patients with moderate and severe pain for concurrent depression and anxiety which can contribute to a complex pain syndrome.

**Geriatric:** May be advantageous for patient if family or care taker keeps a diary of the pain (how much and when) and have patient complete pain screen at home in a comfortable environment. When these are then brought to appointments, provides useful information improving the strategy to address the pain.

### Patient Links and Handouts:

- American Cancer Society, Cancer Pain
- Cancer.Net, Side Effects, Pain
- NCI, Cancer Pain (PDQ)
- NIH, Pain
- Livestrong, Pain Management
- ASCO Answers, Managing Pain

CSOC Patient Handout can be accessed at:

http://cancer-help.me/pain

### References:

- NCCN, Clinical Practice Guidelines in Oncology (NCCN Guidelines) Adult Cancer Pain
- NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines) Older Adult Oncology
- NCCN Continuing Education, Coleman Supportive Oncology Training Modules

Several modules are helpful, specifically:

- Pain Assessment: The Basics and Pain Management: Beyond the Basics
- NIH, Cancer Pain (PDQ)

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Fatigue/Low Energy Answers:
- Not at all (+1)
- A little bit (+2)
- Somewhat (+3)
- Quite a bit (+4)
- Very much (+5)

Total Score:
- 10-13 = Mild
- 14-18 = Moderate
- 19+ = Severe

Assess contributing factors:
- Pain
- Emotional distress
- Mood disorder
- Sleep disorder
- Nutritional deficits
- Anemia
- Deconditioning
- Medications and medication side effects
- Comorbidities

Approach

For any patient indication of fatigue, see NCCN Links below in References for additional information.

Printing the NCCN Cancer Related Fatigue guidelines based on the stage of treatment may help some patients and families.
- Active Treatment, page FT-5
- Post Treatment, page FT-6
- End of life, page FT-7

Share Patient Links and Handouts as appropriate

General intuitive strategies that can be suggested to patient by APC or Nurse:
- Exercise if possible
- Energy conservation (set priorities and realistic expectations, pacing, delegation, use distraction, structuring daily routine)
- Rest when necessary
- Improve diet
- Adjust activity to rhythm of the fatigue/low energy
- Postpone nonessential activities and concentrate on meaningful interactions
- Adjust timing of sedating/activating medications

Refer to Physician/APC or Nurse
(See above General intuitive strategies)

Non-pharmacologic strategies from NCCN guidelines, page FT7 (consider an exercise program, referral to rehabilitation, psychosocial interventions, mind fullness based strategies, massage therapy) can also be offered by nurse or mid-level provider.

Pharmacologic strategies should be offered only by APN, oncologist, or palliative provider.
- Consider psychostimulants like methylphenidate
- Consider dexamethasone
- Consider novel medications like anamorelin

Additional options
- Consider stopping chemotherapy if treatment is contributing to significant fatigue
- Consider whether fatigue is related to endstage disease and whether referral to palliative care and hospice needs to expedited.

Notes
Stages I-III: Focus on FT-5 and FT-6 in NCCN guideline; evaluate whether or fatigue is secondary to chemotherapy or it is post-treatment related fatigue.

Stage IV: Focus on FT-7 in NCCN guideline with a lower threshold to more quickly incorporate pharmacologic solutions into therapy, however other solutions like physical medicine may be helpful but may take longer to realize benefit. Referral to palliative care may be appropriate. Please consider whether significant fatigue is related to a change in performance status from disease progression and whether this significant fatigue could indicate a change in management and goals of care.

Geriatric: Fatigue more common in this population. Anemia, depression and deconditioning can be fatigue factors. If over 75 years of age, issues of cognition and dementia may present themselves as fatigue.

Patients 65 – 74 give Mini-Cog™ screen if patient is depressed, has anxiety or fatigue of any level Patients 75 and over, screen with Mini-Cog™ If any patient fails Mini-Cog™, DO NOT have patient complete any screening for distress without the health care proxy present.

Patient Links and Handouts:
- American Cancer Society, What is Fatigue
- NCCN, Fatigue, Patients and Caregivers
- NCCN, Fighting Cancer Fatigue
- Cancer.Net, Fatigue
- NIH, Fatigue (PDQ®)

CSOC Patient Handout can be accessed at: http://cancer-help.me/fatigue

References:
- NCCN Cancer Related Fatigue
- NCCN Cancer and Chemotherapy-Induced Anemia
- NIH, Fatigue (PDQ®) Health Professional Version
Physical Activity –
Normal and Mild Total Score

<table>
<thead>
<tr>
<th>Start With</th>
<th>Approach</th>
<th>Next Step</th>
<th>Timing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total of 5 Screening Tool Physical Activity Answers:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Without any difficulty (+1)</td>
<td></td>
<td></td>
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<tr>
<td>• With a little difficulty (+2)</td>
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<td></td>
<td></td>
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<tr>
<td>• With some difficulty (+3)</td>
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<tr>
<td>• With much difficulty (+4)</td>
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<tr>
<td>• Unable to do (+5)</td>
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<tr>
<td><strong>Total Score of 0 – 9 = Normal</strong></td>
<td>• Patients scoring within the category of “Normal”</td>
<td>Refer to Physician/APN or Nurse</td>
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<tr>
<td></td>
<td>• Does not need to be assessed further</td>
<td>Advise PT/OT if already involved</td>
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<tr>
<td></td>
<td>• No follow-up referral</td>
<td>Social Worker or Case Manager</td>
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<tr>
<td></td>
<td>• Inform patient about future routine screenings</td>
<td>Can assess but should route back to Nurse or Physician/APN</td>
<td></td>
</tr>
<tr>
<td><strong>Total Score of 10 – 14 = Mild</strong></td>
<td>For Total Scores &gt;14, see Physical Activity Moderate/Severe Follow Up</td>
<td></td>
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<tr>
<td></td>
<td>• May not need in-depth assessment</td>
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<tr>
<td></td>
<td>• Assess ECOG Performance Status</td>
<td></td>
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<tr>
<td><strong>Options/Recourse</strong></td>
<td>General, intuitive strategies that can be suggested to patient:</td>
<td></td>
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<tr>
<td></td>
<td>• Lifestyle modifications</td>
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<td></td>
<td>• Realistic expectation management</td>
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<td></td>
<td>• Discuss:</td>
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<tr>
<td></td>
<td>o pacing</td>
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<td></td>
<td>o delegating</td>
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<td></td>
<td>o limiting naps and sleep hygiene</td>
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<td></td>
<td>o fatigue-inducing medications/timing</td>
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<tr>
<td></td>
<td>o chemotherapy expectations</td>
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<td></td>
</tr>
</tbody>
</table>

Notes

**Stages I-III:** Teach that fatigue may be a symptom throughout treatment and even in survivorship. Discussion with oncologist regarding causes and acceptable levels of fatigue. Early consideration for rehab to improve QOL. Review importance of activity in improving survival. Review that some retrospective studies in certain cancers demonstrate that vigorous physical activity may improve survival and how he or she tolerates therapies.

**Stage IV:** Teach the patient and family about expectations going forward, managing and balancing rest with nap limits ensuring a good sleep-wake cycle. Educate on opioid-related fatigue (expectation that fatigue will always increase with medication increase, improvement may happen over time). Set realistic expectations and goals. Limiting activity may be more important as fatigue progresses.

**Geriatric:** Reduced physical activity more common in this population. Geriatric patients tend to overstate how well they are doing on physical function questionnaire screening. Patients 65 – 74 consider basic physical ability screen, (e.g. FTSST) for possible physical therapy referral and for Patients 75 and over, screen for physical ability (e.g. FTSST). Increased sleep can be trigger for depression or cognitive issues. If suspect loss of physical activity may be due to cognitive issues, screen with Mini-Cog™.

### Patient Links and Handouts:

- American Cancer Society, Physical Activity and the Cancer Patient
- NCCN Exercising During Cancer Treatment
- Cancer.net, Cancer and your Body
- Journey Connections, Medical Services and Hospice & Respite
- Cancer.Net, Physical Activity and Cancer Risk
- NIH, Keep Up with Your Daily Routine
- CSOC Patient Handout can be accessed at: [http://cancer-help.me/being-active](http://cancer-help.me/being-active)

### References:

- NCCN Clinical Practice Guidelines in Oncology (NCCN® Guidelines) Palliative Care
- NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) Older Adult Oncology
- Clinical Implementation of Exercise Guidelines for Cancer Patients: Adaptation of ACSM’s Guidelines to the Italian Model
- DME Resource Devices 4 the Disabled

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### Physical Activity –
**Moderate, Severe or Very Severe Total Score**

<table>
<thead>
<tr>
<th>Start With</th>
<th>Approach</th>
<th>Next Step</th>
<th>Timing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Score of 18-18 = Moderate</td>
<td>Refer to Physician/APC or Nurse</td>
<td>Moderate Routine - within 1 week</td>
<td></td>
</tr>
<tr>
<td>Total Score of 19+ = Severe or Very Severe</td>
<td>Advise PT/OT if already involved or referral to PT/OT</td>
<td>Severe Discuss same day</td>
<td></td>
</tr>
</tbody>
</table>

**Assess and treat underlying factors**
- Basic assessment - duration, change, causes/mitigating factors, review of systems (ROS) and medication history
- Co-morbidities - cardiac or renal dysfunction, pulmonary diagnoses (assess and treat as possible)
- Lab tests - if indicated, check CBC for anemia, WBC for infection if clinically relevant. Treat anemia as appropriate.
- TSH to evaluate if other endocrine issues involved hepatic and chemistry panel
- Medication induced - Review dosing and timing of all fatigue causing medications (opioids, some antidepressants, sleep agents, chemotherapy) adjust timing or reduce if possible
- Evaluate sleep disturbance - Assess sleep pattern, causes of insomnia or poor sleep. If applicable, control pain/anxiety at night. Sleep agent if indicated. Also may try CBT for sleep hygiene. Ensure diuretics, corticosteroids, amphetamines, activating agents are taken in AM. Rule out sleep disorders (obstructive sleep apnea, narcolepsy)
- Nutritional assessment - Dietary referral, assess imbalances in intake (fluid or caloric)
- Depression
- Radiation-induced - Discuss cumulative nature of radiation fatigue, expectations of improvement over time

**NOTE:**
- May be indicator of intolerance of cancer-directed therapy
- Consider appropriateness of chemotherapy, risks verses benefits given severity of limitation.
- Consider rehab prior to or concurrent to therapy if able.

Share Patient Links and Handouts as appropriate
See Reference links below for additional information

### Notes

**Stage I-III:** Teach that fatigue may be a symptom throughout treatment and even through to survivorship. Discussion with oncologist regarding causes and acceptable levels of fatigue. Early consideration for rehab to improve QOL. Review importance of activity in improving survival. Some retrospective studies in certain cancers found that vigorous physical activity may improve survival and in tolerating therapies.

**Stage IV:** If patient has shorter prognosis (weeks to months) or upcoming trip/event, consider corticosteroid therapy. Discuss goals of PT/OT, may be for caregiver safety and maintaining function rather than improving/gaining strength. Social worker to assess further for need(s) of caregivers and resources at home. Increase support for caregivers and emphasize their self-care. Assess for Durable Medical Equipment (hospital bed, commode, gait belt, safety equipment) needs. May need skilled nursing facility or assisted living referral. Review natural progression of illness and the dying process. May be time to begin discussion of hospice services (even if not quite ready or appropriate), natural course of disease progression. Also should discuss impact of this on prognostic expectations for family and patient’s planning.

**Geriatric:** Reduced physical activity more common in this population. Geriatric patients tend to overstate how well they are doing on physical function questionnaire screening. Patients 65 – 74 consider basic physical ability screen, (e.g., FTSST) for possible physical therapy referral; and Patients 75 and over, screen for physical ability (e.g., PTSSST). Increased sleep can be trigger for depression or cognitive issues. If suspect loss of physical activity may be due to cognitive issues, screen with Mini-Cog™.

### Patient Links and Handouts:
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### References:
- NCCN, Clinical Practice Guidelines in Oncology, (NCCN® Guidelines) Palliative Care
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### Physical Concerns — “YES” to Falls

#### Start With
Asking the patient the below question

- Have you had any falls in the past few months?
- If so, where, how and when did these falls happen?
- Were you injured?
- Are you on a blood thinner?

#### Document all answers in referral and patient record.

**NOTE:** 2 or more falls in the last 6-12 months, or an injury from a fall should trigger immediate action by notifying MD.

#### Refer to Physician/APC or Nurse

- Review medications
- Assess for underlying illness i.e., dehydration, generalized weakness, confusion, uti, anemia
- Assess blood pressure take ortho-hypostatic BP
- Check for anemia, electrolyte imbalance, vitamin D level etc
- Discuss proprioception/neuropathy
- Assess for progression of heart (a fib) or neurological disease (Parkinson's) or new disease is these areas
- Discuss environmental factors that could contribute to a fall (loose rugs, low lighting, clutter, cords, slippers/socks vs shoes, handrails or grab bars installed etc)

#### If patient has had one or more falls assess for frailty by screening for ADLs/IADLs

- Assess for patient frailty or physical function.
- Physical difficulties may be partially or fully reversible, consider PT referral if clinically appropriate and patient has issues with weakness/gait/balance
- Discuss progression and treatment if there is a lack of understanding
- Screen for cognitive issues if indicated and clinically appropriate

Share Patient Links and Handouts as appropriate
See Reference links below for additional information

### Notes
- **Any Stage** – Falls can be more prevalent for patients who are on specific therapies or medications (i.e. sedatives, antihistamines, Benadryl, any meds that cause sedation), have bone thinning, are geriatric or have cancers that are bone avid. Work with caregivers and patients willingness to make changes to reduce fall risk (assistive device, moving rugs etc). OT Assess home environment and work with patient to recognize fall risk areas and activities
- Reduce dosage of psychiatric medications, any medications with sedative properties including over the counter medications, antihypertensive medications etc if medically possible

**Does patient have enough support at home?** SW may have resources

**Geriatric** - The use of early and preventative use of durable medical equipment and in-home safety evaluations is recommended for patients with neurotoxicities at high risk for falls.

### Patient Links and Handouts:

- **American Cancer Society, Avoiding and Dealing with Falls During Cancer Treatment**
- **NYT, Falls Can Kill You.**
- CSOC Patient Handout can be accessed at: [http://cancer-help.me/falls](http://cancer-help.me/falls)

### References:

- [CDC, STEADI Stopping Elderly Accidents, Deaths & Injuries](https://www.cdc.gov/steadi/index.html)
- [Preventing Falls in Elderly Person](https://www.seniordynamics.com/preventing-falls-in-elderly-person/)
- [Prospective Study of Falls and Risk Factors for Falls in Adults With Advanced Cancer](https://jco.ascopubs.org/content/30/17/2128)
- [Falls Training: Interprofessional Geriatrics Education and Training in Texas: Fall Risk Education & Assessment](https://jop.ascopubs.org/content/11/6/475)
- [Are We Falling Short? Incorporating Falls Assessment Into Cancer Care for Older Adults](https://jop.ascopubs.org/content/11/6/475)

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**Follow Up Reference for Clinicians**
### Treatment or Care Concerns

**Start With**

- Asking the patient the below questions

<table>
<thead>
<tr>
<th>Start With</th>
<th>Approach</th>
<th>Next Step</th>
<th>Timing</th>
</tr>
</thead>
</table>
| **What do you understand about your illness?** | Write a short summary of:  
- the patient’s understanding of their illness  
- What they want to better understand  
- Who they would want present for the conversation when getting information for better understanding. | Refer to Physician/APC  
Based on patient’s desired level of understanding and input from Approach questions review:  
- What cancer is and what that means to this particular patient  
- Patient’s type of cancer  
- Stage of patient’s cancer and how the stage affects prognosis  
- Patient’s pathology report  
- Patient’s radiologic studies  
- Surgical procedures/options  
- Patient’s treatment plan  
  - The various components  
  - Estimated length of time for each component  
  - Goal of patient’s care: Curative or palliative/extend life  
Consider palliative care referral for patients with difficulty understanding their diagnosis or coping  
See link in References for CSOC Palliative Training Module *Goals of Care*  
See Reference links below for additional information  
Share Patient Links and Handouts as appropriate | Discuss at next scheduled physician visit |
| **What would you like to understand better?** | | | |
| **Is there anyone who you would want to be with you to discuss your illness more?** | | | |

**Approach**

Encourage patient to:  
- Bring someone else along to all visits  
- To take notes  
- To ask questions  
Communicate the above answers in referral or notes for Next Step

**Next Step**

Refer to Physician/APC  
Based on patient’s desired level of understanding and input from Approach questions review:  
- What cancer is and what that means to this particular patient  
- Patient’s type of cancer  
- Stage of patient’s cancer and how the stage affects prognosis  
- Patient’s pathology report  
- Patient’s radiologic studies  
- Surgical procedures/options  
- Patient’s treatment plan  
  - The various components  
  - Estimated length of time for each component  
  - Goal of patient’s care: Curative or palliative/extend life
Consider palliative care referral for patients with difficulty understanding their diagnosis or coping

**Timing**

Discuss at next scheduled physician visit

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**Notes**

**Stages I-III:** important to assess what patient understands about his or her illness and to address any misconceptions. Assess patient’s fears and worries. Recommend that patient assign a health care Power of Attorney (POAH).  

**Stage IV:** important to assess what patient understands about his or her illness and to address any misconceptions. Patients may not realize that chemotherapy and/or radiation is palliative and not curative. Explain what palliative means. Assess patient’s fears and worries. If patient has a health care POA, ask if patient will allow that person to be present for these conversations and appointments.  

**Geriatric:** Having health care proxy and a family member present at all appointments if possible, especially if there are any cognitive issues. Concerns or questions of the primary caregiver are just as important to be addressed if patient has a hard time understanding. Geriatric patients may be more comfortable asking questions of a social worker than an oncologist as compared to a patient of a younger generation. Address polypharmacy and assess reduction of medications for better quality of life.

---

**Patient Links and Handouts:**

- American Cancer Society, Understanding Your Diagnosis  
- American Cancer Society, Staging Cancer  
- NCCN, Understanding a Diagnosis  
- Cancer.Net, Diagnosing Cancer  
- Cancer.Net, Stages of Cancer  
- POAH, Illinois  
- NIH, Communication in Cancer Care (PDQ®)

CSOC Patient Handout can be accessed at: [http://cancer-help.me/diagnosis](http://cancer-help.me/diagnosis)

**References:**

- NCCN Guidelines® for Treatment of Cancer by Site  
- NCCN Palliative Care Guidelines  
- NCCN Continuing Education, Coleman Supportive Oncology Training Modules  
  - Several modules are helpful, specifically:  
    - Goals of Care  
    - NIH, Communication in Cancer Care (PDQ®)

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How much do you want to know?
• Some people want to know every little detail, some people don’t want to know anything.
• Where are your thoughts on this?

What do you know about your cancer?
What would you like to understand better?
What info about the future would be useful for you?

How to Communicate Prognosis

Cancer.Net, Understanding Statistics Used to Guide Prognosis and Evaluate Treatment
NIH Understanding Cancer Prognosis
POAHC, Illinois

CSOC Patient Handout can be accessed at: http://cancer-help.me/prognosis

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### Treatment or Care Concerns –

**“YES” to I have questions or concerns about my treatment options**

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<th>Start With</th>
<th>Approach</th>
<th>Next Step</th>
<th>Timing</th>
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</thead>
<tbody>
<tr>
<td>Asking the patient the below questions</td>
<td>Relay the specific questions or specific lack of understanding in referral or notes for Next Step</td>
<td>Refer to Physician/APN</td>
<td>Discuss same day if possible Or Routine - within 1 week</td>
</tr>
<tr>
<td>What are your questions?</td>
<td></td>
<td>Refer to Physician/APN • have a Goals of Care discussion with Patient • See link in References for CSOC Palliative Training Module Goals of Care</td>
<td></td>
</tr>
<tr>
<td>What would you like to understand better?</td>
<td>Consider a Palliative Care Referral Share Patient Links and Handouts as appropriate</td>
<td>See Reference links below for additional information</td>
<td></td>
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</tbody>
</table>

#### Financial Questions
Refer to Social Worker or Financial Counselor

#### Medication Side Effects, Risks and Benefits
Refer to Physician/APN or Nurse

#### Treatment Options
Refer to Physician/APN

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### Notes

**Stages I-III:** Use language patients will understand, expect emotion and empathize, and map the future to align with the patient’s goals of care. Plan medical treatments that match patient’s goals.

**Stage IV:** Consider referral to Palliative Care provider when having difficulty understanding or coping with a Stage IV diagnosis.

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### Patient Links and Handouts:
- American Cancer Society, Learn About Cancer Topics
- American Cancer Society, Find Support & Treatment
- Cancer.Net, Managing Your Care
- Cancer.Net, How Cancer is Treated
- Cancer.Net, Types of Cancer
- NIH, Cancer Treatment
- NCCN, Cancer Treatment
- ASCO Answers, Understanding Immunotherapy
- ASCO Answers, Understanding Chemotherapy
- NIH, Communication in Cancer Care (PDQ®)

CSOC Patient Handout can be accessed at: http://cancer-help.me/treatment

### References:
- NCCN Guidelines for Treatment of cancer by Site
- NCCN Palliative Care Guidelines
- NCCN Continuing Education, Coleman Supportive Oncology Training Modules
  - Several modules are helpful, specifically:
    - How to Communicate Prognosis, Goals of Care, Advance Care Planning Over Time
- NIH, Communication in Cancer Care (PDQ®)

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Start With
asking patient the below questions

Whom do you need communication help with?

What specific areas would you want help communicating?

Examples:
- Struggling with side effects of treatment affecting quality of life.
- Wanting to focus more on quality of life than quantity of life.

Approach

Explore and define the whom:
- e.g., partner, children, other family members, work or friends

Explore any barriers
- E.g., anxiety, confusion, family conflict
- Those who would provide support and advocacy

In addition to discussion, ask if they have documented their wishes in a written document?
- Healthcare Power of Attorney Form and/or
- POLST (if relevant)

Give a brief description of both Healthcare Power of Attorney (naming someone you trust to make medical decisions for you, if you are unable to make medical decisions for yourself) and POLST (documents your wishes for your care in critical medical situations)

Communicate the above answers in referral or notes for Next Step

Next Step

Refer to Physician/APC if patient is unclear about treatment options.

Refer to SW or Psych if patient has barriers to having treatment conversations with loved ones.

Schedule family meeting with patient and loved ones (determine who they want present, including team members)
- Provide online reference to: The Stanford Letter Project
- IMPORTANT:
  - Explore their wishes
  - Document patient’s wishes about priorities, worries, tradeoffs related to treatment in patient’s records

See Reference links below for additional information

Share Patient Links and Handouts as appropriate

Timing

Routine - within 1 week

Notes

Stages I-III: All adults, including early-stage cancer patients benefit from advance care planning discussions and designation of medical power of attorney. However, these discussions tend not to occur with curative-intent patients because physicians fear it will cause patients to worry. National guidelines tend to focus on disease understanding and advance care planning for incurable patients.

Stage IV: Consider Palliative Care Referral if the primary team is not able to carry out these discussions. It is essential that a patient’s disease understanding, values, and needs are assessed.

Geriatric: Having health care proxy and a family member present at all appointments if possible, especially if there are any cognitive issues. Concerns or questions of the primary caregiver are just as important to be addressed if patient has a hard time understanding.

Geriatric patients may be more comfortable asking questions of a social worker than an oncologist as compared to a patient of a younger generation. Address polypharmacy (multiple medication use) and possible reduction of medications for better quality of life.

Patient Links and Handouts:

- NCI Support for People with Cancer, Taking Time
- Cancer.Net, Advanced Cancer
- American Cancer Society, Advance Directives
- NIH, Advance Directives
- NCCN, Advance Directives
- POLST Illinois
- POAHC, Illinois
- The Conversation Project

CSOC Patient Handout can be accessed at: http://cancer-help.me/decisions

References:

- National POLST Paradigm, comparison between POLST and Advance Directive
- NCCN Palliative Care Guidelines, (PAL 29, PAL 30)
- Goals of Care Discussion, How Hard It Can Be
  doi:10.1001/jamainternmed.2014.7740
- NCCN Continuing Education, Coleman Supportive Oncology Training Modules
  Several modules are helpful, specifically:
  - How to Communicate Prognosis, Goals of Care, Advance Care Planning Over Time, POLST Paradigm

Communication SKILLS PATHFINDER – one door portal for clinician communication skills training.
Treatment or Care Concerns – “YES” to “I want help discussing and deciding on the kinds of medical care I want or don’t want with my family, friends or doctor”

Start With
asking patient the below question

Do you need help deciding what type of medical care you would want or not want?

Normalize the discussion:
This is something we discuss with all patients that have a serious illness. It's important to know your wishes if you get really sick, before there is a crisis.

IF YES

Do you know what you want or do not want and need help discussing with someone?
Do you have someone you trust to make medical decisions for you, if you are unable to make medical decisions for yourself?
• Have you ever completed a document appointing that person to be your decision maker, such as a Power of Attorney Health Care (POAHC)?
  o If form had been completed, obtain a copy to include in EMR.
  o If no form has been completed, record name, relationship, contact info.
• Confirm if person agreed to serve this role.

Give a brief description of POLST. The POLST form documents your wishes for your care in critical medical situations. Ask if they would like to complete one or if they have one, ask for a copy to be included in EMR

Communicate the above answers in referral or notes for Next Step.

IF NO

Do you want help discussing and deciding on the kinds of medical care I want or don’t want with my family, friends or doctor?

Next Step
Refer to your institution’s care team member who would assist patient with Advance Care Planning.

Follow Up Reference for Clinicians
Refer to Physician or opportunity for SW/chaplain to engage to assist patient with discussions with others and arrange for family meeting.

Help the patient identify someone they would trust to make decisions and surrogate order if someone is not selected and documented.

Provide online reference to:
The Conversation Project

<IMPORTANT:>
  o Loop back to the physician and other providers so that the patient’s wishes are well explained and understood
  o Document these discussions and any completed forms in patient’s records

See Reference links below for additional information
Share Patient Links and Handouts as appropriate

Notes
Stages I-III: All adults, including early-stage cancer patients benefit from advance care planning discussions and designation of healthcare power of attorney. However, these discussions tend not to occur with curative-intent patients because physicians fear it will cause patients to worry. National guidelines tend to focus on disease understanding and advance care planning for incurable patients.

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Several modules are helpful, specifically:
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Supportive Oncology Execution
Patient Handouts

To further support patients, the CSOC also created one-page patient handouts for each item on the CSOC screening tool. These patient handouts provide basic information to patients about their concern, suggestions for self-help and resources available by phone and online for further information. These handouts are available in pdf format, online, can be printed and shared, and/or can be added to a patient’s medical record for access via the patient medical record portal. A full set of the patient handouts will be available at http://cancer-help.me/ in pdf form. If you use these handouts and make adjustments to them, please share with our team via CSCO@colemanfoundation.org so we can share the improvements you have made.

List of Patient Handouts available online and on subsequent pages:

1. Feeling Stressed, Worrying
2. Help with Having Little Interest or Depressed
3. Help Needed with Hospital Materials and/or Medical Forms
4. Child Care
5. Paying for Food
6. Paying for Housing
7. Transportation
8. Work Issues
9. School Issues
10. Insurance
11. Paying for Medicine
12. Living Alone
13. Self-Care
14. Concerns for Children
15. Concerns for Partners
16. Concerns for Caregivers
17. Help with Family
18. Ability to have Children
19. Spiritual
20. Breathing Issues
21. Constipation
22. Diarrhea
23. Fevers
24. Nausea/Vomiting
25. Sleep
26. Urination
27. Chewing/Swallowing
28. Cough
29. Mouth Sores
30. Dry Mouth
31. Dental Issues
32. Swollen Arms and Legs
33. Swollen Abdomen
34. Sexual Concerns
35. Skin Issues
36. Tingling in the Hands and Feet
37. Appearance
38. Nicotine
39. Alcohol
40. Drugs
41. Dental Issues
42. Memory
43. Weight Gain
44. Weight Loss
45. Taste Issues
46. Nutrition
47. Pain
48. Fatigue
49. Physical Activity
50. Falls
51. Understanding Diagnosis
52. Understanding Prognosis
53. Understanding Treatment Options
54. Discussing and Deciding Options

Complete Set of Patient Handouts for downloading HERE
Help With Feeling Stressed, Worrying

A disease such as cancer can be one of the most stressful experiences of a person's life. Nearly half of cancer patients report experiencing significant distress. Anxiety and distress may affect a patient's ability to cope with a cancer diagnosis or treatment. Stress has not been shown to cause cancer, but experiencing stress over a long period of time can weaken the immune system, leading to other physical health problems. Untreated anxiety and long-term stress can also make other aspects of your care and health, like managing pain and getting a good night's sleep, more difficult. Even mild anxiety, arising from stress from work, family, or financial concerns, can make coping with cancer more difficult.

There are a variety of ways to cope with anxiety including relaxation techniques, psychological treatment (or counseling) and medication. Many are used together. Talk with your doctor or a mental health professional to find the best options for you. Many cancer centers have social workers, counselors, support groups and psychologists who specialize in helping cancer patients manage anxiety and stress during cancer treatment.

There are support resources directly available to cancer patients - see Local Organizations below.

Self-help stress management strategies may include: exercising regularly, spending time outside, scheduling social activities, eating well, getting plenty of sleep, joining a support group, taking time to relax daily, doing things you enjoy, writing in a journal, or learning a new hobby. Some patients want to figure out ways to cope on their own, when possible. Many people with cancer have found that learning and practicing relaxation or imagery exercises (see below) has helped them cope with pain and stress. You can also take a stress reducing yoga class or listen to a relaxation DVD, CD or podcast, or find other relaxation tools online or in your home or spiritual community.

Relaxation techniques may be used alone or along with other types of treatment. Some of the following methods may be done with little guidance. Others may require the help of an instructor.

- Deep breathing. Done slowly for a few breaths in and out, this way of breathing can be done anywhere, anytime to reduce the body’s natural response of fight or flight to a threat or unknown experience.
- Progressive muscle relaxation. This is a technique that involves lightly tensing one muscles group after another beginning at the toes or the head and slowly relaxing those muscles.
- Guided imagery. This technique uses your imagination to direct the mind’s attention on a peaceful scene that generates a sense of calm and safety.
- Meditation strengthens your mind’s ability to maintain attention to the sensory experiences occurring within the present moment. Meditation helps redirect distressing thoughts about the past and future uncertainty.
- Hypnosis may useful for guided relaxation, intense concentration, and focused attention as a means to relax.
- Biofeedback technique uses painless electrical sensors called electrodes to provide a visual representation of how the body is reacting to experiences and environment (e.g. heart rate, changes to body temperature, etc)
- Yoga. This technique uses breathing and posture exercises to promote relaxation.


Local Organizations providing support for anyone impacted by cancer:

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Access an interactive map of these local resources at: http://cancer-help.me/communitycancerresourcecenters

Resources for Additional Information:
- American Cancer Society, Anxiety, Fear, and Depression
- NIH, Learning to Relax
- NIH, Adjustment to Cancer: Anxiety and Distress (PDQ®)
- Cancer.Net, Anxiety
- CancerCare.org, Anxiety and Cancer
- NCCN, Patient and Caregiver Resources, Advocacy and Support Groups

Información Española:
- NIH, Instituto Nacional Del Cáncer, Cómo hacer frente al cáncer
- NIH, Instituto Nacional Del Cáncer, Adaptación al cáncer: ansiedad y sufrimiento (PDQ®)–Versión para pacientes
- CancerCare.org, Técnicas de relajación y prácticas de la mente y el cuerpo: cómo pueden ayudarle a superlevar el cáncer

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Help With Having Little Interest or Feeling Depressed

There are many resources available to cancer patients to talk about their feelings. Social workers, counselors, support groups and psychologists who specialize in supporting cancer patients are available at many cancer centers. See Resources below.

Depression is not simply feeling sad. Depression is a disorder with specific symptoms that can be diagnosed and treated. Up to 25% of patients with cancer report experiencing symptoms of depression. Some people with cancer may experience depression before, during, or after cancer treatment. A person with cancer may also have cancer specific symptoms of depression, such as feelings of disbelief, denial, or despair, trouble sleeping, loss of appetite, anxiety or worry about the future. These symptoms of depression can be mild, moderate or severe.

Depression may make it harder to cope with cancer treatment. It may also reduce your ability to make choices about your care. As a result, identifying and treating depression are important aspects of cancer treatment. Treatment for depression will depend on your symptoms and how often you have them.

Although it may be hard, try to talk openly with your health care team about depression. This will help them address your concerns and create a treatment plan. Discuss your feelings, specific sources of concern, your physical symptoms and the effect on daily life.

Treatment of depression

There are many effective treatments for depression. For people with moderate or severe depression, a mix of psychological treatment (or counseling) and medication is often the most effective approach. For some people with depression, talking with a mental health professional may be enough to relieve symptoms. For others, medication alone may work to treat symptoms.

Psychological treatment

Mental health professionals include licensed counselors, social workers, psychologists, and psychiatrists. They provide tools to improve coping skills, develop a support system, and reframe distorted thoughts. Options include individual therapy, couples or family therapy, and group therapy. In addition, psychiatrists are the mental health professionals who can prescribe medications.

Medications

Different types of antidepressant medications are available. If your doctor recommends medication for helping with your depression, the most appropriate antidepressant suggested will be based on these factors:

- The severity of your depression symptoms
- Potential side effects
- Other medications you take
- Your medical history

Tell your doctor about all medications and supplements you take. Some may interfere with certain antidepressants. Some people experience improvement within 2 weeks after starting an antidepressant medication. However, it often takes up to 6 to 8 weeks for the medication to have full effect.

Medication is particularly effective for improving mood and the physical symptoms (e.g., fatigue, difficulty sleeping, changes in eating habits) associated with major depressive disorder. Your oncologist can prescribe antidepressant medication, but a referral to a psychiatrist may also be made if further medication management is needed. Adding psychological treatment to medication may be helpful for managing distressing thoughts and low self-esteem and practicing better coping strategies.

Resources for Additional Information:

- American Cancer Society, Depression
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- NIH, Adjustment to Cancer: Anxiety and Distress (PDQ®)

Información Española

- NIH, Instituto Nacional Del Cáncer, Cómo hacer frente al cáncer
- NIH, Instituto Nacional Del Cáncer, Depresión (PDQ®) – Versión para pacientes
- CancerCare.org, Consejería para lidiar mejor con un diagnóstico de cáncer

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Help Needed with Hospital Materials and/or Medical Forms

Internet version of this handout with active resource links at: http://cancer-help.me/reading-understanding

Ask:

1. What is my main problem?

2. What do I need to do?

3. Why is it important for me to do this?

Discuss who can help you with the materials and medical forms: family, friends, caregivers, hospital staff.

Try to have someone with you when you go to the hospital or doctor appointments.

The person with you, or you if you are alone, should always take some notes or write down information given. You can also ask for patient handouts or resources, printed or online.

Be sure that all of your questions are answered. Ask for a different explanation if you are unclear of any information given. If you have any additional questions regarding your main problem and what to do about it, please ask. If you want help, ask to speak with a social worker who may be able to help you.

Above content adapted from: Ask Me 3: Good Questions for Your Good Health, http://www.npsf.org/page/askme3

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<td>Northwest &amp; West Suburbs</td>
<td>Wellnesshouse.org</td>
<td>630-323-5150</td>
</tr>
</tbody>
</table>

Access an interactive map of these local resources at: http://cancer-help.me/communitycancerresourcecenters

Resources for Additional Information:

- Ask Me 3™ Video
- NCCN, Patient and Caregiver Resources
- Cancer.Net, Navigating Cancer Care
- CancerCare.org, Ways to Improve Communication with Your Health Care Team

Información Española

- American Cancer Society, Tratamiento y apoyo
- CancerCare.org, ¿Doctor, podemos hablar?: Consejos para comunicarse con su médico

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Cancer and treatment may affect how you feel and what you are capable or not capable of doing including caring for children. Using your answers to the below questions may help you to find resources for children you care for and at the time care is needed.

• Will childcare be a barrier at any point during your cancer treatment? Knowing how you might be affected by your treatment will help to inform you of your ability to care or not care for children.
• Do you feel you need support to address the childcare concern today?
• What stands in the way of you (or your family) getting childcare now? Financial? Other?
• Do you have friends or family in the community?
• Are you affiliated with a local spiritual/faith community or other community organization?

Steps you can take that may be useful to you and/or your family:
• Have a discussion with a social worker, child life specialist, patient advocate, patient navigator, or nurse at your treatment site to review options and make a plan for action.
• Discuss this concern with family members, friends and neighbors.
• Discuss this concern with a representative from the school/daycare who may be able to offer assistance or resources.
• What has worked in the past when you needed childcare? Is that option available?
• Who usually takes care of your children when you have a childcare need? Can you ask more of them?
• Talk with your partner/spouse about parenting responsibilities and what may need to change.
• Investigate possible options within your or your partner’s Employee Assistance Program through the employer.

Local Organizations providing support for anyone impacted by cancer:

<table>
<thead>
<tr>
<th>Cancer Wellness Center</th>
<th>Gilda’s Club Chicago</th>
<th>Living Well Cancer Resource Center</th>
<th>The Cancer Support Center</th>
<th>Wellness House in Chicago</th>
</tr>
</thead>
<tbody>
<tr>
<td>Northern Suburbs</td>
<td>Chicago</td>
<td>Far West Suburbs</td>
<td>South Suburbs</td>
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</tr>
<tr>
<td>Cancerwellness.org</td>
<td>Gildasclubchicago.org</td>
<td>Livingwellrc.org</td>
<td>CancerSupportCenter.org</td>
<td>Wellnesshouse.org</td>
</tr>
<tr>
<td>847-509-9595</td>
<td>312-464-9900</td>
<td>630-262-1111</td>
<td>708-798-9171</td>
<td>630-323-5150</td>
</tr>
</tbody>
</table>

Access an interactive map of these local resources at: http://cancer-help.me/communitycancerresourcecenters

Resources for Additional Information:

- American Cancer Society (800) 227-2345
- ASCO Cancer Net, Parenting While Living With Cancer
- Illinois Department of Human Services, Child Care Assistance Program (CCAP)
- Illinois Department of Human Services, Temporary Services for Needy Families (TANF)
- Illinois Department of Human Services, Cash
- CancerCare.org, Financial and Co-Pay Assistance
- American Cancer Society, Programs and Resources to Help With Cancer-related Expenses
- CFAC, Cancer Financial Assistance Coalition

Child Care options with cost:

- Care.com
- Sittercity
- MoniCare

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Información Española

- American Cancer Society, ¿Cómo pueden los familiares y amigos ayudar a mis hijos?
Keeping your body well fed is important to your health. If you are having difficulty paying for food there are several options that may be useful to you and/or your family. Ask your care team providers if they have any food resources; some institutions partner with outside food pantries. There are websites and phone numbers below for local resources of food and financial help. If you qualify as low income, there are several resources described in the list below that you may qualify for.

Greater Chicago Food Depository - more than 700 partners across Cook County ensure that nutritious food is available all year to neighbors in need. Find a food pantry, soup kitchen, shelter or mobile program in your community by going to their website and click on “Find Food” (www.chicagosfoodbank.org) or calling them at 773.247.3663.

Government programs that help with food or food costs for low income
The programs listed below are from the US Department of Agriculture (although some are run by states) for different groups of people, and offer food help in different ways. Some families may qualify for more than one type of help.

For more information about these programs, call the National Hunger Hotline at 1-866-348-6479 (1-866-3-HUNGRY); for Spanish, call 1-877-842-6273. Or visit www.networks.whyhunger.org.

- **Supplemental Nutrition Assistance Program or SNAP** Formerly the Food Stamp Program, SNAP is the best known one. It allows people to shop for food in grocery stores using a special Electronic Benefits Transfer card, much like a bank card. To ask about SNAP by phone, call your state or local health department or social services department, or call 1-800-221-5689 to get the local number.

- **Food distribution programs (these programs distribute food directly to needy families):**
  - Commodity Supplemental Food Program (CSFP)
  - The Emergency Food Assistance Program (TEFAP)

- **Voucher and coupon programs** such as Women, Infants and Children (WIC, for pregnant women, infants, and children) include access to fresh foods for families and senior citizens:
  - Farmers’ Market Nutrition Program
  - Senior Farmers’ Market Nutrition Program

School meals (served to children only in schools) such as the National School Lunch Program or School Breakfast Program. Summer Food Service Program are meals for kids at community sites when school’s out and may be available in your community.

**Meals on Wheels**
For people who are disabled, homebound, or elderly. Volunteers deliver ready-to-eat meals to your home. Costs or fees vary depending on your age and where you live. Contact Meals on Wheels at 888-998-6325 or visit their website at www.mealsonwheelsamerica.org.

Adapted from websites below

**Food Resources**
- Greater Chicago Food Depository (food banks) (773) 247-3663
- Illinois Department of Human Services, Cash, SNAP & Medical Assistance (800) 843-6154
- City of Chicago, Human Services, Community Service Center Location

**Resources for Additional Information:**
- American Cancer Society, Programs and Resources to Help With Cancer-related Expenses Ph: 800-227-2345
- Livestrong, Navigate Your Cancer Journey
- Supplemental Nutrition Assistance Program (SNAP)
- Social Security Disability
- Cancer.Net, Financial Resources
- PAF, Patient Advocate Foundation, National Finance Resource Directory

Información Española
- American Cancer Society, Programas y recursos para ayudar con los gastos relacionados con el cáncer

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Help with short-term housing near the cancer treatment center
Some treatment centers have short-term housing possibilities or discount arrangements with nearby motels and hotels. Ask your social worker or oncology nurse who may have ideas for low-cost housing during hospital or clinic treatment.

Help with housing needs or mortgage payments when you have cancer
The extra costs of cancer treatment or a major loss of family income may make it hard for families to pay their mortgage or rent on time. To keep a good credit rating and stay in your home, talk with your creditor or landlord about your situation and try to make special arrangements. Family, friends, or church members may be able to give you short-term help if they’re told about the problem. Talk about your situation with the cancer treatment team social worker who may know of special resources.

Families who need to move out of their homes after a cancer diagnosis should talk with their county department of social services to find out if they can get into low-cost or government-supported housing programs. In some states this may be listed under the health department or welfare department.

See Resources for Additional Information below for housing resources and help with paying for housing.

Adapted from websites below

Resources for Additional Information:

General Cancer Resources
- American Cancer Society, Programs and Resources to Help With Cancer-related Expenses Ph: 800-227-2345
- Livestrong, Navigate Your Cancer Journey

Financial Resources
- PAF, Patient Advocate Foundation, National Finance Resource Directory
- Social Security Disability Benefits
- Illinois Department of Human Services
- City of Chicago Emergency Rental Assistance
- Cancercare Financial Assistance Program Ph: 800-813-4673
- The Pink Fund for breast cancer Ph: 877-234-7465
- CancerCare, Financial Assistance Program Ph: 800-813-4673

Short-Term Housing Resources
- Illinois Medical District Guest House
- The Catholic Charities, Housing Services
- Joe’s House, Lodging Guide for Cancer Patients
- American Cancer Society Hope Lodge® Ph: 800-227-2345
- American Cancer Society, Extended Stay America Leave a Key help save a life™ Ph: 800-227-2345
- The Boulevard, Medical Respite for Chicago homeless
- All Chicago, making homelessness history
- Thresholds, for pts with co-occuring mental illness

Información Española
- American Cancer Society, ¿Cómo pueden los familiares y amigos ayudar a mis hijos?

Internet version of this handout with active resource links at: http://cancer-help.me/housing

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Transportation Resources

There are many options to support transportation to and from medical treatments, appointments and tests.

- Some hospitals have specific programs / vans
- Ask to speak with a social worker who may have resources
- See resources listed below in Websites/National Organizations
- Cancer patients with Medicaid medical insurance may be eligible for non-emergency transportation to doctor appointments that address Medicaid-approved care. Rides in your area may be offered by taxi, car, van, or a form of public transportation. Call your Medicaid caseworker for more information and eligibility.
- Depending upon the patient’s age, government-provided financial aid for transportation may be available. Many non-profit organizations specialize in specific age or veteran-related assistance for example, The Catholic Charities, Senior Services 312-655-7700.
- Transportation assistance can be available based on the city, county or township in which a patient resides.
  - Larger towns or cities may offer transportation and services for disabled and/or older adults for whom public transportation is not manageable.
  - If you live in the Chicago-land area, ask for assistance with registering for PACE (suburban public transportation) or CTA if needed. American Cancer Society may provide PACE Vouchers and Ventra (CTA) cards.
- Some private insurance policies will cover transportation costs through medical transportation companies.
- Private pay options are available for those who can afford it in terms of paratransit, taxi, Uber, Lyft or public transportation.
- If friends, family, community members offer their help, ask if they could drive you to and from an appointment.

Resources for Additional Information:

- American Cancer Society, Road to Recovery 800-227-2345
- CancerCare, Transportation 800-813-4673
- LiveStrong, Transportation and Other Cancer Support Services 855-220-7777
- Patient Advocate Foundation, Getting to Your Medical Appointments 800-532-5274
- Chicago Transit Authority
- Regional Transportation Authority
- City of Chicago Senior Transportation Programs
- Leukemia & Lymphoma Society®, Susan Lang Pay-it-forward Patient Travel Assistance Program 844-565-2269
- Medicaid Assurance of Transportation
- The Pink Fund for Breast Cancer 877-234-7465

Información Española

- American Cancer Society, Programas y recursos para ayudar con los gastos relacionados con el cancer
- CancerCare, Fuentes de Asistencia Financiera

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Determining whether to tell your employer that you have been diagnosed with cancer is a very personal decision.

Factors to consider when deciding whether to disclose are:
• Whether the cancer or side effects from cancer treatment will impact your ability to do the essential job duties
• Whether you will need accommodations or extended time off
• The culture of your work environment

If you choose to disclose, here are some tips to consider:
• Different managers may be more or less supportive of your situation. If you are uncomfortable discussing your issue with your supervisor, read your personnel manual or employee handbook or speak to a human resources staff member.
• To decrease the likelihood of misinterpretations from supervisors, it is best to give supervisors ample notice to arrange for accommodations and/or needed coverage.
• Consider sharing with them when and why you may be late for work, need to leave early or changes in your ability to concentrate or changes in your mood.
• Ask human resources staff or supervisors about all company benefits or services that could help, such as donated Paid time off, flex-time, job-sharing, working from home, short and long term disability, employee assistance funds, etc.

Know Your Rights –
The Americans with Disability Act (ADA)
• Protects eligible people living with a disability from discrimination in the workplace
  • Requires eligible employers to make “reasonable accommodations” to allow employees to function properly on the job
  • Ensures that employers must treat all employees equally

To be eligible the employee must:
• Disclose they have a “major medical illness” to a manager or HR
• Be employed by an employer with 15 or more employees
• Includes cancer or a history of cancer in its definition of disability

Federal Family and Medical Leave Act. (FMLA)
• You can ask employer for a copy of the FMLA or download from the internet using the link below.
• The law requires a covered employer must grant an eligible employee up to 12 work weeks of unpaid leave in a 12-month period to care for an immediate family member (spouse, child or parent, but not in-laws) with a serious health condition without loss of job security or health benefits.
• The law permits you to use, or your employer may require you to use, any accrued paid leave, such as vacation or sick leave, for some or all of the FMLA leave period.
• Employees are eligible to take FMLA leave if they:
  • have worked for their employer for at least 12 months, and have worked for at least 1,250 hours over the previous 12 months
  • work at a location where at least 50 employees are employed by the employer within 75 miles

Legal Rights Links:
➢ Americans with Disabilities Act (ADA)
➢ US Equal Employment Opportunity Commission, Q&A about Cancer in the Workplace and the ADA
➢ LAF, Free Legal Assistance for those living in poverty in Cook County Illinois
➢ Triage Cancer, Beyond Diagnosis

Resources for Additional Information:
➢ CancerandCareers.org
➢ American Cancer Society, Working During and After Treatment
➢ LiveStrong, Employment Issues
➢ US Department of Labor, Family and Medical Leave Act (FMLA)
➢ Social Security Disability Benefits
➢ National Cancer Legal Services Network
➢ Leukemia & Lymphoma Society, Balancing Work
➢ American Cancer Society, Keeping employer-sponsored health insurance coverage
➢ Cancer Support Community, Employment and Cancer
➢ American Cancer Society, El trabajo durante y después del tratamiento

Información Española
➢ CancerandCareers.org
➢ American Cancer Society, Trabajo durante y después del tratamiento
➢ National Cancer Legal Services Network
➢ Leukemia & Lymphoma Society, Balancing Work
➢ American Cancer Society, Manteniendo la cobertura de salud del empleador
➢ Cancer Support Community, Empleo y Cancer
➢ American Cancer Society, El trabajo durante y después del tratamiento

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After you are diagnosed with cancer, one of your concerns may be how to handle both school and treatment. Depending on your treatment plan, you may be able to continue to attend school and keep up with schoolwork, with short breaks for appointments and treatment, or you may need to take more time off from school.

Talking with staff
If you need to take a long break from school, need to miss class frequently, or struggle to complete schoolwork, contact your school to discuss these situations. Depending on the school, you may need to talk with the registrar, your advisor, instructors and/or professors. If possible, the best time to discuss the issues or options listed below is before treatment begins and before returning to school after a long absence:

- Attendance, since you may need to miss days or classes for treatment and appointments
- Any accommodations you might need such as fewer classes, a shortened school day, a closer parking space, or additional time to complete assignments or tests
- Some hospitals have educational coordinators or social workers who can meet with school staff to explain your situation and needs.
- If possible, ask your doctor to give you an estimate for how long and how often you may be away from school.

Staying involved
There may be times during treatment when you can’t go to school on a regular basis. However, staying involved with school can help you feel like you’re missing less and make it easier to return when you are ready.

- Keep in touch with your friends, through texting, instant messaging, video chats, e-mail, phone calls, or visits.
- Ask a classmate to take notes for you if you need to miss a class.
- Ask teachers, instructors, professors if you can photocopy their notes or tape record their class.
- Try to arrange to attend school for special events that are important to you.

Keeping up with schoolwork
You may expect yourself to keep up with the demand of school or expect yourself to resume school at the level you did before cancer, but going to school may be tiring during and after cancer. Take it easy at first and don’t overdo things. Your health is the most important priority. Be aware of your body’s energy level and take breaks, or delay restarting some activities until your energy level improves. Sometimes talking through your responsibilities and expectations with another person can help you re-prioritize your tasks.

If you find that school is harder than it used to be or you have more difficulty keeping up with your schoolwork, ask for help. Some cancers and treatments can affect your ability to concentrate, your memory, your ability to understand reading material or your ability to put thoughts together. Some of these challenges may be temporary, or some may last longer. Not everyone will have difficulties with learning during and after cancer treatment, but if you notice differences talk with your doctor about your concerns and talk to your school about possible options to make school possible for you.


Legal Rights:
The following 3 federal laws help protect the rights of students with educational needs resulting from cancer treatment:

- The Americans with Disabilities Act (ADA)
- The Individuals With Disabilities Education Act (IDEA)
- The Rehabilitation Act of 1973 – Section 504

Resources for Additional Information:

- Scholarships and Resources, National Collegiate Cancer Foundation
- Scholarships, Cancer for College
- Gildas Club Chicago, GCC@School: Cancer Support for the Classroom
- College Scholarships.org
- Dana-Farber, Cancer Institute, Tips for Starting College During Cancer Treatment

Información Española

- American Cancer Society, Para la persona a cargo del cuidado de alguien con cáncer
Insurance Coverage or Having No Health Insurance Tips

If you have health insurance:
• Make sure you read and understand your policy.
• Learn which services are covered and the portion of medical expenses you are responsible for paying.
• If you are being denied health coverage for specific treatments, meet with the hospital administrator or a patient advocate to discuss the situation.
• Places to go for help:
  o Call you insurance company and talk with them about any coverage issues you may be having.
  o Connect with a social worker, patient advocate or patient navigator at your treatment center.
    • Can help you to understand insurance coverage as well as help submit claims and paper work for Medicare or Medicaid
    • May be able to refer you to assistance programs from organizations that may help with your healthcare costs.
  o Refer to your institution’s financial (billing) counselor if one is available to assist with billing issues, a payment plan or other means to pay for your care.

If you do not have health insurance:
• Health care insurance can be acquired through several avenues based on income, age, employment, lack of employment, dependents, etc.
  o Some options may include private health insurance, employer provided, Affordable Care Act Health Insurance Marketplace policies, Medicare or Medicaid.
  o Undocumented immigrants might apply for coverage on behalf of documented individuals.
  o Charity care may also be available through your institution.

If you do not receive health insurance through work, and are not eligible for Medicare or Medicaid.
  o HealthCare.gov is the official resource for health insurance provided through the 2010 Patient Protection and Affordable Care Act (ACA). This legislation also changed many rules for health care insurance coverage in the United States. Learn more about the Affordable Care Act and Cancer (https://www.cancer.net/node/24921).
• Charity care may also be available through your institution.

Adapted from: https://www.cancer.net/navigating-cancer-care/financial-considerations/health-insurance

Resources for Additional Information:
➢ American Cancer Society, PH: (800) 227-2345
➢ American Cancer Society, Health Insurance Options
➢ American Cancer Society, Understanding Health Insurance
➢ American Cancer Society, If You Can’t Get Health Insurance at Work
➢ Leukemia & Lymphoma Society Speak on-on-on with Information Specialist, PH: 800-955-4572
➢ Leukemia & Lymphoma Society, Finances and Insurance Coverage
➢ Cancer.Net, Managing the Cost of Cancer Care, Practical Guidance for Patients and Families
➢ Cancer.Net, Financial Considerations
➢ CancerCare.org, Coping with Cancer When You’re Uninsured
➢ Affordable Care Act, (ACA) Health Insurance Marketplace
➢ ACA Premium Payments, Grace Periods & Termination Information
➢ HealthCare.gov, Health coverage for immigrants
➢ HealthWell Foundation® Improving Access to Care for Underinsured
➢ Patient Advocate Foundation, Co-pay relief
➢ Livestrong, Health and Disability Insurance
➢ Livestrong, Cancer Navigation
➢ Social Security Disability
➢ Medicaid
➢ Medicare

Información Española
➢ American Cancer Society, Si tiene dificultades para pagar
➢ CancerCare.org, Cómo ayudan las fundaciones de asistencia de co-pago

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Patients who have prescription drug plans may find that their plan’s formulary does not cover certain drugs they need. A formulary is a list of prescription drugs that has been approved by a state, health plan or hospital. Typically there are processes that enable access to non-formulary drugs when they are documented as medically necessary. A plan sponsor must have an exceptions process for these situations and denials of exceptions must be subject to an appeals process.

People without adequate insurance to cover the cost of prescription medications for cancer treatment may get help with the cost of their medicines from public and private programs. Some of these programs let people buy drugs at discounted prices. Others help people who can’t afford any part of their medicine costs. All the programs will make you complete an application form, and most will require information from your doctor.

Each pharmaceutical (drug) company with a patient assistance program sets requirements for its own program. You are more likely to qualify if:

- You are not covered by a private insurance plan that pays for your prescription drugs.
- You are insured, but your plan doesn’t pay for one or more of the drugs your doctor prescribed.
- You do not qualify for any government (state or federal) program that will pay for your prescription drugs.
- Payment for your prescription drugs at the retail price will cause you a financial hardship.
- You complete their application process with all the required information. Some programs allow your doctor to simply write a letter stating that you have a financial hardship. You’ll need to get an application for each program you wish to apply to. If you’re taking more than one drug, you can apply to more than one program. (You can get the applications from their websites or calling the program to have them sent to you.)

Read and follow the instructions on each form very carefully. For the most part, they will need your name, address, and contact information.

- Some forms request proof of income, you must provide this to help. (copies of your paycheck stubs for the past 3 months, last year’s income tax form, a social security benefit letter, or other proof listed on the instructions)
- You must answer each question. If you don’t, the application might be rejected.
- Take each application form to your doctor. They will fill in medical information, including a prescription for your drugs.
- Make copies of completed forms and letters before mailing them. Keep your copies in a safe place so that you can use them to fill out the renewal requests.
- Mail/Send the forms to the drug companies. Be sure that your doctor’s office mails the forms to each drug company. If you mail the forms yourself, be sure to include the prescriptions that go with each application.

The drug company will review and decide whether to approve your application. If approved, the drugs are mailed within a few weeks. Some pharmaceutical companies ship to your doctor’s office and some could be directly shipped to you. Be sure to verify where drugs will be shipped.

For refills, you’ll need to re-apply with a new prescription from your doctor a few weeks before you run out of the drug. Some drug companies will include a renewal application in your shipment; with others you may need to call for a renewal form. It’s up to you to submit your refill request in time.

Remember that drug companies rely on your doctor’s recommendations, so your doctor plays a key role in your acceptance. If your doctor doesn’t know about these programs, ask him or her to call or go to the website of the assistance program you are looking at. If a drug company doesn’t approve your application, ask your doctor to prescribe a different or generic medicine, and then re-apply to the new drug company.

### Resources for Additional Information:

- [American Cancer Society, Programs That Help Pay for Prescription Drugs](https://www.cancer.org/treatment/costs/financial-assistance/patient-assistance.html)
- [American Cancer Society, Applying for a Patient Drug Assistance Program](https://www.cancer.org/treatment/costs/financial-assistance/patient-assistance.html)
- [American Cancer Society, Finding and Paying for Treatment](https://www.cancer.org/treatment/costs/financial-assistance/patient-assistance.html)
- [American Cancer Society, Compassionate Drug Use](https://www.cancer.org/treatment/costs/financial-assistance/patient-assistance.html)
- [Leukemia & Lymphoma Society®, Cancer and Your Finances](https://www.cancer.gov/cancer-information/financial-assistance)
- [National Cancer Institute, Managing Costs and Medical Information](https://www.cancer.gov/cancer-information/financial-assistance)
- [NeedyMeds, Find help with the cost of medicine](https://www.needymeds.com)
- [CancerCare.org, Managing the Cost of Cancer](https://www.cancer.org/treatment/costs/financial-assistance/patient-assistance.html)
- [PAN Foundation, help for underinsured](https://www.panfoundation.org)
- [Partnership for Prescription Assistance®](https://www.ppa.org)
- [Patient Advocate Foundation, Co-pay relief](https://www.patientadvocate.org)
- [HealthWell Foundation®, Improving Access to Care for Underinsured](https://www.healthwellfoundation.org)
- [RX Assist, current list of prescription assistance programs](https://www.rxassist.com)
- [Social Security, Benefits for People with Disabilities](https://www.ssa.gov)
- [BenefitsCheckUp, National Council on Aging](https://www.benefitscheckup.org)

### Información Española

- [American Cancer Society, Cómo buscar y pagar por el tratamiento](https://www.cancer.org/treatment/costs/financial-assistance/patient-assistance.html)
- [CancerCare.org, Fuentes de Asistencia Financiera](https://www.cancer.org/treatment/costs/financial-assistance/patient-assistance.html)

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At some point in your cancer experience, you may need help. Knowing how your cancer diagnosis, and/or your treatment, may affect your abilities to care for yourself is very important. Ask your care provider if you do not have a clear understanding of how you may be affected.

If you do or think you will need help, ask for support from the people around you. Initiating a request for practical help or emotional support can be difficult for people who are used to living independently. This is the time, however, to open up and let people know how you’re feeling and what you need help with.

- Ask your friends and family to help and be a part of your caregiving network. Ask each of them how they can best support you. Different people can provide different types of care. It is sometimes helpful to let people know specifically what kind of help you need.
  - Can they provide something concrete, like child care or dog-walking, or are they the people you call when you simply need a listening ear?
  - Can they bring a meal you would prefer/can tolerate, drive you to your treatment appointment, do lawn work, house care, transporting children, etc?
- Find new sources of support by expanding your circle of people. For example, who among your neighbors can you call for a chat or help with the yard work? Do you belong to a church, temple, mosque, or other type of spiritual community? Co-worker or your children’s school community?
- Sometimes it’s easier to leave the organizing of your care network to someone else if possible. No matter if you do it or another, your community will appreciate knowing exactly what – and how – you need to be supported. There are online tools to help do this, see below for resources.
- Consider joining a support group in-person, by phone, or online. People often find that support groups offer a sense of camaraderie and encouragement, inspire new ways of coping, help them feel less isolated and can be a good source of information and additional resources.
- If you do not have a healthcare proxy, someone appointed legally in writing to make healthcare decisions on your behalf if you become incapable of making and executing decisions, ask someone in your circle to become yours. This should be someone who clearly understands your health care wishes and whom you trust to carry them out in the event that you cannot.
- Ask your friends, family, neighbors, or coworkers if you can list them as emergency contacts, and then post their names and contact information on a visible place inside your home (refrigerator, back of your door, etc.). You might also want to give one or more of your contacts a key to your home.
- Talk to a hospital social worker or patient navigator about planning for short or long-term care if needed.

Adapted from: https://www.cancercare.org/publications/265coping_with_cancer_when_you_re_on_your_own_how_to_get_the_support_you_need

### Websites for communicating, organizing help and support

- CaringBridge: [https://www.caringbridge.org/](https://www.caringbridge.org/)
- Take them a meal: [https://www.takethemameal.com/](https://www.takethemameal.com/)
- PostHope: [https://posthope.org/](https://posthope.org/)
- MyLifeLine: [https://www.mylifeline.org/](https://www.mylifeline.org/)

### Resources for Additional Information:

- Cancer Care, Coping With Cancer When You’re On Your Own: How to Get the Support You Need
- American Cancer Society, Finding Support Programs and Services in Your Area
- Little Brothers, Friends of the Elderly®
- Cancer Support Community
- Care.com
- The Catholic Charities, Get Help
- Ill Dept of Human Services, Home Services Program
- Imerman Angels

**Información Española**

- NIH, Instituto Nacional Del Cáncer, Superación de sus sentimientos

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Self-Care Resources

At some point in your cancer experience, you may need help doing what you used to be able to do yourself.

- Needing assistance may arise as a result of not feeling well because of the cancer itself or the cancer treatment.
- Ask your care provider if you do not have a clear understanding how your cancer diagnosis or treatment may affect your abilities to care for yourself.

Resources for help may include:

- Asking your friends and family how they can best support you.
  - Different people can provide different types of care. Saying “you’ve offered to help, could you _______?” Can they provide something concrete like lawn care or dog-walking. People typically like to feel useful and usually mean it when they say to let them know if you need anything.
  - Invite people to become part of your caregiving network. It is sometimes helpful to let people know specifically what kind of help you need (e.g., bringing a meal you would prefer/can tolerate, driving you to your treatment appointment, lawn work, house care, transporting children).
  - Sometimes it’s easier to leave the organizing to someone else if possible. No matter if you do it or another, your community will appreciate knowing exactly what – and how – you need to be supported. There are online tools to help do this, see below for resources.
  - Expand your circle of people. For example, who among your neighbors can you call to ask for help? Co-workers or club members? Do you belong to a church, temple, mosque, or other type of spiritual community who’s members may offer assistance?
  - Accept all offers of help. Then make the most of that help.

- Talk to a hospital social worker or patient navigator for possible resources for help or about planning for short or long-term care if needed.

- See Resources for Additional Information below for possible assistance

- However you do it, taking the time to care for yourself, or finding the right help to take good care of yourself is important. Self-care is a necessary part of your overall well being.

Adapted from: CancerCare®, Coping With Cancer When You’re On Your Own: How to Get the Support You Need
https://www.cancercare.org/publications/265-coping_with_cancer_when_you_re_on_your_own_how_to_get_the_support_you_need

Websites for communicating, organizing help and support

- My Cancer Circle
- MyLifeLine
- CaringBridge
- CaringBridge (Spanish)
- Take them a meal
- Meal train
- PostHope
- Lotsa Helping Hands

Resources for Additional Information:

- Coping With Cancer When You’re On Your Own: How to Get the Support You Need
- American Cancer Society, Support Programs and Services in Your Area
- Cancer Support Community
- Family Caregiver Alliance®
- Care.com
- The Catholic Charities, Get Help
- IL Dept of Human Services, Home Services Program

Información Española

- American Cancer Society, Cuidado y apariencia personal durante el tratamiento

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Tips for Communicating with Children

Internet version of this handout with active resource links at: http://cancer-help.me/children

A cancer diagnosis has a profound impact on an entire family. There is new information to learn and treatment decisions to make.

Set the tone. How you talk to your children is as important as what you tell them. Use a calm, reassuring voice, even if you become sad. This will help children see how you are trying to cope, and will help them do the same. All feelings are OK. Don’t be afraid to show emotions in front of your kids. Parents help to model that it is ok for children to have emotions and can model ways to cope with challenging emotions.

Give your children accurate, age-appropriate information about cancer. Don’t be afraid to use the word “cancer.” Tell or show them where the cancer is. A simple explanation is “cells that are fast growing and crowd out the good, healthy cells.” Tell them cancer is not contagious. This will help reduce kids’ fears about “catching” cancer.

Explain the treatment plan and how it will affect their lives. Tell children how you hope to get rid of cancer (i.e. surgery, radiation, chemotherapy, etc.) Prepare them for any physical changes expected during treatment (hair loss, extreme tiredness, or weight loss). Let them know that their needs will be taken care of (for example, “Another family member or family friend will take you to soccer practice instead of Mom for a little while.”)

Explain side effects
Tell children about any side effects of treatment that you expect to happen. Preparing children for these side effects will help them understand what is happening. Often, children see the side-effects of treatment and conclude that you are getting sicker.

Answer children’s questions as accurately as possible. Take into account their age and prior experience with serious illness in the family. If you do not know the answer to a question, don’t panic. It’s ok to say, “I don’t know. I will try to find out the answer and let you know.”

Reassure children. Explain that no matter how they have been behaving or what they’ve been thinking, they did not do anything to cause the cancer.

Let them know they can turn to other members of your support system, too. These people include your spouse or partner, relatives, friends, clergy, teachers, coaches and members of your health care team. Let your children know that they can ask questions of these adults and talk to them about their feelings.

Allow children to participate in care. Give them age-appropriate tasks such as bringing you a glass of water or an extra blanket.

Encourage children to express their feelings. Share with them that they can express any feelings, even those that are uncomfortable. Let them know, too, that it’s ok to say, “I don’t feel like talking right now”.

Reassure children that they will be cared for. Let them know that even if you can’t always provide the care directly, their needs are important, will be taken care of.

As always, show your children a lot of love and affection. Let them know that although things are different now, your love for them has not changed. Trust your sense of how to best support them during this difficult time.

Local Organizations providing support for anyone impacted by cancer:

- **Cancer Wellness Center**
  - Northern Suburbs
  - [Cancerwellness.org](http://cancerwellness.org)
  - 847-509-9595
  - Programs en Español

- **Gilda’s Club Chicago**
  - Chicago
  - [Gildasclubchicago.org](http://gildasclubchicago.org)
  - 312-464-9900
  - Programs en Español

- **Living Well Cancer Resource Center**
  - Far West Suburbs
  - [Livingwellcrc.org](http://livingwellcrc.org)
  - 630-262-1111

- **The Cancer Support Center**
  - South Suburbs
  - [CancerSupportCenter.org](http://cancerSupportCenter.org)
  - 708-798-9171

- **Wellness House in Chicago**
  - Northwest & West Suburbs
  - [Wellnesshouse.org](http://wellnesshouse.org)
  - 630-323-5150

Access an interactive map of these local resources at: [http://cancer-help.me/communitycancerresourcecenters](http://cancer-help.me/communitycancerresourcecenters)

Books for Children:

- **The Jester Has Lost His Jingle** by David Saltzman (ages 3 - 12)
- **Sammy’s Mommy Has Cancer** by Sherry Kohlenber (ages 3 - 8)
- **Mothers Can’t Get Sick by Sylvia Wickstrom** (ages 3 - 9)
- **When Someone You Love Has Cancer: A Guide to Help Kids Cope by Alaric Lewis** (ages 5 - 10)
- **Books for Parents**
  - **How to Help Children Through a Parent’s Serious Illness** by Kathleen McCue
  - **Moms Don’t Get Sick by Pat Brick and Ben Brick**
  - **When a Parent Has Cancer – A Guide to Caring for Your Children by Wendy Schissel Harpham**
Tips for Communicating with your Partner

Your spouse or partner may feel just as scared by your cancer as you do. You both may feel anxious, helpless, or afraid. You may even find it hard to be taken care of by someone you love. Nearly all couples feel more stress than usual when cancer occurs. You and your partner may feel stress about:

- Knowing how to best support each other and how to communicate
- Dealing with new feelings that come up
- Making decisions
- Juggling lots of roles (such as childcare, housekeeping, work, and caregiving)
- Changing their social life
- Changing daily routines
- Not feeling connected sexually or dealing with sexual dysfunction

It helps to know that people express their emotions in different ways and react to stress differently. Some like to talk things out or focus on other people. Others like to focus inward by doing things, such as washing the dishes or fixing things around the house.

**Ways to Improve Communication** Some couples find it easier to talk about serious issues than other couples. Only you and your partner know how you feel about this. The sections below may help you think about ways to communicate that work for both of you.

**Share the Decisions** Including your spouse or partner in treatment decisions is important. Together you can meet with your doctor and learn about common symptoms, your treatment choices, and their side effects. This will help you plan for the upcoming weeks and months.

**Your Treatment Site** may have on site resources, support groups, counselors, or other team members who can help support you and your partner individually or together.

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Cancer Support Resources for Patients

Help Each Other You may have always been the "strong one" in your family, but now is the time to let your loved one help you. This can be as simple as letting the other person fluff your pillow, bring you a cool drink, or read to you. And in turn, make sure you help your partner. Expressing gratitude lets them know you understand it's a tough time for them too.

**Be Open about Stress** Some things that cause stress for you and your partner can't be solved right now. And yet sometimes talking about these things can be helpful. Look at the issues that bother you such as dealing with the unknown or feeling a strain between you. You may want to say up front, "I know we can't solve this today. But I'd like to just talk about how it's going and how we're feeling." Getting things out into the open may help you both.

**Be a Team** You and your partner may need to be a team now more than ever. It may help to think things through together. Talk about what decisions you should make together and which ones you should make alone. You may want to decide what tasks to share and if other people in your life could help with them.

**Make Dates** Many couples find that it helps to plan special occasions. Some days may end up being better than others, depending on how you or they feel. Be okay with last-minute changes. A date is about spending time together such as watching a movie, going out to eat or for an event, or looking through old photos. It can be whatever you both like to do. You can also plan these dates to include other people, if you miss being around others.

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Access an interactive map of these local resources at: [http://cancer-help.me/communitycancerresourcecenters](http://cancer-help.me/communitycancerresourcecenters)

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Resources for Additional Information:

- [American Cancer Society](tel:1-800-227-2345)
- [LIVESTRONG](tel:1-855-220-7777)
- [LIVESTRONG, Communicating With Your Partner](tel:)
- [Stanford Medicine, When Your Spouse Has Cancer](tel:)
- [CancerCare, Online Caregiver Support Group](tel:)
- [Well Spouse Organization, Support, Sharing, and Social Community](tel:)
- [NIH, Facing Cancer with Your Spouse or Partner](tel:)
- [Cancer.Net, Talking With Your Spouse or Partner](tel:)
- [National LGBT Cancer Network](tel:)
- [Imberman Angels](tel:)
- [American Cancer Society, Caregivers and Family](tel:)
- [NIH, Instituto Nacional Del Cáncer, Enfrentar al cáncer con su cónyuge o su pareja](tel:)

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Tips for Caregivers

Internet version of this handout with active resource links at: http://cancer-help.me/caregiver


Caregivers may be spouses, partners, children, relatives, or friends who help the patient with activities of daily living and health care needs at home. It is important that the caregiver is a part of the team from the start.

The caregiver’s role changes as the patient’s needs change. Different stages of care can be at diagnosis, during treatment at the hospital, during care/treatment outside of the hospital, during care in the home, after treatment ends and at the end of life, if applicable. The caregiver works with the health care team and has an important role in improving the patient’s health and quality of life. Caregiving includes everyday tasks such as helping the patient with medicines, doctor visits, meals, schedules, and health insurance matters. It also includes giving emotional and spiritual support, such as helping the patient deal with feelings and making hard decisions. The family caregiver has the very important job of watching for changes in the patient’s medical condition while giving long-term care at home. Family caregivers can help plan treatment, make decisions, and carry out treatment plans all through the different parts of treatment.

Caregivers may need help and emotional support themselves

Caregivers need to be mindful of their own health, too. Caregiving can be demanding. Caregivers will provide the best care to their patients when they are well taken care of.

Find YOUR Support System. When a friend or loved one is diagnosed with cancer, it’s an emotional time. Roles and expectations may change (or you may wonder if they are going to change). Sometimes it’s difficult to talk with your loved one about your feelings, because you both have so much going on. Many find one of the best ways to cope with stress, uncertainty, and loneliness is to talk to others who share similar experiences. You can learn from the personal experiences of others how to be effective in your new role as a caregiver.

Work Options. If you are a working caregiver, it is important to discuss your needs with your employer. Telecommuting, flextime, Family Medical Leave Act (FMLA), job sharing or rearranging your schedule can help to minimize stress. Increasingly, companies are offering resource materials, counseling, and training programs to help caregivers.

Involve Older Children. Older children living at home may be able to assist you and/or your loved one. Such responsibility can help young people become more empathic, responsible, and self-confident and give you needed support.

Ask Others to Help, Do What You Can. You can and should ask other family members to share in caregiving. A family conference can help sort out everyone’s tasks and schedules. Friends and neighbors also may be willing to provide transportation, respite care, and help with shopping, household chores or repairs. Create a list of things that need to be done, such as grocery shopping, laundry, errands, lawn care, housecleaning, or spending time with your loved one or friend, and keep handy. If someone says, “Let me know if there is anything I can do to help” you can refer to the list.

Take a break from caregiving. Even if it is only 15 or 20 minutes a day, make sure you do something just for you.

Exercise and Eat healthy. Whether it is a 20 minute walk outside or taking a yoga class, exercising is a great way to take a break, decrease stress and enhance your energy. Your health and nutrition is just as important as your loved one’s, so take the time to eat well. If you are having difficulty doing that, ask for help and get others to fix meals for you.

Seek professional help. Many caregivers have times when they feel lonely, anxious, guilty, angry, scared, frustrated, confused, lost and tired. If you feel like these feelings are overwhelming you, call your doctor, hospice or another community resource for help.

See Resources Below, subscribe to caregiving newsletters or list serves for support, attend a support group for caregivers in person or online.

Local Organizations providing support for anyone impacted by cancer:

Cancer Wellness Center Western Suburbs Cancerwellness.org 847-509-9595 Programas en Español
Gilda’s Club Chicago Chicago Gildasclubchicago.org 312-464-9900 Programas en Español
Living Well Cancer Resource Center Far West Suburbs Livingwellcrc.org 630-262-1111
The Cancer Support Center South Suburbs CancerSupportCenter.org 708-798-9171 Online Support Groups:
Wellness House in Chicago Northwest & West Suburbs Wellnesshouse.org 630-323-5150 ASCO, Cancer Net Online Communities for Support

Access an interactive map of these local resources at: http://cancer-help.me/communitycancerresourcescenter

Websites/National Organizations:

- American Cancer Society (800) 227-2345
- American Cancer Society, Caregivers and Family
- LIVESTRONG. For Caregivers (855) 220-7777
- Cancer Support Community, Caregivers
- NCCN, Patient and Caregiver Resources
- NIH, Support for Caregivers of Cancer Patients
- NCI, Support for Caregivers, When Someone You Love Has Advanced Cancer
- Cancer Net, Caring for a Loved One
- Caregiver Action Network
- National Hospice and Palliative Care Organization, Caregiving
- National LGBT Cancer Network

Información Española

- American Cancer Society. Para la persona a cargo del cuidado de alguien con cancer
- CancerCare org. Consejos para los proveedores de cuidado: ¿Cómo puede ayudarse usted mismo?

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Concerns about Ability to Have Children After Cancer

Internet version of this handout with active resource links at: http://cancer-help.me/have-children

During cancer treatment, patients have important and complex issues to consider, including present and future fertility. Because many cancer treatments can damage future fertility, patients who are or will be at a childbearing age (or parents of children with cancer) should ask their cancer care team about the possible impact treatment might have on their ability to have children so they can discuss their options. Patients should be referred to or can ask to be referred to reproductive specialists who can collaborate with the oncologists and other members of the cancer treatment team. The impact of cancer treatment is affected by the age of the patient, the drugs or agents and dosages used, and the underlying cancer itself. In addition to the types of drugs or agents used, patients and their doctors must also consider surgical or radiation therapies when discussing how treatment will specifically affect reproductive health.

How Some Treatments Impact Reproductive Health
Cancer treatment may affect reproductive health in a variety of ways; however, it is important to recognize that not all patients encounter fertility problems after treatment. Knowing who will have trouble is difficult. Fertility problems that do develop may be temporary or permanent.

For men and/or boys: Surgery of reproductive structures may result in erectile dysfunction or retrograde ejaculation, leading to the inability to release sperm naturally into the vagina. Radiation to the testes and some chemotherapy drugs can impair your ability to produce healthy sperm. You may recover from this after treatment; however, this may take months or even years. Predicting who will regain sperm production and who will not is difficult. Radiation or surgery to certain areas of the brain may reduce development of the pituitary gland hormones that stimulate sperm production.

For women and/or girls: Surgery may require removal of organs needed to become pregnant or maintain a pregnancy (for example, hysterectomy, removal of ovaries). Radiation to the pelvis and some chemotherapy drugs may destroy eggs in the ovary, making it impossible to become pregnant. Monthly menstrual periods may stop and may start again after some months. Some women develop premature (early) menopause, stop ovulating and are not able to become pregnant. Predicting who will be affected is difficult. Radiation to the pelvis may cause changes in the uterus. As a result, an embryo may not be able to implant, or the uterus may not be able to expand to hold a growing fetus. This can result in complications during pregnancy such as miscarriage, preterm (early) birth, or low birth weight babies. Radiation or surgery to certain areas of the brain may reduce development of pituitary gland hormones that stimulate the ovaries each month, disrupting the monthly menstrual cycle and interfering with ovulation.

Fertility Preservation
Men: Preservation involves collecting and freezing semen before beginning cancer treatment. The sperm can later be thawed and used to fertilize eggs of a partner when they are ready to start a family. For boys who have not reached puberty, testicular tissue banking is available at a handful of centers, but experts do not know how successful this procedure is.

Women: Fertility preservation for women involves collecting eggs before beginning cancer treatment, a procedure performed by a reproductive endocrinologist. One approach is embryo freezing (cryopreservation). The first step is to stimulate the ovaries using medication so that multiple eggs will mature. When the eggs have matured, the woman undergoes egg retrieval during an office visit. The eggs are fertilized with sperm to create embryos (in vitro fertilization). The embryos are monitored for several days and then frozen and stored. Embryos can be stored for many years. The embryos can later be thawed and transferred into that woman’s uterus or into the uterus of another woman (or “gestational carrier”).

Children With Cancer: Even for young children, ovarian tissue banking is available for pre-pubertal girls, although again there is not a lot of information on how successful this technique is. As the effects on reproduction of some new treatments are still unfolding, and as investigational options for fertility preservation may become available or more established, it is important first and foremost to discuss this topic with your cancer care team.

Content Adapted from: Cancer and Fertility adapted from NCCN https://www.nccn.org/patients/resources/life_with_cancer/fertility.aspx

Local Resources
- Northwestern Medicine Fertility and Reproductive Medicine
- Northwestern Patient Navigator for Fertility Preservation
- Ann & Robert H. Lurie Children's Hospital of Chicago, Fertility & Hormone Preservation & Restoration Program
- UI Health, Fertility Preservation Program
- Fertility Hotline 312-503-3378
- 312-503-3378
- 312-926-2000
- 312-355-2634

Resources for Additional Information:
- NIH, Sexual and Fertility Problems (Men)
- NIH, Sexual and Fertility Problems (Women)
- CancerCare.org, Coping With Fertility Concerns
- NIH, Instituto Nacional Del Cáncer, Cuestiones de fecundidad en las mujeres con cáncer: niñas y adultos
- NIH, Instituto Nacional Del Cáncer, Cuestiones de fecundidad en los hombres con cáncer: niños y adultos

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Cancer affects family and friends, not just the person with the disease. The people in your life may also feel worried, angry, or afraid. Family members may be very supportive, or they may start acting differently towards you. Some may feel guilty that they're not sick, or they may feel helpless, not knowing how to help you. When you find out you have cancer, daily routines may change for everyone. Schedules may be focused around treatment. Someone in your family may need to take time off from work to drive you to treatments. Or, perhaps you need help paying bills or cooking meals. You may need help with chores and errands.

If your family is having trouble talking about cancer related issues and changes, ask for help from your health care who may be able to refer you to someone who can help families talk about cancer. See Resources below for additional help.

Changing Roles When someone has cancer, everyone in the family takes on new roles and responsibilities. A child may have to do more chores, or a spouse may have to help shop or do carpool. It can be hard to adjust.

Money Cancer can reduce the amount of money your family has to spend or save. If you're not able to work, someone else in your family may need to get a job. You and your family may need to learn more about health insurance and find out what will be covered and what you need to pay for.

Living Arrangements People with cancer sometimes need to change where they live or whom they live with. You may need to move in with someone else to get the care you need. Or, you may need to travel far from home for treatment. This can be stressful because you may feel that you're losing your independence, even if it's just for a little while.

Daily Activities You may need help with duties such as paying bills, cooking meals, or coaching your children's teams. Asking others to do these things for you can be hard. But most people want to help and like to do so when you ask.

Do What You Can You probably can, and want to keep doing things on your own. It's important to let people know that you can still do some things for yourself. As much as you're able, keep up with your normal routine by making decisions, doing chores and errands, and taking part in things you enjoy.

Help from Other Family and Friends You can help your friends cope with the news by letting them assist you in some way. Make a list of things you think you might need help with, so they can pick something they're able to do for you. You can also find volunteers to help you through churches or community groups. Professional helpers can be hired to assist you with physical care and other needs. You could also ask your doctor about respite care, someone takes care of you in your home while your family member goes out for a while.

Show Gratitude for Your Caregivers Cancer and its treatment are hard on everyone, especially the people who take care of you. Sometimes loved ones become run down and get sick from the stress. Because of this, they need to have balance in their life—time to take care of personal chores and errands, rest, be with friends, or enjoy hobbies. Your caregivers will also need time to sort through their feelings about cancer. Let them know that you want them to have a break, and that it's okay for other people to take care of you for a while.

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- CaringBridge (Spanish)
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- Lotsa Helping Hands

Resources for Additional Information:

- NIH, National Cancer Institute, Changes for the Family
- American Cancer Society, After Diagnosis: A Guide for Patients and Families
- American Cancer Society, Helping Children when a Family Member Has Cancer
- American Cancer Society, When Someone You Know Has Cancer
- Cancer.Net, Family Life
- Cancer.Net, Talking with Family and Friends
- NCCN, Patient and Caregiver Resources, Advocacy and Support Groups
- NCCN, Patient and Caregiver Resources, Cancer and Family
- Cancer Support Community, Family and Friends

Información Española

- NIH, Instituto Nacional Del Cáncer, Familiares a cargo de pacientes de cáncer: funciones y desafíos (PDQ®)—Versión para profesionales de salud
- NIH, Instituto Nacional Del Cáncer, Apoyo para quienes cuidan a pacientes con cáncer

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It is normal for people diagnosed with cancer to struggle with finding meaning, purpose or joy in their lives, or to question or doubt their previously held religious or spiritual beliefs.

Spirituality can be thought of as one dimension of human life that focuses on the essence of being human, the human soul, or the beliefs and values held that makes life meaningful and purposeful. Spirituality is the relationship people have with a force or power beyond themselves that helps them feel connected and enriches their lives. Religion is a specific set of beliefs or practices usually connected to an organized group. Some people exercise spirituality by practicing their religious beliefs, while others find it outside of an organized religion such as in nature, the arts, or philosophy.

Each person has unique spiritual needs based on his/her family, culture, or religious community. Therefore, you may be unsure about how to bring up the subject with your health care team. However, doctors and nurses are accustomed to talking to patients and families about spiritual needs. Your cancer care professionals know that these beliefs can influence patients’ attitudes and beliefs toward cancer, treatment decisions and other challenges. Most hospitals and cancer centers have pastoral care departments to help you cope with the challenges you are facing. Social workers or other care team members may be helpful, too.

Experts say that spiritual or religious practices can help you adjust to the life changes cancer and its treatment can produce. Patients who rely on their faith or spirituality tend to experience increased hope and optimism, freedom from regret, higher satisfaction with life, and feelings of inner peace.

Studies show that spirituality can have a direct impact on quality of life. Benefits shown in studies include:
- Decreased feelings of anxiety, depression, and destructive anger
- Decreased feelings of loneliness
- Decreased alcohol and drug abuse
- Lowered blood pressure
- Better control of pain, nausea, and discomfort

Spiritual practices that may help you cope with your cancer and its treatments include:
- Participating in religious ceremonies or gatherings
- Praying or having someone else pray for you
- Meditation or meditative breathing
- Reading scripture or other holy works
- Repeating a passage from your religious tradition to reinforce its message
- Using the language of your religion, such as Hebrew, Greek, Arabic, or Latin, in your prayers
- Listening to classical or spiritual music
- Yoga
- Engaging with the arts such as painting, drawing, music, or dance
- Talking about spiritual matters with someone else

During times of pain and discomfort, during treatments, or when you feel alone, these and other practices may bring a sense of wholeness, connectedness and peace.

Spirituality may help patients and families find a deeper meaning or purpose to their life and experience personal growth.

Adapted from: https://www.nccn.org/patients/resources/life_with_cancer/spirituality.aspx

### Resources for Additional Information:
- NCCN, Finding Comfort in Spirituality
- NIH, Spirituality in Cancer Care (PDQ®)
- NCI Support for People with Cancer, Taking Time Booklet
- HealthCare Chaplaincy Network™, Can’t Believe I Have Cancer
- CancerCare.org, Strengthening the Spirit

### Información Española:
- American Cancer Society, ¿Cómo podría la progresión de mi cáncer afectar la espiritualidad y fe religiosa de mi hijo?
- NIH, Instituto Nacional Del Cáncer, NLa espiritualidad en el tratamiento del cáncer (PDQ®)
- NIH, Instituto Nacional Del Cáncer, Su fe y espiritualidad
Dyspnea is the medical term for a feeling of breathlessness. Many people with advanced cancer may experience this symptom. People with earlier-stage cancers who have other conditions that affect the heart or lungs, such as a blood clot, may also experience dyspnea. It is important to tell your doctor right away about sudden shortness of breath or worsening symptoms.

Common symptoms of dyspnea include:

- Uncomfortable breathing
- Shortness of breath
- Inability to get enough air
- A feeling of smothering, tightness, drowning, or suffocation

A person may experience dyspnea even though the actual levels of oxygen are within normal range. To learn more about your symptoms, your doctor will review your medical history. They will ask you to describe your symptoms and what makes the symptoms worse. He or she may also ask you to rate your symptoms on a scale of intensity.

Relieving side effects is an important part of cancer care and treatment. This is called symptom management or palliative care. Talk with your health care team about any symptoms you experience and any change in symptoms.

Causes of shortness of breath

Dyspnea may be caused by a tumor or another condition related to cancer but many of these causes are treatable. Some common causes of dyspnea include:

- Narrowed or blocked airway, such as by a tumor or mucous plug
- Sudden narrowing of the airway, such as a bronchospasm
- Shortage of oxygen in blood, called hypoxemia
- Fluid between the lung and the chest wall
- Pneumonia
- Inflammation of lungs after radiation treatment, called radiation pneumonitis
- Low red blood cell count (i.e. anemia)
- A blood clot in or near the lung or heart
- Anxiety
- Stress
- Uncomfortable breathing
- Shortness of breath
- Inability to get enough air
- A feeling of smothering, tightness, drowning, or suffocation
- Inflammation of lungs after radiation treatment, called radiation pneumonitis
- Low red blood cell count (i.e. anemia)
- A blood clot in or near the lung or heart
- Anxiety
- Stress
- Uncomfortable breathing
- Shortness of breath
- Inability to get enough air
- A feeling of smothering, tightness, drowning, or suffocation
- Inflammation of lungs after radiation treatment, called radiation pneumonitis
- Low red blood cell count (i.e. anemia)
- A blood clot in or near the lung or heart
- Anxiety
- Stress

Treating shortness of breath

An important step in managing dyspnea is discovering and treating the actual cause, such as a tumor or blood clot. Once the cause of dyspnea is determined, the doctor may also recommend some the following to help relieve dyspnea symptoms:

- Receiving extra oxygen
- Sitting in front of a household fan
- Breathing cooler air by lowering the temperature in a room
- Breathing cleaner air: open or close windows, use a humidifier, get rid of smoke & pet dander
- Getting a sense of open space by seeing a view of the outside or being in an empty room
- Keeping your head/chest raised, use pillows to lift your head to nearly sitting or using a recliner
- Practicing techniques that take your focus away from the problem, such as relaxation techniques and meditation
- Taking medications that act on the central nervous system to relax the sensation of breathlessness, such as morphine or other opioid medications
- Taking anti-anxiety drugs to manage the anxiety causing or caused by the dyspnea

The above content adapted from: https://www.cancer.net/navigating-cancer-care/side-effects/shortness-breath-or-dyspnea

Resources for Additional Information:

- Cancer.Net, Shortness of Breath or Dyspnea
- American Cancer Society, Shortness of breath
- Cancer.Net, Shortness of Breath or Dyspnea
- Cancer.Net, Long-Term Side Effects of Cancer Treatment
- Chemocare, Dyspnea (Shortness of Breath)
- NIH, Home Oxygen Safety

Información Española

- Cancer.Net, Dificultad para respirar o disnea
- Chemocare, Problemas pulmonares y otros problemas respiratorios

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**Physical Concerns - Constipation**

Constipation is when you are not able to have a bowel movement (poop), struggle to have a bowel movement, or are not pooping as often as usual. Bowel changes are common in people who have cancer. Constipation may be caused by the cancer itself, chemotherapy, or many of the supportive medications that you require through treatments.

People with constipation may also experience the following symptoms:

- Belly pain and cramping
- Bloating
- Loss of appetite
- New or worsening heartburn
- Pressure in the rectum or worsening hemorrhoids
- Nausea or vomiting

Talk with your health care team about any new or changing symptoms you experience or what you can do to prevent constipation from happening. Preventing and managing your symptoms is an important part of cancer care and treatment, often called supportive or palliative care.

Relieving side effects is an important part of cancer care and treatment. This is called symptom management or palliative care. Talk with your health care team about any symptoms you experience and any change in symptoms.

**Managing constipation**

It is important to prevent and treat constipation appropriately. More severe constipation can result in rectal bleeding, dehydration, or unavoidable urgent care visits. It can slow the body's absorption of medications in some cases. Talk with your health care team early about the best way to manage your constipation given your circumstances.

Some of the following suggestions may help:

- Drink more liquids. Hot or warm fluids in the morning may help.
- More fiber (along with liquids) can often be helpful. If you have a narrowed bowel, your doctor may recommend a low-fiber or low-residue diet, Ask your doctor if fiber is right for you.
- Limit foods that can cause constipation such as dairy, calcium supplements, iron pills and bananas.
- Limit carbonated/fizzy drinks that can increase intestinal bloating
- Keep track of your laxative use and bowel movement so that problems can be identified and remedied quickly
- With the advice of the health care team, ask about changing the dose or stopping medicines that cause constipation, particularly calcium and iron.
- Increase physical activity, if possible.
- Ask your health care team whether laxatives, enemas, or suppositories are right for you. Though usually safe, these may be harmful in some cases.

Adapted from: [https://www.cancer.net/navigating-cancer-care/side-effects/constipation](https://www.cancer.net/navigating-cancer-care/side-effects/constipation)

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**Resources for Additional Information:**

- Cancer.Net, Constipation
- American Cancer Society Constipation Information
- Chemocare, Constipation and Chemotherapy
- NCI, Gastrointestinal Complications (PDQ®)
- NIH, Constipation and Cancer Treatment
- CancerCare.org, Coping With Constipation

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**Información Española**

- NIH, Instituto Nacional Del Cáncer, Estreñimiento
- Cancer.Net, Estreñimiento
- Chemocare, Estreñimiento y quimioterapia

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Diarrhea is frequent, loose, or watery bowel movements (poop). This includes loose stools that are hard to hold in (incontinence) or just the need to have a bowel movement more often than usual. Your medical team may call the usual number of bowel movements you have in a day your “baseline.” If you experience a change in your bowels, share it with your health care team to explore the best ways to manage it. Occasionally diarrhea can be caused by a treatable infection commonly acquired in hospital settings.

Relieving side effects is an important part of cancer care and treatment. This is called symptom management or palliative care. Talk with your health care team about any symptoms you experience and any change in symptoms.

Risks of Diarrhea
Mild diarrhea usually does not result in serious problems, however can be uncomfortable. More significant diarrhea can cause dehydration and imbalance of electrolytes as a result of all of the water lost. Severe dehydration can lead to kidney failure, so it is best to prevent diarrhea or treat it as soon as it develops.

Prevention and Treatment of Diarrhea
The best prevention and treatment will depend on your symptoms and the cause of your diarrhea. Ask your doctor if you need medicines to prevent diarrhea such as loperamide (Imodium) or the prescription diphenoxylate/atropine (Lomotil). It is always best to consult with your doctor given your unique medical situation.

Consider these options to help you manage mild diarrhea:
• Avoid caffeine, alcohol, dairy, fat, fiber, orange juice, prune juice, and spicy foods.
• Avoid medicines such as laxatives, stool softeners, and metoclopramide (Reglan). Metoclopramide is used to prevent nausea and vomiting from chemotherapy but can lead to looser stools at times.
• Eat small, frequent meals and choose foods that are very easy to digest such as bananas, rice, applesauce, and toast. Your doctor may recommend a low-residue diet, which includes low-fiber foods
• Drink water and other clear liquids to prevent dehydration. People with severe dehydration may need to receive intravenous (IV) fluids. This means that a health care provider gives fluid to the body through a vein.
• If diarrhea is caused by the pancreas not working well, replacing pancreatic enzymes may help. This occurs in some patients with pancreatic cancer.
• If diarrhea is caused by an infection as determined by your doctor, this can be treated effectively with an antibiotic prescribed by your doctor.
• For severe diarrhea from chemotherapy, ask your doctor about changing the schedule or dose of chemotherapy.

Adapted from: https://www.cancer.net/navigating-cancer-care/side-effects/diarrhea

Resources for Additional Information:
- Cancer.Net, Diarrhea
- NIH, Diarrhea and Cancer Treatment
- NIH, Gastrointestinal Complications (PDQ®)
- National Cancer Institute, Managing Chemotherapy Side Effects, Diarrhea
- Chemocare, Diarrhea and Chemotherapy and Cancer Treatment
- American Cancer Society Diarrhea Information
- CancerCare.org, Coping With Diarrhea

Información Española
- NIH, Instituto Nacional Del Cáncer, Diarrea
- Cancer.Net, Diarrea
- Chemocare, Diarrea y quimioterapia
Contact your healthcare provider immediately, day or night, if you should experience any of the following symptoms:

- Fever of 100.4°F (38°C) or higher
- Shaking chills (possible signs of infection)

A fever may be a sign of an infection. If you get a fever during your chemotherapy treatment, it may be a medical emergency. Fever may be the only sign that you have an infection, and an infection during chemotherapy can be life-threatening. Sometimes a very low temperature (94-95°F) while feeling very sick can also be a sign of infection. Make sure you have an idea of when it is important for you to contact your doctor or seek immediate attention. Often it's better to err on the side of caution, because sometimes symptoms are easier to treat and can be managed more effectively earlier rather than later. Typically your oncology on-call service is equipped to handle these calls 24/7.

Any time you feel warm, flushed, chilled, or not well you should take your temperature. If you have a fever of 100.4°F (38°C) or above, or a body temperature of 95°F or below, call your doctor right away, even if it happens in the middle of the night.

You should also—

- Keep a working thermometer (w/ new battery if battery powered) in a convenient location, know how to use it.
- Know your temperature before you call the on call doctor so that you can report the number to the provider immediately.
- Keep your doctor’s phone numbers with you at all times. Make sure you know what number to call for when their office is open and when closed.
- If you have to go to the emergency room, tell the person checking you in that you are a cancer patient undergoing chemotherapy. If you have a fever, you might have an infection in the setting of a very low white blood cell count. This is a life-threatening condition, and you should be seen quickly.

Prevention of fevers and infection—

- Clean your hands with soap and water and/or hand sanitizer:
  - before, during and after cooking
  - before and after you eat
  - after going to the bathroom
  - after blowing your nose, coughing or sneezing
  - after touching or cleaning up after pet; after touching trash
  - before and after caring for a wound
  - before and after caring for your port, catheter port or other access device.

Encourage visitors, family, friends who have a fever, diarrhea, a cough, or the flu to maintain contact only by phone until they are well again. Ask your health care team if you have further questions.

Relieving side effects is an important part of cancer care and treatment. This is called symptom management or palliative care. Talk with your health care team about any symptoms you experience and any change in symptoms.


### Resources for Additional Information:

- NCCN, *When to Go to the Emergency Room*
- American Cancer Society, *Fever*
- CDC, *Prepare: Watch out for Fever*
- NIH, *NCI Infection and Neutropenia*
- Cancer.Net, *Infection*
- CancerCare.org, *Neutripenia and Infections*
- Chemocare, *Fever, Neutropenic Fever, and their Relationship to Chemotherapy*

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**Información Española**

- American Cancer Society, *Fiebre*
- American Cancer Society, *Sudoración*
- Chemocare, *Fiebre, fiebre neutropénica y su relación con la quimioterapia*
- NIH, *Instituto Nacional Del Cáncer, Infección y neutropenia*

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Physical Concerns – *Nausea or Vomiting*

Nausea is that feeling you have when you are going to throw up. You feel sick to your stomach and may not know how to describe the feeling. Vomiting (emesis) is throwing up what is in your stomach. It usually comes out of your mouth and can also come out through your nose.

Many types of chemotherapy may cause mild to severe nausea and vomiting. Radiation therapy, especially to the brain, spinal cord, abdomen, and pelvis, may also cause nausea and vomiting.

Relieving side effects is an important part of cancer care and treatment. This is called symptom management or palliative care. Talk with your health care team about any symptoms you experience and any change in symptoms.

**What are the risks of nausea and vomiting?**

Mild nausea and vomiting can be uncomfortable. Usually it does not cause serious problems. Vomiting a lot and often is a problem. It can cause dehydration, electrolyte imbalance, weight loss, and depression. Severe vomiting can reopen surgical wounds, create tears in the esophagus (the tube through which food passes from the throat to the stomach), or break bones. This may result in the need to stop cancer treatment, for some people.

It is important to tell your health care team if you experience nausea or vomiting so they can help you prevent or manage it.

**How are nausea and vomiting prevented and treated?**

Nausea and vomiting can be prevented with medications. However, some patients may still have nausea even if they are not vomiting. Medications to prevent nausea and vomiting should be taken as prescribed, even after treatment, because the risk of vomiting can continue for several days after treatment. If you have nausea and vomiting even if you are taking your medication as prescribed, tell your health care team. They can recommend other medications.

Other options, such as distraction, relaxation, positive imagery, and acupuncture, may help. Some herbal medications, like ginger, may help with nausea. However, you should discuss your plans with your health care team before starting any of these other options.

**What if nausea and vomiting don’t stop or get worse?**

If your nausea and vomiting does not stop or gets worse, talk with your health care team. The cause may need to be identified. If you cannot keep food or water in your body because of severe nausea and vomiting, it can lead to serious dehydration and electrolyte imbalance. Dehydration can lead to other health problems.

It is important to talk to your health care team if your symptoms get worse.

Adapted from: https://www.cancer.net/sites/cancer.net/files/asco_answers_nausea_vomiting.pdf & NCCN Guidelines for Patients®, Nausea and Vomiting

**Resources for Additional Information:**

- [NCCN Guidelines for Patients®, Nausea and Vomiting](https://www.cancer.net/sites/cancer.net/files/asco_answers_nausea_vomiting.pdf)
- [ASCO answers, Nausea and Vomiting](https://www.cancer.net/sites/cancer.net/files/asco_answers_nausea_vomiting.pdf)
- [Cancer.Net, Nausea and Vomiting](https://www.cancer.net/sites/cancer.net/files/asco_answers_nausea_vomiting.pdf)
- [NIH, NCI Nausea and Vomiting Related to Cancer Treatment (PDQ®)](https://www.cancer.net/sites/cancer.net/files/asco_answers_nausea_vomiting.pdf)
- [Chemocare, Nausea, Vomiting & Chemotherapy](https://www.cancer.net/sites/cancer.net/files/asco_answers_nausea_vomiting.pdf)
- [American Cancer Society Nausea and Vomiting](https://www.cancer.net/sites/cancer.net/files/asco_answers_nausea_vomiting.pdf)
- [American Cancer Society Anti-nausea/vomiting medicines](https://www.cancer.net/sites/cancer.net/files/asco_answers_nausea_vomiting.pdf)
- [American Cancer Society Other treatments for nausea and vomiting](https://www.cancer.net/sites/cancer.net/files/asco_answers_nausea_vomiting.pdf)
- [CancerCare.org, Chemotherapy-Induced Nausea and Vomiting (CINV)](https://www.cancer.net/sites/cancer.net/files/asco_answers_nausea_vomiting.pdf)

**Información Española**

- [NIH, Instituto Nacional Del Cáncer, Náuseas y vómitos](https://www.cancer.net/sites/cancer.net/files/asco_answers_nausea_vomiting.pdf)
- [Cancer.Net, Náuseas y vómitos](https://www.cancer.net/sites/cancer.net/files/asco_answers_nausea_vomiting.pdf)
- [Chemocare, Acidez Estomacal (reflujo gástrico) y Quimioterapia](https://www.cancer.net/sites/cancer.net/files/asco_answers_nausea_vomiting.pdf)
- [Chemocare, Náuseas, vómitos y quimioterapia](https://www.cancer.net/sites/cancer.net/files/asco_answers_nausea_vomiting.pdf)
- [American Cancer Society, Náuseas y vómitos](https://www.cancer.net/sites/cancer.net/files/asco_answers_nausea_vomiting.pdf)
- [CancerCare.org, Consejos para controlar las náuseas y aumentar el apetito durante el tratamiento del cáncer](https://www.cancer.net/sites/cancer.net/files/asco_answers_nausea_vomiting.pdf)
- [CancerCare.org, Náuseas y vómitos inducidos por la quimioterapia](https://www.cancer.net/sites/cancer.net/files/asco_answers_nausea_vomiting.pdf)

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About half of cancer patients have some sleep-related problems, difficulty sleeping known as insomnia. Sleep problems include being unable to fall asleep and/or stay asleep and are common among people being treated for cancer.

**Ways to Manage Sleep Problems**

There are steps that you and your health care team can take to help you sleep well again.

- **Set good bedtime habits, commonly called “sleep hygiene.”** Go to bed only when sleepy, in a quiet and dark room, and in a comfortable bed. If you do not fall asleep, get out of bed and return to bed when you are sleepy again. Repeat if you are unable to fall asleep. Stop watching television or using other electrical devices a couple of hours before going to bed. Don’t drink or eat a lot before bedtime. Avoid too much caffeine or caffeine later in the day. While it’s important to keep active during the day with regular exercise, exercising a few hours before bedtime may make sleep more difficult.

- **Tell your doctor about problems that interfere with sleep.** Getting treatment to lower side effects such as pain or bladder or gastrointestinal problems may help you sleep better.

- **Cognitive behavioral therapy (CBT) and relaxation therapy may help.** Practicing these therapies can help you to relax. For example, a CBT therapist can help you learn to change negative thoughts and beliefs about sleep into positive ones. Strategies such as muscle relaxation, guided imagery, and self-hypnosis may also help you.

- **Sleep medicine may be prescribed.** Your doctor may prescribe sleep medicine, for a short period if other strategies don’t work. The sleep medicine prescribed will depend on your specific problem (such as trouble falling asleep or trouble staying asleep) as well as other medicines you are taking. If the medicine does not help be sure to let your doctor know so another medication might be considered.

**Talking With Your Health Care Team about Sleep Problems**

Share your thoughts with your health care provider about your sleep problems. One way to do this is by keeping a sleep diary. Chart the times you are asleep and awake. Note what you think may be contributing to your difficulty sleeping.

Prepare for your visit by making a list of questions to ask. Consider adding these questions to your list:

- Why am I having trouble sleeping? Try to identify the cause of your sleep problems. What is insomnia caused by? Are you in pain? Are you worried about something? Are you drinking too much caffeine? Are you having to get up frequently to go to the bathroom at night? Are you napping during the day? Are you feeling depressed or anxious?
- What problems should I call you about?
- What steps can I take to sleep better?
- Would you recommend a sleep specialist or therapist who could help with the problems I am having?
- Would sleep medicine be advised for me?
- Your doctor may refer you for an assessment, which may include a polysomnogram (recordings taken during sleep that show brain waves, breathing rate, and others activities such as heart rate) to correctly diagnose and treat sleep problems. Assessments may be repeated from time to time, since sleeping problems may change over time.

Physical Concerns – Urination

Internet version of this handout with active resource links at: http://cancer-help.me/urination

Call your doctor or nurse if you have:

• A fever of 100.4°F (38°C) or higher
• Chills
• Blood in your urine, or you are not able to urinate
• Pain or burning when you urinate

Tell your doctor or nurse if you have any of these changes:

• A strong urge to urinate more often
• Urine that is cloudy or an unusual color
• Trouble urinating

Relieving side effects is an important part of cancer care and treatment. This is called symptom management or palliative care. Talk with your health care team about any symptoms you experience and any change in symptoms.

Of note, it is common for your urine to change color or smell different during chemotherapy. Talk with your doctor or nurse to learn what changes you should expect and ways to best manage them.

Questions to ask your doctor or nurse:

1. What symptoms should I call you about?
2. How much should I drink each day?
3. What liquids are best for me?
4. Are there liquids that I should drink less of?

Most people need to drink at least 8 cups a day. Keep drinking liquids even if you have to go to the bathroom a lot. Liquids help your body to work well. Be sure to drink liquids other than water to obtain valuable electrolytes that are not contained in water alone.

Some liquids can make bladder problems worse. Talk with your doctor or nurse to learn what you should stop drinking or drink less of.

These include:

• Drinks with caffeine, such as coffee, black tea, and soda
• Drinks with alcohol, such as beer, wine, mixed drinks, and liquor


Resources for Additional Information:

- NCI, NIH, Managing Chemotherapy Side Effects, Urination Changes
- Livestrong, Effects Chemotherapy Has on Urinary Systems
- Chemocare, Urinary Tract Infection (UTI)
- NIH, NCI, Urinary and Bladder Problems
- Cancer.Net, Urinary Incontinence
- Cancer.Net, Infection
- American Cancer Society, Managing Urinary Incontinence for Men with Cancer

Información Española

- NIH, Instituto Nacional Del Cáncer, Problemas urinarios y de vejiga
- American Cancer Society, Cambios urinarios y de excreción
- Chemocare, Problemas renales

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Sometimes cancer, surgery or chemotherapy can cause swallowing problems such as trouble passing food or liquid down the throat. The medical term for difficulty swallowing is dysphagia. Difficulty chewing often results from changes to the mouth, jaw, or tongue. Some people may gag, cough, or choke when trying to swallow. Others may feel like food is stuck in their throat. Many patients benefit from starting chewing and or swallowing therapy before cancer treatment, especially those with cancer in the throat.

Helpful tips: Try different types of food and ways of eating. Find what works best. And remember to eat a nutritious diet. Your food should have enough calories, protein, vitamins, and minerals.

- Liquids tend to be the best tolerated
- Eat soft, smooth foods, such as full fat yogurt or high protein pudding
- Mash or blend foods.
- Moisten dry foods with broth, sauce, butter, oil or whole milk.
- Chew solid foods thoroughly and eat at a slowed pace
- Try thickening liquids. Add gelatin, tapioca, baby rice cereal, or commercial thickening products.
- Try a straw to drink liquids and soft foods though this can sometimes prove more difficult.
- Eat cold or room-temperature foods to reduce sensitivity.
- Try softer versions of your favorite fruits or vegetables. For example, applesauce, pureed carrots, bananas, or peas. Or consider eating baby food.
- Take sips of water or other liquids while eating. This keeps the mouth and food moist.
- Cut food into small bites, and chew slowly and thoroughly.
- If you are losing weight, choose foods high in calories and protein, such as eggs, full fat yogurt, whole milk shakes or nutritional shakes
- Avoid dry, coarse, or hard foods or foods that need a lot of chewing

Medical considerations and therapy may consist of:

- Dental and oral health care. Dentists can help manage potential dental and oral side effects from treatment. For example, radiation therapy may increase risk of tooth decay or gum disease.
- Speech therapy. Speech pathologists are therapists who specialize in helping people use muscles in the mouth and throat. This includes chewing, especially after surgery in the mouth or tongue. This professional will teach you new ways to swallow and to avoid choking and gagging
- Physical therapy. Physical therapists specialize in helping patients with jaw exercises and local treatments, such as heat/cold therapy or massage.
- Medication. Your doctor may prescribe medicine if you have pain chewing or swallowing. Some medicines reduce pain and inflammation. Other medications may treat mouth or throat infections. Some medicines come as mouth rinses used before eating.
- Feeding tube. Sometimes, swallowing problems make it hard to eat a healthy diet. Your doctors may discuss the placement of a tube through the nose into the stomach or placed through abdomen into the stomach. This helps deliver food and liquid, and is usually temporary but can be permanent, depending upon the overall medical picture.

Adapted from:  www.cancer.net  https://www.cancer.net/navigating-cancer-care/side-effects/difficulty-swallowing-or-dysphagia

Resources for Additional Information:
- NCCN, Understanding the Oral Complications - From Cancer Treatment
- Cancer.Net, Difficulty Swallowing or Dysphagia
- Cancer.Net, Difficulty Chewing
- American Cancer Society, Swallowing Problem
- NIH, Chemotherapy and Your Mouth

Información Española
- NIH, Instituto Nacional Del Cáncer, Problemas en la boca y en la garganta
- Cancer.Net, Dificultad para tragar o disfagia
- Chemocare, Consejos para controlar los problemas de alimentación y su dieta después de los tratamientos de quimioterapia
- American Cancer Society, Problemas de deglución (tragar alimento)
Mucositis is a medical term for swelling inside the mouth and throat that is caused by complications of cancer treatment. This reaction may cause painful ulcers, mouth sores or can lead to infection. This can interfere with eating, talking, taste, chewing or swallowing and often lasts days to weeks. Talk with your doctor if you notice pain or other changes in your mouth during cancer treatment.

**Managing mouth sores**

Some suggestions and options for preventing and treating mouth sores:

- Suck on ice chips immediately before and during each chemotherapy treatment. Keeping the mouth COLD may prevent mucositis caused by certain types of chemotherapy.
- Your doctor may recommend specific pain-relief strategies if you develop mouth sores. Options your doctor may recommend might include the following:
  - Prescribing a mouthwash solution that may contain a numbing and/or a coating medication to reduce pain and promote healing
  - Over-the-counter pain medication or prescription pain medication
  - It is important to avoid taking aspirin during cancer treatment unless your doctor tells you otherwise.

The following suggestions below may help you take special care of your mouth during treatment:

- Visit a dentist as soon as possible before starting radiation therapy to the head and neck. There are some dentists, called oncologic dentists, who specialize in dental care for cancer patients but they may be difficult to find. Generally, you want to remove any risk for infection as soon as possible with minimal intervention.
- Brush your teeth gently with fluoride toothpaste several times a day. If mouth sores are severe, you can purchase without a prescription a sponge on a stick (called toothette) to use instead of a toothbrush. Floss gently.
- Rinse or gargle with a solution of either 1/4 teaspoon of salt or 1 teaspoon of baking soda in 1 cup (8 ounces) of warm water. Follow with a plain water rinse.
- Avoid mouthwashes or rinses that have alcohol in them.
- Lessen the time that you wear your dentures. Avoid wearing them at night, and consider removing them between meals to help reduce mouth irritation.
- Choose foods that require little or no chewing.
- Avoid acidic, spicy, salty, coarse, and dry foods.

Adapted from: [www.cancer.net](https://www.cancer.net/navigating-cancer-care/side-effects/mouth-sores-or-mucositis)
Dry Mouth (Xerostomia is the medical term) occurs when the salivary glands do not make enough saliva, or spit, to keep the mouth moist. Because saliva is needed for chewing, swallowing, tasting, and talking, these activities may be more difficult with a dry mouth.

- Chemotherapy causes dry mouth by making saliva thicker. But this is usually a temporary symptom that may resolve within two to eight weeks after treatment ends.
- Radiation therapy to the head, face, or neck may also cause dry mouth. But it can take six months or longer for the salivary glands to start producing saliva again after the radiation therapy ends. Some people notice dry mouth improving during the first year after radiation treatment. But, many people will continue experiencing some level of long-term dry mouth. This is especially likely if the salivary glands were in the area of the radiation therapy. Some medications may also cause dry mouth.

The following tips may help you manage dry mouth and prevent dental problems:

- Visit a dentist before starting radiation treatment or chemotherapy to check the health of your mouth and teeth. If you need to have teeth removed, it should be done at least 3 weeks before treatment so your mouth can heal.
- Brush your teeth after each meal and at bedtime with a soft-bristle toothbrush and fluoride toothpaste. Soak the brush in warm water to make the bristles even softer AND floss gently once a day.
- Rinse your mouth 4 to 6 times a day, especially after meals.
- Rinse or gargle with a solution of either 1/4 teaspoon of salt or 1 teaspoon of baking soda in 1 cup (8 ounces) of warm water. Follow with a plain water rinse.
- Drink sips of water throughout the day. Carrying a bottle of water may help you drink more frequently
- Avoid mouthwashes and other dental products that contain alcohol.
- Saliva substitutes or mouth rinses designed for dry mouth are available without a prescription.
- Saliva may be stimulated by chewing gum or sucking on sugar-free or sour candy.
- Use a cool mist humidifier, especially at night.
- Avoid alcohol and drinks with caffeine (such as coffee, tea, and cola).
- Avoid acidic, spicy, salty, coarse, and dry foods.
- Eat soft, moist foods that are cool or at room temperature.
- Moisten dry foods with broth, sauces, butter, oil or milk.
- Do not smoke or chew tobacco.
- Avoid sticky, sugary foods and drinks.
- Some dentists or doctors may also prescribe medicines to increase saliva or rinses to treat infections in the mouth.

Adapted from: https://www.cancer.net/navigating-cancer-care/side-effects/dry-mouth-or-xerostomia
Physical Concerns – Teeth

Internet version of this handout with active resource links at: http://cancer-help.me/teeth

Problems with the teeth or mouth are common in cancer patients. Preventive dental care before cancer treatment begins is very important. To manage oral complications, your care team will work closely with your dentist and may refer you to other health professionals with special training. Treating new problems as soon as they appear may make oral complications less severe. Sometimes treatment doses need to be decreased or treatment stopped because of oral complications. When there are fewer complications, cancer treatment may work better and you may have a better quality of life.

The goals of oral and dental care are different before, during, and after cancer treatment:

• Before cancer treatment, the goal is to prepare for cancer treatment by treating existing oral problems.
• During cancer treatment, the goals are to prevent oral complications and manage problems that occur.
• After cancer treatment, the goals are to keep teeth and gums healthy and manage any long-term side effects of cancer and its treatment.

General Information About Oral Complications

• They are common in cancer patients, especially with head and neck cancer
• They can make recovery harder
• They may be side effects of the disease or treatment, or they may have other causes.
• Preventing and controlling oral complications can help you continue treatment and enjoy better quality of life.

Cancer patients have a high risk of oral complications for a number of reasons:

• Chemotherapy and radiation therapy slow or stop the growth of new cells. Normal cells in the lining of the mouth also grow quickly, so anticancer treatment can stop them from growing, too. This slows down the ability of oral tissue to repair itself by making new cells.
• Radiation therapy may directly damage and break down oral tissue, salivary glands, and bone.
• Chemotherapy and radiation therapy upset the healthy balance of bacteria in the mouth.
• Chemotherapy and radiation therapy may cause changes in the lining of the mouth and the salivary glands, which make saliva. This can upset the healthy balance of bacteria.
• These changes may lead to mouth sores, infections, and tooth decay.
• Patients with dentures may develop problems with the dentures being ill-fitting if they lose weight or painful if they have mouth sores. They may need to discuss the fit and use of dentures with their dentist.

Helpful Tips

• See a dentist about 1 month before beginning cancer treatment to make sure your mouth is healthy.
• Give your dentist your cancer doctor’s contact information. It’s important they talk about your cancer treatment.
• Take good care of your mouth during and after treatment. Follow instructions how to keep your mouth clean.
• Ask your doctor if flossing should be a part of your oral care during treatment especially during chemotherapy.
• Keep your mouth moist by drinking lots of water, sucking ice chips, and using sugar free gum or candy. Artificial saliva, available over the counter, may also be necessary.
• Avoid foods and drinks that could irritate your mouth such as sharp, crunchy foods or hot, spicy foods.
• Avoid tobacco products and alcoholic beverages.
• Call your healthcare provider if your mouth hurts.
• Talk to your dentist about using fluoride gel to help prevent tooth decay.
• Exercise the jaw muscles three times a day: open and close the mouth as far as possible (without causing pain) 20 times. This helps prevent jaw stiffness.

If you receive radiation to the head and neck area, make sure you discuss additional instructions for mouth care with your treatment team.

Resources for Additional Information:

- ASCO answers, Dental and Oral Health
- Cancer.Net, Dental and Oral Health
- NIH, NCI Oral Complications of Chemotherapy and Head/Neck Radiation(PDQ®) Treatment and Your Mouth
- U.S. Department of Health and Human Services, Head and Neck Radiation
- CancerCare.org, The Importance of Dental Health
- CancerCare.org, Veterans Living With Cancer: Resources and Support
- NIH, Instituto Nacional Del Cáncer, orales de la quimioterapia y la radioterapia a la cabeza y el cuello (PDQ®)
- Cancer.Net, Salud dental y bucal


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A cough is your body’s natural reflex to help clear your airways of irritants and prevent infection. A cough is a sudden, noisy and violent expulsion of air from the chest, caused by irritation in the air passages, or a reflex. Chronic and/or dry cough can be due to cancer, infection, side effects of chemotherapy, and other cancer treatments.

Relieving side effects is an important part of cancer care and treatment. This is called symptom management or palliative care. Talk with your health care team about any symptoms you experience and any change in symptoms.

Coughing can be managed differently based on the underlying cause. Treating the cause may result in the elimination of the symptom.

General practices that may reduce the cough:

• Avoid irritants (smoke, strong smells, overly dry air)
• Keep your head elevated when sitting and sleeping.
• Use saline via a nebulizer to reduce dryness and irritation of airways.
• Chest physiotherapy, an airway clearance technique to drain the lungs, and may include percussion (clapping), vibration, deep breathing and huffing or coughing, may help cough or spit out mucus.

Things you can do for cough management:

• Talk to your doctor about your cough and how it is impacting your day to day activities.
• Describe your cough and how it is impacting your activities the best that you are able to your doctor. Think about what kinds of things/activities worsen or relieve your cough. How long you have had your cough? Do you cough out mucous or blood? Is it a dry cough? Chronic? Have you been losing weight suddenly without explanation? Do you get short of breath? Do you have a fever?
• There are some medications your medical team may try. Be sure to take as prescribed and provide feedback if you find them unhelpful. If you are prescribed an antibiotic for an infection, take it as prescribed. Do not stop taking the antibiotic just because you feel better.
• If you suffer from heartburn, try to avoid foods that aggravate your symptoms (see symptom management - heartburn for further ideas)
• Quit smoking and/or avoid environmental/occupational exposure to irritants.
• You may try using a humidifier to keep your throat and nasal passages moist if you have a chronic, persistent dry cough.
• If it is okay with your doctor, you may try using cough drops or an over the counter preparation (see drug categories below).
• If you have a cold or a viral infection, try getting rest and plenty of fluids.
• If you suffer from allergies it is a good idea to vacuum and dust furniture weekly since dust can aggravate your symptoms. You may try reducing the humidity in your home to less than 50%. Also, use air conditioning instead of leaving the windows open so that outside irritants do not get inside your home.


Resources for Additional Information:

- NIH, Cough
- Chemocare, Cough and Chemotherapy
- Cancer.net, When to call doctor during treatment

Información Española

- Chemocare, Tos y quimioterapia

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Lymphedema is a condition in which the lymph fluid does not drain properly. Fluid may build up in the tissue and cause swelling. **Tell your health care provider right away if you notice symptoms of lymphedema.**

**Keep the skin and nails clean and cared for, to prevent infection.** Bacteria can enter the body through a cut, scratch, insect bite, or other skin injury. Fluid that is trapped in body tissues may allow bacteria to take hold and cause infection. Look for signs of infection such as redness, pain, swelling, warmth, fever, or red streaks below the surface of the skin. Call your doctor right away if you notice any of these signs or symptoms as it is usually a medical emergency.

**Careful skin and nail care helps prevent infection:**
- Use cream or lotion to keep the skin moist.
- Treat small cuts or breaks in the skin with an antibacterial ointment.
- Avoid needle sticks of any type into the limb (arm or leg) with lymphedema. This includes injections, IV (intravenous) lines, or blood tests.
- Use a thimble for sewing.
- Wear gloves when gardening and cooking.
- Wear sunscreen and shoes when outdoors.
- Avoid testing bath or cooking water using the limb with lymphedema. There may be less feeling (touch, temperature, pain) in the affected arm or leg, and skin might burn in hot water more easily.
- Cut toenails straight across. See a podiatrist (foot doctor) as needed to prevent ingrown nails and infections.
- Keep feet clean and dry and wear cotton socks.

**Avoid blocking the flow of fluids through the body.** It is important to keep body fluids moving, especially through an affected limb or in an area where lymphedema may develop.
- Do not cross legs while sitting.
- Stand up or change sitting position at least every 30 minutes.
- Wear only loose jewelry and clothes without tight bands or elastic.
- Do not carry a heavy handbag on the arm with lymphedema.
- Do not use a blood pressure cuff on the arm with lymphedema.
- Do not use elastic bandages or stockings with tight bands.

**Keep blood from pooling in the affected limb.**
- Keep the limb with lymphedema raised higher than the heart when possible.
- Do not swing the limb quickly in circles or let the limb hang down. This makes blood and fluid collect in the lower part of the arm or leg.
- Do not apply heat to the limb.

**Studies have shown that carefully controlled exercise is safe for patients with lymphedema.** Slow and carefully controlled exercise is safe and may even prevent lymphedema from developing. Talk to your doctor about what kind of exercise may be best in your situation.

**Resources for Additional Information:**
- American Cancer Society, Lymphedema
- NCCN, What You Should Know About Lymphedema
- NIH, NCI Lymphedema (PDQ®) Patient Version
- NIH, National Library of Medicine Compression Stockings
- Cancer.Net, Lymphedema
- NCI Managing Chemotherapy Side Effects, Swelling
- Chemocare, Swelling

**Información Española**
- Cancer.Net, Acumulación de líquido o linfedema
- NIH, Instituto Nacional Del Cáncer, Edema
- Cancer.Net, Hinchazón
- Cancer.Net, Retención de líquidos o edema
- Chemocare, Hinchazón
- American Cancer Society, Hinchazón

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Swelling, otherwise known as edema, is a build up of fluid in the body. Swelling most often affects the dependent extremities (like the feet, ankles and hands), but swelling can also affect other parts of the body, such as the abdomen.

Causes of swelling include:
- Fluid retention, which may be related to diet (salt and water), intravenous fluids, medication, heart disease, liver disease, or kidney failure
- Blockage of veins or the lymph system
- Malnutrition due to the cancer

Ascites is the medical term for a build up of fluid in the space surrounding the organs in the abdomen. When ascites is caused by cancer, it is sometimes called malignant ascites.

Symptoms of ascites
Ascites can sometimes cause discomfort. With ascites you may experience weight gain, abdominal swelling, sense of fullness or bloating, a sense of heaviness, indigestion, nausea or vomiting, changes to the belly button, fatigue, and decreased appetite.

Managing and treating ascites
The goal of treating ascites is to relieve the symptoms that are causing discomfort. You may not need treatment if the ascites is not causing discomfort. Ascites treatment may have unpleasant side effects. Talk with your doctor about the risks and benefits of each option before deciding on a treatment plan. Depending on the cause of your ascites, treatment will be different.

Options to help minimize ascites include:
- Diet modification -- reducing the amount of salt you eat or drinking less water or other liquids may be effective. Some people may find this regimen unpleasant and difficult to follow. If this causes dizziness or thirst let your doctor know.
- Diuretics: commonly caused “water pills,” diuretics are medications which can reduce the amount of water in the body. Diuretics can be effective and safe but often do not work for cancer patients. They may cause dehydration, low blood pressure, dizziness, loss of sleep, fatigue, or contribute to depression.
- Paracentesis: paracentesis is a simple procedure to drain the fluid. This can be helpful if the ascites is significantly impacting your quality of life. If you need frequent drainage of the fluid, a special tube called a catheter can be placed in the abdomen. This catheter will help remove the fluid more easily, and this can be done any time at home.
- Shunts: A shunt is a small tube that is placed to help bypass or divert fluid from one place to another. In more severe or chronic cases, a shunt may be helpful.

Call your doctor or health care provider immediately if you are short of breath.

Adapted from: https://www.cancer.net/navigating-cancer-care/side-effects/fluid-abdomen-or-ascites
http://chemocare.com/chemotherapy/side-effects/swelling.aspx

Resources for Additional Information:
- American Cancer Society, Swelling
- Cancer.Net, Fluid Retention or Edema
- Cancer.Net, Fluid in the Abdomen or Ascites
- NIH, NCI, Edema
- Chemocare, Swelling

Información Española
- NIH, Instituto Nacional Del Cáncer, Edema
- Cancer.Net, Hinchazón
- Cancer.Net, Retención de líquidos o edema
- Chemocare, Hinchazón
- American Cancer Society, Hinchazón

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It's common for people to have problems with sex as a result of cancer and its treatment. Sexual problems can last longer than other side effects of cancer treatment. **It's important to seek help in learning how to adapt to these changes.** Until then, you and your spouse or partner may need to find new ways to show that you care about each other. This can include touching, holding, hugging, and cuddling.

- Erection problems. Medicine, assistive devices, counseling, surgery, or other approaches
- Vaginal dryness. Ask your health care provider whether using a water-based lubricant during sex, using vaginal dilators before sex, and/or taking hormones or using a hormone cream are options for you.
- Muscle weakness. You can strengthen muscles in your genital area through Kegel exercises.
- Talking with a counselor. Some people find that sexual problems related to cancer start to strain their relationship with their partner. If this is the case, ask a nurse or social worker if you can talk to a counselor. Talking to someone alone, or with your partner, may help.
- Seeing a specialist. A sex therapist may be able to help you talk openly about your problems, work through your concerns, and come up with new ways to help you and your partner re-establish intimacy.

**Tell Your Partner How You Feel** Talking to your loved one and sharing your feelings and concerns is very important. Even for a couple that has been together a long time, it can be hard to stay connected. Let your partner know if you want to have sex or would rather just hug, kiss, and cuddle. He or she may be afraid to have sex with you. Or your partner may be worried about hurting you or think that you're not feeling well.

**Finding Ways to Be Intimate** You can still have an intimate relationship in spite of cancer. Intimacy isn't just physical. It also involves feelings.

- Focus on just talking and renewing your connection.
- Protect your time together. Turn off the phone and TV. If needed, find someone to take care of the kids for a few hours.
- Take it slow. Plan an hour or so to be together without being physical. For example, you may want to listen to music or take a walk.
- Try new touch. Cancer treatment or surgery can change a patient’s body. Areas where touch used to feel good may now be numb or painful. Some of these changes will go away. Some will stay. For now, you can figure out together what kinds of touch feel good, such as holding, hugging, and cuddling.

**Feeling Intimate after Treatment** Although cancer treatment may be over, sexual problems may remain for a while. You can find other ways to show that you care about each other. Feeling close to your partner is important.

- Be proud of your body. It got you through treatment!
- Think of things that help you feel more attractive and confident.
- Focus on the positive. Try to be aware of your thoughts, since they can affect your sex life.
- Be open to change. You may find new ways to enjoy intimacy.

Adapted from NIH – NCI: [https://www.cancer.gov/about-cancer/coping/self-image](https://www.cancer.gov/about-cancer/coping/self-image) There is a great deal of information at this website with additional links that are specific to different needs. If you have access to the internet, please look directly at this site as the below is only a summary.

### Resources for Additional Information:

- [American Cancer Society, Cancer, Sex, and the Female Body](https://www.cancer.org/about-cancer/coping/self-image)
- [American Cancer Society, Sex and the Man With Cancer](https://www.cancer.org/about-cancer/coping/self-image)
- [Cancer.Net, Dating and Intimacy](https://www.cancer.org/about-cancer/coping/self-image)
- [NIH, NCI, Self-Image and Sexuality](https://www.cancer.org/about-cancer/coping/self-image)
- [Chemocare, Sexuality and Chemotherapy](https://www.cancer.org/about-cancer/coping/self-image)
- [CancerCare.org, Intimacy During and After Cancer Treatment](https://www.cancer.org/about-cancer/coping/self-image)

### Información Española

- [NIH, Instituto Nacional Del Cáncer, Problemas de salud sexual en mujeres con cáncer](https://www.cancer.gov/about-cancer/coping/self-image)
- [NIH, Instituto Nacional Del Cáncer, Problemas de salud sexual en hombres con cáncer](https://www.cancer.gov/about-cancer/coping/self-image)
- [Cancer.Net, Sexualidad y tratamiento contra el cáncer: mujeres](https://www.cancer.org/about-cancer/coping/self-image)
- [Cancer.Net, Sexualidad y tratamiento contra el cáncer: hombres](https://www.cancer.gov/about-cancer/coping/self-image)
- [Chemocare, Sexualidad](https://www.cancer.gov/about-cancer/coping/self-image)
- [American Cancer Society, Cómo el cáncer afecta la sexualidad](https://www.cancer.gov/about-cancer/coping/self-image)
Physical Concerns – Dry, Itchy/Blister or Painful Skin

Internet version of this handout with active resource links at: http://cancer-help.me/skin

Dry and itchy skin. Dry or itchy skin may be common with cancer, chemotherapy, radiation therapy, and stem cell transplants.

To treat dry skin:
• Use a moisturizing cream at least twice a day and within 15 minutes of showering.
• Avoid products that irritate the skin. This includes soaps, detergents, and creams with fragrance.
• Avoid products that scratch or scrub the skin, such as sponges, bath scrubs, or loofahs.
• Shower and bathe with warm water. Hot water can dry the skin even more.
• When skin is very dry and cracked, use moisturizers such as Eucerin Advanced Repair Creme (not Lotion) or Aquaphor Healing Ointment – both of which come in a tub or pot. The lotion should be so thick that it cannot be squirted from a pump. This forms the best barrier for moisturizing and healing.

To treat itchy skin:
• Avoid fragranced skin products.
• You may try Sarna lotion over the counter.
• Use frequent reapplication of above lotions & try to increase the moisture content of your skin.
• If these do not work, your doctor may prescribe a steroid cream
• Talk with your doctor about the itching. Your doctor may have you try oral medications called antihistamines.

Sensitivity to light. Some types of chemotherapy, radiation therapy, and stem cell transplants may make the skin more sensitive to light. This is called photosensitivity.

To protect sensitive skin from sunburns when outside:
• Cover up with clothing or a hat, especially from 10 AM to 4 PM.
• Use a sunscreen that is labeled as broad-spectrum (blocks UVA and UVB rays) and has a sun protection factor (SPF) of at least 15. Make sure to apply enough to cover your entire body (1 ounce or 35 mL). Reapply every 2 hours or every hour if swimming or sweating.

Radiation-related skin problems. Radiation may affect healthy skin cells. This can cause the skin to peel, itch, or hurt. Skin damage from radiation treatment often starts after 1 or 2 weeks of treatment. Most often, it gets better a few weeks after treatment ends. If it becomes a problem, your doctor may change your radiation dose or schedule until the condition improves. Corticosteroid skin creams, such as mometasone (Elocon) cream, may help prevent skin changes from radiation. But, make sure you do not apply these creams within 4 hours of radiation treatment. Tell your doctor if you see any open sores or areas where the skin is moist. This may be a sign of an infection that needs treatment with oral antibiotics. Your doctor may also change the treatment for your cancer, or change the recommended lotions for your skin.

Pressure ulcers or bed sores. Pressure ulcers are caused by constant pressure on one area of the body. They often form on the heels of the feet, the tailbone, and other parts of the body with a thin layer of fat. To prevent and treat pressure ulcers and bed sores, try using an air or water pad that lies on top of your mattress. Or, if possible, use a low-air-loss bed or air-fluidized bed. Patients should change positioning every 2 hrs. It is important to seek treatment for pressure ulcers and bed sores to reduce pain and keep them from getting worse so be sure your medical team is aware.

Malignant wounds. When cancer breaks the skin down, it can cause a wound. Malignant wounds can easily become infected and be very painful or itchy. They are often very difficult to treat and might not heal. Talk with a member of your health care team if you have a malignant wound.

Información Española

Dry, Itchy/Blister or Painful Skin

American Cancer Society, Dry Skin
American Cancer Society, Side Effects of Targeted Cancer Therapy Drugs
Cancer.Net, Skin Conditions
NCCN, Skin Rashes
PubMed Health, PDQ® Patient Version, Pruritus
NIH, NCI, Skin and Nail Changes
Chemocare, Skin Reactions
CancerCare.org, Caring for Your Skin During Cancer Treatment

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Resources for Additional Information:

Adapted from Cancer.net: https://www.cancer.net/navigating-cancer-care/side-effects/skin-conditions
Tingling in the hands and/or feet, or numbness, is known as peripheral neuropathy. Some cancer treatments cause peripheral neuropathy, a result of damage to the peripheral nerves. These nerves carry information from the brain to other parts of the body. Side effects depend on which peripheral nerves (sensory, motor, or autonomic) are affected.

Relieving side effects is an important part of cancer care and treatment. This is called symptom management or palliative care. Talk with your health care team about any symptoms you experience and any change in symptoms.

Damage to sensory nerves (nerves that help you feel pain, heat, cold, and pressure) can cause:
- tingling, numbness, or a feeling of pins-and-needles in your hands and feet spreading to the arms or legs.
- inability to feel a hot or cold sensation, such as a hot stove
- inability to feel pain, such as from a cut or sore on your foot

Damage to motor nerves (nerves that help your muscles to move) can cause:
- weak or achy muscles. You may lose your balance or trip easily. It may also be difficult to button shirts or open jars
- muscles that twitch and cramp or muscle wasting (if you don’t use your muscles regularly)
- swallowing or breathing difficulties (if your chest or throat muscles are affected)

Damage to autonomic nerves (nerves that control functions such as blood pressure, digestion, heart rate, temperature, and urination) can cause:
- digestive changes such as constipation or diarrhea
- dizzy or faint feeling, due to low blood pressure
- sexual problems; men may be unable to get an erection and women may not reach orgasm
- sweating problems (either too much or too little)
- urination problems, such as leaking urine or difficulty emptying your bladder

If you start to notice any of the problems listed above, talk with your doctor or nurse. Early diagnosis and treatment is the best way to control the problems, prevent further damage, and to reduce pain and other complications.

Ways to Prevent or Manage Problems Related to Nerve Changes and Prevent Falls. Move rugs out of your path so you will not trip on them. Put rails on the walls and in the bathroom, so you can hold on to them for balance. Put bathmats in the shower or tub. Wear sturdy shoes with soft soles. Get up slowly after sitting or lying down, especially if you feel dizzy.

Take extra care in the kitchen and shower. Use potholders in the kitchen to protect your hands from burns. Be careful when handling knives or sharp objects. Ask someone to check the water temperature, to make sure it’s not too hot.

Protect your hands and feet. Wear shoes, both inside and outside. Check your arms, legs, and feet for cuts or scratches every day. When it’s cold, wear warm clothes to protect your hands and feet.

Ask for help and slow down. Let people help you with difficult tasks. Slow down and give yourself more time to do things.

Ask about pain medicine and integrative medicine practices. You may be prescribed pain medicine. Sometimes practices such as acupuncture, massage, physical therapy, yoga, and others may also be advised to lower pain. Talk with your health care team to learn what is advised for you.

Resources for Additional Information:
- American Cancer Society, Peripheral Neuropathy Caused by Chemotherapy
- Cancer.Net, Peripheral Neuropathy
- NCCN, What is Peripheral Neuropathy
- NIH, Nerve Problems (Peripheral Neuropathy) and Cancer Treatment
- NIH, Chemotherapy-Induced Peripheral Neuropathy
- Chemocare, Numbness & Tingling
- CancerCare.org, Understanding Peripheral Neuropathy

Adapted from NIH: [https://www.cancer.gov/about-cancer/treatment/side-effects/nerve-problems](https://www.cancer.gov/about-cancer/treatment/side-effects/nerve-problems)

Información Española

- NIH, Instituto Nacional Del Cáncer, Problemas de los nervios (neuropatía periférica)
- Cancer.Net, Neuropatía periférica
- Chemocare, Entumecimiento y hormigueo

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Each of us has a mental picture of how we look, our "self-image." Although we may not always like how we look, we're used to our self-image and accept it. But cancer and its treatment can change how you look and feel about yourself. Know you aren't alone in how you feel. Many others have similar feelings.

Body Changes during and after Treatment
Some body changes are short-term while others will last forever. Either way, your looks may be a big concern during or after treatment. For example, people with ostomies after colon or rectal surgery are sometimes afraid to go out. They worry about carrying equipment around or fear that it may leak. Some may feel ashamed or afraid that others will reject them. Even if others can't see them, your body changes may trouble you. Feelings of anger and grief about changes in your body are natural. Feeling bad about your body can also lower your sex drive. This loss may make you feel even worse about yourself. Changes in the way you look can also be hard for your loved ones, which in turn, can be hard on you.

Coping with Body Changes
How do you cope with body changes?

• Mourn your losses and know it's okay to feel sad, angry, and frustrated. Your feelings are real, and you have a right to grieve.
• Try to focus on the ways that coping with cancer has made you stronger, wiser, and more realistic.
• If your skin has changed from radiation, ask your doctor about ways you can care for it.
• Look for new ways to enhance your appearance. A new haircut, hair color, makeup, or clothing may give you a lift. If you're wearing a wig, you can take it to a hairdresser to shape and style.
• If you choose to wear a breast form (prosthesis), make sure it fits you well. Don't be afraid to ask the clerk or someone close to you for help. And check your health insurance plan to see if it will pay for it.

Coping with these changes can be hard. But, over time, most people learn to adjust to them and move forward. If you need to, ask your doctor to suggest a counselor who you can talk with about your feelings.

Staying Active
Many people find that staying active can help their self-image. Some things you can try are: Walking or running, Swimming, Playing a sport, Taking an exercise class, Weight training, Stretching or yoga. You may find that being active helps you cope with changes. It can reduce your stress and help you relax. It may also help you to feel stronger and more in control of your body. Start slowly if you need to and take your time. Talk with your doctor about ways you can stay active.

Hobbies and volunteer work can also help improve your self-image and self-esteem. You may like to read, listen to music, do crossword or other kinds of puzzles, garden or landscape, or write a blog, just to name a few. Or you could volunteer at a church or a local agency, or become a mentor or tutor, for example. You may find that you feel better about yourself when you get involved in helping others and doing things you enjoy.

Adapted from NIH / NCI: https://www.cancer.gov/about-cancer/coping/self-image

Resources for Additional Information:

- American Cancer Society, Look Good Feel Better
- Cancer.Net, Self-Image and Sexuality
- Cancer.Net, Teens, Coping with Changes to Your Body
- Cancer.Net, Young Adults, Cancer and Your Body
- CancerCare.org, Tips for Managing Hair Loss
- Chemocare, Hair Loss and Chemotherapy
- CancerCare.org, Hair Loss During Treatment
- CancerCare.org, Synthetic Wig Care and Resources
- CancerCare.org, Prostheses Resources

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Quitting smoking, or using other nicotine products like e-cigarettes or vaping, improves the prognosis of cancer patients.

- For patients with some cancers, quitting smoking at the time of diagnosis may reduce the risk of dying by 30% to 40%.
- For those having surgery, chemotherapy, or other treatments, quitting smoking helps improve the body’s ability to heal and respond to therapy.
- Quitting smoking also lowers the risk of pneumonia and respiratory failure.

In addition, quitting smoking or vaping may lower the risk that:

- the cancer will recur
- a second cancer will develop
- the person will die from the cancer or other causes.

Regardless of your age, people who quit smoking or vaping have substantial gains in life expectancy, compared with those who continue to smoke.

Health care professionals can be good sources of information about the health risks of tobacco products and the benefits of quitting. Talk to your doctor, dentist, pharmacist, or other health care provider about the proper use and potential side effects of nicotine replacement products and other medicines. There are also behavioral interventions that can help with quitting and staying quit. Your health care providers can help you find local resources for assistance in quitting.

NCI’s Smokefree.gov (http://www.smokefree.gov/) offers science-driven tools, information, and support that has helped smokers quit. You will find state and national resources, free materials, and quitting advice from NCI.

NCI’s Smoking Quitline at 1–877–44U–QUIT (1–877–448–7848)

- offers a wide range of services, including individualized counseling, printed information, referrals to other resources, and recorded messages.
- Smoking cessation counselors are available to answer smoking-related questions in English or Spanish, Monday through Friday, 8:00 a.m. to 8:00 p.m., Central time.
- Smoking cessation counselors are also available through LiveHelp (https://livehelp.cancer.gov/), an online instant messaging service. LiveHelp is available Monday through Friday, 8:00 a.m. to 8:00 p.m., Eastern time.

Addition Information on tobacco/nicotine and Help for Quitting Smoking:

- American Cancer Society 1-800-ACS-2345
- American Heart Association 1-800-AHA-USA1
- American Lung Association 1-800-LUNG-USA

Resources for Additional Information:

- National Cancer Institute, Smokefree.gov
- NIH, NCI Where To Get Help When You Decide To Quit Smoking
- NIH, NCI, Harms of Cigarette Smoking and Health Benefits of Quitting
- ASCO Stopping Tobacco Use After a Cancer Diagnosis
- Cancer.Net, How to Quit Smoking and Using Tobacco
- Cancer.Net, Stopping Tobacco Use After a Cancer Diagnosis
- American Cancer Society, Tobacco and Cancer
- CDC, Smoking & Tobacco Use
- American Lung Association, Smoking Facts
- CancerCare.org, Veterans Living With Cancer: Resources and Support

Información Española

- NIH, Instituto Nacional Del Cáncer, Consumo de cigarrillo: riesgos para la salud y cómo dejar de fumar (PDQ®)
- Cancer.Net, Recursos para ayudarlo a dejar de fumar
- Cancer.Net, Dejar de consumir tabaco después de un diagnóstico de cáncer
- American Cancer Society, Tabaco y cáncer
- American Cancer Society, Cómo dejar de fumar o de consumir tabaco que no produce humo

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The evidence indicates that the more alcohol a person drinks—particularly the more alcohol a person drinks regularly over time—the higher his or her risk of developing an alcohol-associated cancer. Alcohol consumption may also be associated with an increased risk of second primary cancers.

What are the levels of alcohol use?
Alcohol can be an addictive substance. Not everyone who consumes alcohol will become addicted, but continuing to use alcohol despite risks and consequences can be a sign of a problem. Moderate alcohol use is considered having 1 drink per day for women and 2 drinks per day for men. Heavy alcohol use is considered having more than 7 drinks per week for women (3+ drinks on any day) and more than 14 drinks per week for men (4+ drinks on any day).

What are the risks of heavy alcohol use?
Most people know that heavy drinking can cause health and other alcohol-related problems. But many people might not know that drinking alcohol also can raise their risk of developing cancer, worsen symptoms of cancer, or interact with cancer treatments to cause harmful side effects.

Can I drink alcohol during treatment?
It’s important for you to speak to your health care team about whether or not it is safe to drink alcohol during or immediately following treatment. The doctors and nurses administering treatment will be able to give specific advice about whether drinking alcohol is safe with particular drugs.

Where can I get help with my alcohol use?
Alcohol is frequently used as a coping strategy during times of stress, like managing a cancer diagnosis and treatment. However, there are a number of treatments available to support recovery from alcohol use disorder and/or to help you adopt and maintain healthy coping strategies and lifestyle behaviors. If you believe you need support, talk to your care team. Your doctors and nurses can help you to navigate options. A team social worker may be a particularly good resource for you.

To talk with someone at anytime:

SAMHSA - Substance Abuse and Mental Health Services Administration
SAMHSA’s National Helpline – 1-800-662-HELP (4357)
  • Free and confidential information in English and Spanish for individuals and family members facing substance abuse and mental health issues.
  • 24 hours a day, 7 days a week.

Adapted from: https://www.cancer.gov/about-cancer/causes-prevention/risk/alcohol/alcohol-fact-sheet

Resources for Additional Information:
- NIH, National Institute on Drug Abuse, Cancer
- NIH, National Cancer Institute, Alcohol and Cancer Risk
- Cancer.Net, Alcohol
- American Cancer Society, Nutrition and Physical Activity During and After Cancer Treatment
- Center for Disease Control and Prevention, CDC, Alcohol and Cancer

Información Española
- NIH, Instituto Nacional Del Cáncer, Alcohol y el riesgo de cáncer
- Cancer.Net, Alcohol
- American Cancer Society, La relación entre el consumo de alcohol y el cáncer

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What is substance use?
Substance abuse refers to the harmful or hazardous use of psychoactive substances, including alcohol, illicit drugs, and tobacco. Examples include taking more over-the-counter or prescription medications than prescribed, like opioid pain relievers, in addition to substances such as heroin, cocaine, marijuana, and tobacco products. Someone might be considered dependent on a substance when he/she continues using it despite harmful consequences of develops increased tolerance for or withdrawal symptoms from the substance.

What are the risks of substance use?
Most people know that substance use can cause health and other drug-related problems. But many people might not know that using drugs can also raise their risk of developing cancer, worsen symptoms of cancer, or interact with cancer treatments to cause harmful side effects.

Can I use drugs during treatment?
It’s important for you to speak to your health care team about whether or not it is safe for you to use any legal or illicit substances during or immediately following treatment. The doctors and nurses administering treatment will be able to give specific advice about whether using various substances is safe with particular drugs.

Where can I get help with my recreational drug use?
Substances are frequently used as a coping strategy during times of stress, like managing a cancer diagnosis and treatment. However, there are a number of treatments available to support recovery from drug use disorders and/or to help you adopt and maintain healthy coping strategies and lifestyle behaviors. If you believe you need support, talk to your care team. Your doctors and nurses can help you to navigate options. A team social worker may be a particularly good resource for you.

To talk with someone at anytime:
SAMHSA - Substance Abuse and Mental Health Services Administration
SAMHSA’s National Helpline – 1-800-662-HELP (4357)
Free and confidential information in English and Spanish for individuals and family members facing substance abuse and mental health issues. 24 hours a day, 7 days a week.

Resources for Additional Information:
- Dana-Farber Cancer Institute, Drug Abuse and Cancer: What You Should Know
If you are experiencing difficulty remembering things, thinking, or concentrating, it’s important for you or a family member to tell your health care team.

We all occasionally forget someone’s name, where we put the keys, or the date. But, if memory loss is becoming troublesome, and you notice that it’s happening more and more, it may be more than normal aging. Memory or concentration issues or trouble processing information can be caused by different conditions, such as depression, cancer related treatment, mild cognitive impairment (MCI) or other health related problems.

Memory or Concentration Problems and Cancer Treatment
Whether you have memory or concentration problems (sometimes described as a mental fog or chemo brain) depends on the type of treatment you receive, your age, and other health-related factors. Cancer treatments such as chemotherapy may cause difficulty with thinking, concentrating, or remembering things. So can some types of radiation therapy to the brain and immunotherapy. These cognitive problems may start during or after cancer treatment. Some people notice very small changes, such as a bit more difficulty remembering things, whereas others have much greater memory or concentration problems.

Your doctor can assess your symptoms and advise you about ways to manage or treat these problems. Treating conditions such as poor nutrition, anxiety, depression, fatigue, and insomnia may also help.

Ways to Manage Memory or Concentration Problems:
Plan your day. Do things that need the most concentration at the time of day when you feel best. Get extra rest and plenty of sleep at night. If you need to rest during the day, short naps of less than 1 hour are best. Long naps can make it more difficult to sleep at night. Keep a daily routine.

Exercise your body and mind. Exercise can help to decrease stress and help you to feel more alert. Exercise releases natural chemicals in the body called endorphins, which give people a feeling of well-being. Ask what physical exercises may be helpful for you. Mind-body practices, such as meditation or guided imagery, as well as mental exercises such as puzzles or games also help some people.

Get help to remember things. Write down and keep a list handy of important information. Use a daily planner, recorder, or other electronic device to help you remember important activities. Make a list of important names and phone numbers. Keep it in one place so it’s easy to find.

Talking with Your Health Care Team about Memory or Concentration Problems
It’s important for you or a family member to talk with your doctor or nurse about any memory, concentration or thought processing changes you may have. Prepare for your visit by making a list of questions to ask.

Consider adding these questions to your list:
- Am I at increased risk of cognitive problems based on the treatment I am receiving?
- When might these problems start to occur? How long might they last?
- Are there steps I can take to decrease these problems?
- What symptoms or other problems should I, or a family member, call you about?
- Could I meet with a social worker to get ideas about additional support and resources?
- Are there specialists who could assess, treat, or advise me on these problems (such as neuropsychologists, occupational therapists, vocational therapists, and others)?

Resources for Additional Information:
- ASCO answers, Chemobrain
- NIH, Memory or Concentration Problems
- Chemocare, Central Neurotoxicity, Memory Loss, and Their Relationship to Chemotherapy
- Family Caregiver Alliance®, Mild Cognitive Impairment
- American Cancer Society, Chemo Brain
- CancerCare, Chemobrain: What You Need to Know
- CancerCare.org, Coping With Chemobrain
- CancerCare.org, Improving Your Concentration
- Cancer.Net, Attention, Thinking, or Memory Problems

Información Española
- NIH, Instituto Nacional Del Cáncer, Problemas de memoria o de concentración
- Cancer.Net, problemas de la atención, el pensamiento y la memoria
- Chemocare, Náuseas, Neurotoxicidad central y pérdida de la memoria, y cuál es su relación con la quimioterapia

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Physical Concerns – Weight Loss or Lack of Appetite

Cancer treatments can cause multiple different side effects including nausea, vomiting, decreased appetite, diarrhea, constipation, and changes in the way you taste or smell food. These changes may affect your body weight. What you need in your diet can also change. You may need more calories and protein and more or less fiber. Once treatment ends, many of these changes subside. However it is important that during treatment you get the best nutrition. Healthy eating can boost your immune system, repair damaged tissue, and help you get through treatment.

Relieving side effects is an important part of cancer care and treatment. This is called symptom management or palliative care. Talk with your health care team about any symptoms you experience and any change in symptoms.

Tips for getting the most from your meals

When you have decreased appetite, large meals can seem overwhelming or unappealing. This can happen when you have a decreased appetite. The suggestions below can help you get enough calories:

- Eat small meals 6 to 8 times a day instead of 3 main meals.
- Drink beverages high in calories such as hot chocolate, fruit juices, milkshakes and nectars.
- Eat your favorite foods and snacks at any time of the day. For example, eat breakfast foods such as pancakes or omelets for lunch or dinner.
- Include different colors and textures of foods in your meals to make them more appealing.
- Make dining a good experience by eating your meals in a pleasant, relaxing setting with family or friends.

Tips for adding more protein to your diet

If you recently had surgery or have wounds, eating more protein will help you heal. The suggestions below will help you increase the amount of protein in your diet:

- Eat foods rich in protein, such as chicken, fish, pork, beef, lamb, eggs, milk, cheese, beans, nuts and tofu.
- Use Double Milk or Ensure®-type supplements in hot or cold cereals.
- Add cheese and diced, cooked meats to your omelets.
- Add powdered milk to creamy soups, mashed potatoes, milksakes, and casseroles.
- Snack on cheese, nuts or nut butters (peanut, cashew, and almond butter) with crackers or eat with apples, bananas, or celery.
- Blend a nut butter into your chocolate or vanilla shakes.
- Snack on roasted nuts and sunflower, pumpkin, or chia seeds, hummus with pita bread.
- Add cooked meats and beans to soups, casseroles, salads, and omelets.
- Add wheat germ or ground flax seeds to cereals, casseroles, yogurt, and meat spreads.

Tips for adding more calories to your diet

- While you’re healing, it’s more important that you get enough calories.
- Don’t eat foods that are fat-free or reduced in fat. Avoid food and drink labels that say “low-fat,” “non-fat,” or “diet.” Use whole milk instead of skim.
- Snack on dried fruits, nuts, or dried seeds. Add them to hot cereals, ice cream, or salads.
- Add butter, margarine, or oils to potatoes, rice, and pasta. Also add them to cooked vegetables, sandwiches, toast, and hot cereals.
- Add cream cheese to toast or bagels or use it as a spread on vegetables. Spread cream cheese and jam or peanut butter and jelly on crackers, add jelly or honey to breads and crackers.
- Mix jam with diced fruit, use as a topping for ice cream or cake.
- Snack on tortilla chips with guacamole. Add avocado to salads.
- Use high-calorie dressings on salads, baked potatoes, and on chilled cooked vegetables, such as green beans or asparagus.
- Add sour cream, half and half, or heavy cream to mashed potatoes and cake and cookie recipes. You can also add it to pancake batter, sauces, gravies, soups, and casseroles.
- Top cakes, waffles, French toast, fruits, puddings, and hot chocolate with whipped cream.
- Make vegetables or pasta with cream sauces.
- Use mayonnaise, creamy salad dressing, or aioli sauce in sandwiches, toast, and hot vegetable dips.
- Mix granola with yogurt or put it on top of ice cream or fruits.
- Drink high-calorie, high-protein drinks, such as Carnation Breakfast Essentials® or Ensure®

Resources for Additional Information:

- NCCN, Information on Diet and Weight Changes
- American Cancer Society, Appetite Changes
- American Cancer Society, Weight Changes
- Cancer.Net, Appetite Loss Handout
- Cancer.Net, Weight Loss
- NIH, Nutrition in Cancer Care (PDQ®)
- ASCO Answers Fact Sheet, Appetite Loss
- Chemocare, Weight Changes
- Memorial Sloan Kettering Eating Well During and After Your Cancer Treatment
- CancerCare.org, Coping With Cancer-Related Weight Changes and Muscle Loss

Food Resources

- Greater Chicago Food Depository (773) 247-3663
- Illinois Department of Human Services, Cash, SNAP & Medical Assistance (800) 843-6154
- City of Chicago, Community Service Center Location

Información Española

- American Cancer Society, Cambios en el apetito
- Cancer.Net, Pérdida de peso
- Chemocare, Cambios de peso

Adapted from: https://www.nccn.org/patients/resources/life_with_cancer/managing_symptoms/impact_on_diet.aspx

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Physical Concerns – **Weight Gain**

Internet version of this handout with active resource links at: [http://cancer-help.me/weightgain](http://cancer-help.me/weightgain)

Slight increases in weight during cancer treatment are generally not a problem. But significant weight gain can affect a person's health. Reports show that weight gain during treatment is linked to a poorer chance of recovery. Being overweight before treatment begins also increases the risk of serious health conditions. These include high blood pressure, diabetes, and heart problems. Significant amounts of weight gain after treatment can also increase risk of recurrence in some types of cancer.

Relieving side effects is an important part of cancer care and treatment. This is called symptom management or palliative care. Talk with your health care team about any symptoms you experience and any change in symptoms.

**Causes of weight gain during cancer treatment**

Chemotherapy can lead to weight gain in several ways by:

- Causing the body to hold on to excess fluid, called edema.
- Causing people to reduce physical activity, usually because of fatigue.
- Causing nausea that is improved by eating.
- Triggering intense food cravings.
- Decreasing a person’s metabolism, which is the rate that the body uses energy.
- Causing menopause in some women, which decreases the metabolism.

Steroid medications may be prescribed during cancer treatment for several reasons, including to reduce symptoms of inflammation, such as swelling and pain and to treat nausea. Steroids can also cause certain side effects. Short and long term steroid use can lead to increased appetite causing excess caloric intake. Long term steroid use can lead to weight gain and/or increased fatty tissue which can increase the size of a person’s abdomen and cause fullness in the neck or face. Additionally long term steroid use can lead to loss of weight and muscle mass also called wasting.

Hormonal therapy may be used to treat breast, uterine, prostate, and testicular cancers. It involves medicines that decrease the amount of estrogen or progesterone in women and testosterone in men. Decreases in these hormone levels can increase fat, decrease muscle, and lower the metabolism.

**Managing weight gain**

If weight gain becomes a concern, talk with your doctor or a registered dietitian (RD) before starting a diet or changing your eating habits. Consider the following ways to address weight gain through diet and physical activity:

- Eat plenty of fruits, vegetables, and whole grains.
- Limit fat, added sugar, and refined flour.
- Eliminate sugar sweetened beverages including soda, fruit juice, sports drinks and sweet teas.
- Drink plenty of water. A good goal is 8 cups per day.
- Use healthier cooking methods whenever possible. For example, try steaming instead of frying.
- Identify everyday eating patterns that lead to overeating and inactivity. Your RD can help you with this.
- Find physical activities, such as walking or bicycling, that you enjoy. Check with your doctor before starting any new type.

**Managing fluid retention-related weight gain**

Call your doctor if you experience any of the following signs of fluid retention:

- Skin that feels stiff or leaves small indentations after pressing on the swollen area.
- Swelling of arms or legs, especially around ankles and wrists.
- Rings, wrist watches, bracelets, or shoes that fit tighter than usual.
- Decreased flexibility in hands, elbows, wrists, fingers, or legs.

The following tips can help you manage fluid retention:

- Ask a doctor about prescribing a medication that increases urination to rid the body of excess water. This is called a diuretic.
- Lower the amount of salt in your diet. A registered dietician can help with this if available.
- Avoid standing for long periods and elevate your feet as often as possible. Avoid crossing your legs, which restricts blood flow.
- Weigh yourself at the same time each day and write down the number. Bring this log to appointments for your care team to evaluate.
- Avoid tight clothing and footwear.
- Ask your health care team if wearing support or compression stockings may help.

**Resources for Additional Information:**

- NCCN, Information on Diet and Weight Changes
- Memorial Sloan Kettering Eating Well During and After Your Cancer Treatment
- American Cancer Society, Information on Weight Gain
- Cancer.Net, Weight Gain
- Cancer.Net, Obesity, Weight, and Cancer Risk
- Cancer.Net, Obesity, Weight, and Cancer Risk
- NIH, Nutrition in Cancer Care (PDQ®)
- Memorial Sloan Kettering Eating Well
- Chemocare, Weight Changes
- American Institute for Cancer Research, Weight and Cancer Risk

**Información Española**

- American Cancer Society, Aumento de peso
- Cancer.Net, Aumento de peso
- Chemocare, Cambios de peso

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Some people with cancer experience taste changes during or after cancer treatment. Foods may taste differently than before, especially bitter, sweet, and/or salty foods. Some foods may taste bland and you may experience a metallic or chemical taste in your mouth, especially after eating meat or other high-protein foods.

Taste changes can lead to loss of appetite, weight loss, and food aversions, which is strongly disliking specific foods. Tell your health care team if you experience any taste changes that are affecting your ability to eat. Relieving such side effects is an important part of cancer care and treatment, called symptom management or palliative care.

**Causes of taste changes:**
- Chemotherapy
- Other medicines
- Radiation therapy
- Other causes such as surgery to the nose, throat, or mouth, dry mouth, damage to the nerves involved in tasting, mouth infections, dental or gum problems, nausea and vomiting.

**Managing taste problems**
Usually, there are no specific treatments for taste problems but sometimes treating the cause of the taste changes can help.
- Choose foods that smell and taste good, even if the food is unfamiliar.
- Eliminate cooking smells by using an exhaust fan, cooking on an outdoor grill, or buying precooked foods. Cold or room-temperature foods also smell less.
- Eat cold or frozen foods, which may taste better than hot foods. However, if you are receiving chemotherapy with oxaliplatin (Eloxatin) it may be difficult to tolerate cold foods and beverages.
- Use plastic utensils and glass cookware to lessen a metallic taste.
- Try sugar-free gum or hard candies with flavors such as mint, lemon, or orange. These flavors can help mask a bitter or metallic taste in the mouth.
- If red meats don’t taste good, try protein sources, such as poultry, eggs, fish, peanut butter, beans, or dairy products.
- Marinate meats in fruit juices, sweet wines, salad dressings, or other sauces.
- Flavor foods with herbs, spices, sugar, lemon, or sauces.
- Avoid eating 1 to 2 hours before chemotherapy and up to 3 hours after chemotherapy. This helps prevent food aversions caused by nausea and vomiting.
- Rinse your mouth with a salt and baking soda solution before meals. Try a solution of ½ teaspoon of salt and ½ teaspoon of baking soda in 1 cup of warm water. It may help neutralize bad tastes in the mouth.
- Keep a clean and healthy mouth by brushing frequently and flossing daily.
- Consider zinc sulfate supplements, which may improve taste for some people. However, talk with your doctor before taking any dietary supplements, especially during active treatment.

Adapted from: [http://www.cancer.net/navigating-cancer-care/side-effects/taste-changes](http://www.cancer.net/navigating-cancer-care/side-effects/taste-changes)

**Resources for Additional Information:**
- American Cancer Society, Taste and Smell Changes
- Cancer.Net, Taste Changes
- American Institute for Cancer Research®, Heal Well, A Cancer Nutrition Guide
- NIH, Nutrition in Cancer Care (PDQ®)
- NCI, Eating Hints, Before, During and After Cancer Treatment
- Chemocare, Taste Changes
- CancerCare.org, The Importance of Nutrition During Treatment

**Información Española**
- American Cancer Society, Cambios en el gusto y el olfato
- Cancer.net, Cambios en el gusto

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Physical Concerns – Nutrition and Food Concerns

People with cancer need to maintain a healthy body weight and eat nutritious foods. Sometimes the side effects of surgery, radiation therapy, immunotherapy, and chemotherapy may cause a person to eat less and lose weight. And some treatments may cause weight gain. As a cancer patient you should try to be eating healthier foods, find safe and effective ways to add physical activity to your life, stop tobacco use, limit the amount of alcohol you drink and find positive ways to manage stress. This is called symptom management or palliative care. Talk with your health care team about any symptoms you experience and any change in symptoms.

Nutrition Guidelines During Cancer Treatment

• Maintain a healthy weight. For people who are overweight, this may mean losing weight but may also mean avoiding weight loss by getting enough calories every day. Ask your health care team for your healthy weight goal.
• Get essential nutrients. These include protein, carbohydrates, fats, and water.
• Be as active as you can. For example, take a daily walk. If you sit or sleep too much, you may lose muscle mass and increase your body fat, even if you are not gaining weight.
• Ways to get essential nutrients and manage a healthy weight
  • Experts recommend eating plant-based foods, such as fruits, vegetables, whole grains, and plant-based proteins such as nuts, beans and tofu. Lean protein (in moderation) and low-fat dairy products are also recommended. Avoid highly processed foods and red meats as much as possible. Learn more about the effect of diet and nutrition during and after treatment.
  • Nutrition counseling with a registered dietitian (RD) or a registered dietitian nutritionist (RDN), can help people with cancer get essential nutrients, such as protein, vitamins, and minerals. It can also help them maintain a healthy body weight. Ask your health care team to help you find one of these professionals. You can also find a dietitian through the Academy of Nutrition and Dietetics.

Side Effects and Nutrition

Cancer treatment often causes side effects, such as nausea, mouth sores, and taste changes. These side effects may make it difficult to eat or drink. Follow these tips to help get the nutrition you need:

• If water tastes unpleasant to you, take in more liquid through foods and other drinks. For example, eat soup or watermelon and drink tea, milk, or milk substitutes. A sports drink is a great alternative. Consider flavoring water by adding fresh cut fruit.
• If food tastes bland, try seasoning it with flavorful spices. For example, try using lemon, garlic, cayenne, dill, and rosemary. If your mouth is sore, you may need to choose non-acidic and non-spicy foods until it heals.
• Eat 6 small meals throughout the day instead of 3 large meals. Make sure you reach your calorie goal with these smaller meals.
• If meat is no longer appealing, get protein from other foods. For example, try fish, eggs, cheese, beans, nuts, nut butters, tofu, or high-protein smoothies or shakes.
• If you have a metallic taste in your mouth, suck on mints, chew gum, or try fresh citrus fruits. Use plastic utensils and cook in nonmetal pots and pans. Also, try brushing your teeth before eating.
• If you have mouth sores or a gum infection, use a blender or food processor to make the texture of vegetables and meats smooth. For added smoothness and more calories, add butter, mild sauces, gravy, or cream. Try juicing or making smoothies because the extra moisture can help soothe a sore mouth.
• Some side effects are often treated with medication. If your side effects are affecting your hydration and nutrition, talk with your health care team.

Resources for Additional Information:
- American Cancer Society Nutrition Information
- Cancer.Net, Nutrition Recommendations During and After Treatment
- Cancer.Net, Food and Cancer Prevention
- ASCO Answers, Food Safety & Cancer Treatment
- NIH, NCI, Nutrition in Cancer Care (PDQ®)
- American Institute for Cancer Research, Diet – What to Eat for Lower Cancer Risk
- CancerCare.org, The Importance of Nutrition During Treatment

Acosta from: https://www.cancer.net/survivorship/healthy-living/nutrition-recommendations-during-and-after-treatment
Help with Pain

Internet version of this handout with active resource links at: http://cancer-help.me/pain

Many patients and survivors experience pain during and after cancer treatment. Pain and the associated thoughts and emotions can impact quality of life. It may help to know that cancer-related pain can be treated successfully for most patients. Relieving side effects is an important part of cancer care and treatment. This is called symptom management or palliative care. Talk with your health care team about any symptoms you experience and any change in symptoms.

Causes of Pain

- The cancer. When cancer grows in an organ, such as the liver, it may stretch part of the organ causing pain. If a cancer grows and spreads to the bones or other organs, it can put pressure on nerves causing pain.
- Surgery. It is normal to experience pain from cancer surgery. Most pain goes away in days to weeks, occasionally it may last for months. This long-lasting pain can be from permanent damage to the nerves and the development of scar tissue.
- Radiation therapy. Pain may develop after radiation therapy and go away on its own. It can also develop months or years after radiation therapy to some parts of the body, such as the chest, breast, or spinal cord.
- Chemotherapy. Some chemotherapy can cause pain and numbness in the fingers and toes, called peripheral neuropathy. Usually this pain goes away when treatment is finished. But sometimes the damage is permanent.
- Other causes. People with cancer can still have pain from other causes not related to the cancer. These include migraines, arthritis, or muscle strain. The treatment plan your health care team develops with you should include these kinds of pain. Any pain decreases your quality of life.

Diagnosing pain

You know your pain best. It is important to discuss any new symptoms or a change in symptoms with your doctor or a pain specialist. They may order certain tests like x-rays or other scans, and can help you find a medication or other pain relief method that works for you.

Keep a diary of your pain. Things to include are:

- When did the pain start? What were you doing when you had pain?
- What does the pain feel like? Is it "knifelike," "stabbing," "dull," "aching" or "cramping"?
- Where is the pain? Can you point to it with your finger, or is it spread all over?
- How bad is your pain most of the time? How severe is the pain when you do certain activities? Can you rate the pain, on a 1-10 scale, with the number "10" being the worst pain imaginable? Or can you rate it as mild, moderate or severe pain?
- How long did the pain last?
- Does the pain come and go whenever you perform a certain activity, or is it unpredictable?
- What can you do to reduce the pain or make it go away? What have you tried before that has worked?
- How is your mood? Are you depressed or anxious? Does this make the pain worse?

Managing and treating pain

There are many ways to manage and treat cancer-related pain, including non-opioid medications and non-medication methods. Non-medication methods include things like acupuncture, physical therapy, and psychotherapy. Talk with your doctor to find the best treatment for your pain.

Opioid medications are sometimes prescribed for managing cancer pain and can be very effective. Some people worry that they will become dependent on opioid medications, but close monitoring significantly reduces this risk. Managing pain effectively is a very important part of your cancer care.

Be sure you understand how your prescribed pain medication works (is it fast or long acting) and exactly how and when to take it. For example, “with food” or “before going to bed”. Discuss potential or experienced side effects with your doctor as they can often be managed.

Should you need to go to the emergency department (ED), always take your pain medication with you. Waits can be long, ED may not be able to give you what you need for your pain in a timely fashion.

Resources for Additional Information:

- American Cancer Society, Cancer Pain
- NIH, Cancer Pain (PDQ®)
- NIH, Pain
- Livestrong, Pain Management
- ASCO Answers, Managing Pain
- Chemocare, Pain & Chemotherapy
- Cancer.Net, Side Effects, Pain
- Cancer.Net, Treating Pain with Medication

CancerCare.org, Managing Cancer Pain
- CancerCare.org, Medical Marijuana and Cancer
- CancerCare.org, Opening the Door Effective Pain Management
- CancerCare.org, Pain and Symptom Management

Información Española

- NIH, Instituto Nacional Del Cáncer, Efectos secundarios
- NIH, Instituto Nacional Del Cáncer, Dolor
- Instituto Nacional Del Cáncer, Control del dolor

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Help with Feeling Fatigued or Exhausted

Cancer or cancer treatment may cause fatigue. This fatigue feels like persistent physical, emotional, and mental exhaustion. It is different than feeling tired after not getting enough rest.

- It interferes with daily life.
- It does not match the person’s level of activity.
- It does not improve with rest.

Most people receiving cancer treatment experience fatigue. Some will have fatigue that lasts months or years after finishing treatment. People with cancer, especially those who are older, may have other health conditions including heart disease, arthritis, reduced lung or kidney function, etc., that may impact energy level.

If you experience fatigue, talk with your health care team. Share any new symptoms or changes in symptoms.

Treating the causes of fatigue

Medical Conditions that contribute to your fatigue may include the following:

- **Pain.** Living with constant pain is often exhausting and many medicines prescribed for pain cause drowsiness and fatigue. Ask your doctor about options for managing pain if current treatment is too fatiguing.

- **Depression, anxiety, and stress** can increase exhaustion and complicate treatment. Managing and treating these often reduces fatigue.

- **Insomnia,** having trouble falling asleep or staying asleep. Some medicines disturb normal sleep patterns. Ask your healthcare team for help managing insomnia if medicine related.

- **Poor nutrition.** A well-balanced diet may help reduce fatigue. Consider talking with a nutrition counselor or registered dietitian (RD), especially when you have taste issues or nausea and vomiting.

- **Anemia,** can be common in cancer patients, is a decrease in the amount of red blood cells you have. Patients with anemia may feel extreme and overwhelming fatigue. Anemia treatment may include nutritional supplements, drugs, or blood transfusions.

Treatment side effects. Certain treatment types contribute to fatigue. For example, people commonly experience fatigue at these times:

- A few days after chemotherapy.
- A few weeks after beginning radiation therapy.
- After immunotherapy.

Other strategies to cope with fatigue

Lifestyle changes may help you cope with fatigue. These include:

- Being more physical active can help relieve cancer-related fatigue. Ask your doctor which types of physical activity are best for you. These recommendations may change during and after cancer treatment.

- Some people may benefit from working with a physical therapist, particularly if they have a higher risk of injury. Physical therapists can help patients increase or maintain physical functions.

- Counseling may help reduce fatigue. For example, cognitive behavioral therapy may help you reframe your thoughts about fatigue, improve coping skills, overcome sleep problems that contribute to fatigue.

Mind-body strategies. Evidence suggests that these can reduce fatigue in cancer survivors:

- Mindfulness practices
- Yoga
- Acupuncture

Resources for Additional Information:

- American Cancer Society, What is Fatigue
- NCCN, Fatigue, Patients and Caregivers
- NCCN, Fighting Cancer Fatigue
- Cancer.Net, Fatigue
- NIH, Fatigue (PDQ®)
- Chemocare, Fatigue and Cancer Fatigue
- CancerCare.org, Managing Fatigue

Información Española

- American Cancer Society, Cómo controlar la fatiga
- Cancer.Net, Fatiga
- NIH, Instituto Nacional Del Cáncer, Fatiga (PDQ®)
- NIH, Instituto Nacional Del Cáncer, Cansancio por tratamiento de cáncer
- Chemocare, Fatiga y fatiga relacionada con el cáncer

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Help with Being Physically Active

Internet version of this handout with active resource links at: http://cancer-help.me/being-active

Cancer or cancer treatment may diminish your ability to do your normal daily activities. Most people receiving cancer treatment experience some reduced physical ability. People with cancer, especially those who are older, may have other health conditions including heart disease, arthritis, reduced lung or kidney function, etc., that may impact physical ability or energy level.

If you feel a change in physical ability that is altering your quality of life, talk with your health care team. Share any new symptoms or changes in symptoms with your doctor.

Although reduced daily physical activity is a common and often expected side effect of cancer and its treatments, feel free to mention such feelings to the people providing your care. New or worsening symptoms may be a clue to understanding an underlying medical problem. Symptomatic treatment may be available, such as physical therapy or occupational therapy.

Exercise is safe during cancer treatment and can improve physical functioning and many aspects of quality of life. Moderate exercise has been shown to improve fatigue (extreme tiredness), anxiety, and self-esteem.

People getting chemotherapy and radiation who already exercise may need to do so at a lower intensity. The main goal should be to stay as active as possible and slowly increase your level of activity over time after treatment.

What Your Health Care Provider May Recommend:

• The first step in treating loss of physical ability is knowing that the problem exists. Many people do not bother to mention this loss to their doctors because they believe it is normal. It is vital that you discuss this and all symptoms or side effects with your health care provider.
• Efforts can be directed at determining the cause of the problem and prescribing appropriate treatment. Your particular cancer treatment regimen, with its known side effects may provide clues for your doctor or health care professional. A simple blood test, for example, can determine if you are anemic.

Good nutrition and keeping hydrated are very important and will help.

A registered dietitian can provide suggestions for a healthy diet and suggest ways of maximizing calories and proteins to provide what your body needs to keep as active as possible.

Prioritize Your Time

Decide what activities are important to you, and what activities can be delegated to others. Use your energy on important tasks.


Resources for Additional Information:

- American Cancer Society, Physical Activity and the Cancer Patient
- American Cancer Society, Nutrition and Physical Activity During and After Cancer Treatment
- NCCN Exercising During Cancer Treatment
- Cancer.net, Cancer and your Body
- Cancer.Net, Physical Activity and Cancer Risk
- NIH, Keep Up With Your Daily Routine
- American Cancer Society, What is Fatigue
- Cancer.Net, Physical Activity and Cancer Risk
- NIH, Fatigue (PDQ®)

Información Española

- American Cancer Society, Actividad física y el paciente de cáncer
- Cancer.Net, Actividad física: Sugerencias y consejos
- Cancer.Net, Actividad física y riesgo de cáncer
- NIH, Instituto Nacional Del Cáncer, Actividad física y cáncer

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Information about Falls

Internet version of this handout with active resource links at: http://cancer-help.me/falls

Falls are a common problem among people with cancer, regardless of age. People with cancer who fall are often more at risk of serious injury or even death because of bone weakness or low platelets. Fall risk is particularly high for older patients and patients that are hospitalized. Always be sure to let your care team including your physician know about any falls, even those without injury.

Some of the reasons for the increased risk of falls for patients with cancer are:

- Certain medications or taking multiple medications at the same time
- Medications that cause frequent nighttime awakenings for trips to the bathroom
- Bone involvement of the cancer
- Dizziness or lightheadedness
- Dehydration
- Low blood counts
- Urinary or bowel changes
- Numbness in the feet from chemotherapy

What you can do:

- If you notice changes or problems with weakness, balance, numbness, or confusion, let your care team know and ask for help.
- When you need to get up, sit on the side of the bed or chair for a minute first.
- If you fall, let your cancer team and your caregivers know.
- If you have trouble walking, ask about a home health nursing visit for an in-home safety evaluation.
- If you feel you may fall, the use of durable medical equipment such as a cane or a walker can be fall preventative.
- If a walker or wheelchair is recommended, keep it by the bed or next to where you sit. Use it every time you get up, even for short trips.

Making your home a safer environment:

- Increase lighting throughout the house, especially at the top and bottom of stairs.
- Ensure that lighting is readily available when getting up in the middle of the night.
- Make sure there are two secure rails on all stairs and use them (Set up a bed to reduce your use of stairs if possible)
- Install grab bars in the tub/shower and near the toilet. Use bath mats or non-slip stickers in the tub/shower.
- Consider using a shower chair and hand-held shower.
- Remove all loose rugs from your home and/or tape the edges of rugs to the floor.
- Avoid wearing slippery shoes.
- Make sure walking spaces are clutter free.
- Tape down any electrical cords that may be tripping hazards.

Caregivers can play an important role in preventing and/or managing falls. For guidance on falls for caregivers, please see the link below.


Resources for Additional Information:

- American Cancer Society, Avoiding and Dealing with Falls During Cancer Treatment
- NIH, National Cancer Institute, Persistent Peripheral Neuropathy Increases Fall Risk among Cancer Survivors
- Chemocare, Weakness

Información Española

- NIH, Instituto Nacional Del Cáncer, Neuropatía periférica persistente aumenta el riesgo de caídas en supervivientes de cáncer
- Chemocare, Debilidad

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- NIH, National Cancer Institute, Persistent Peripheral Neuropathy Increases Fall Risk among Cancer Survivors
- Chemocare, Weakness

Información Española

- NIH, Instituto Nacional Del Cáncer, Neuropatía periférica persistente aumenta el riesgo de caídas en supervivientes de cáncer
- Chemocare, Debilidad

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Understanding your diagnosis
Cancer is the name given to a group of related diseases. Cancer can start any place in the body. In all types of cancers, some of the body’s cells begin to divide without stopping and may spread and grow out of control and crowd out normal cells. It is important to know what the specific type of cancer you have been diagnosed with.

Take an active role in your cancer care by asking questions and using resources available from your care team. Question examples:
• What type of cancer do I have?
• Where is it located?
• What are the risk factors for this disease?
• Is this type of cancer caused by genetic factors? Are other members of my family at risk?
• What lifestyle changes—such as diet, exercise, and rest—should I make to be healthy before, during, and after treatment?
• Where can I find more information about this type of cancer?

It is important to use good judgment when searching for health information online. See below for respected, trustworthy resources. Learning about your specific diagnosis will help you make informed treatment decisions.

During your initial doctor’s visit, you may struggle to process the amount of information you receive. The unfamiliar medical language may confuse you. Ask your care team to explain any medical terms you don’t understand. Don’t be afraid to ask questions or ask for something to be repeated or rephrased for better understanding.

Consider bringing a family member or friend to your appointments to help listen and take notes. You may want to record the conversation, asking for permission from all present, so you can replay it later.

What is cancer staging?
Cancer staging is a process of using different tests and examinations to find out how much cancer is in a person’s body and where it is located.
• Specialized tests are often used to determine how much the cancer has grown within tissue removed from your body.
• Imaging tests may also be used for cancer staging. Imaging tests make pictures of the insides of your body. The pictures allow your doctors to see where the cancer has grown and possibly has spread.
• Sometimes other information is needed to determine where and how much cancer is in your body. Such information may include blood test results or special examination of the tissue removed.
• Cancer staging is important as it tells the doctors the amount of cancer and where it is in your body to be able to choose the best options for treatment for you and gives information about possible outlook
• The stage of cancer is determined only when the cancer is diagnosed and does not change over time, even if the cancer shrinks, grows, spreads or comes back.

Resources for Additional Information:

- NCCN, What is Cancer?
- NCCN, Understanding a Diagnosis
- NCCN, Cancer Staging Guide
- Cancer.Net, Diagnosing Cancer
- Cancer.Net, Stages of Cancer
- NIH, Understanding Cancer
- NIH, Questions to Ask Your Doctor About Your Diagnosis
- American Cancer Society, 24/7 questions about cancer or need help finding resources, 800-227-2345
- American Cancer Society, Understanding Your Diagnosis
- American Cancer Society, Cancer Staging

Información Española

- NIH, Instituto Nacional Del Cáncer
  - Diagnóstico y estadificación
- Cancer.Net, Materiales educativos para el paciente

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How much do you want to know?
Deciding how much you want to know about the cancer and its treatment is the first step in being able to talk comfortably with your doctor. Some patients desire more information, while others prefer less.

- Tell your health care team your preferences for receiving information about your prognosis and chance of recovery or recurrence
- Ask if there is a learning resource center available or see education resources below.
- Don’t be afraid to tell your doctor how much or how little you want to learn.

Understanding Your Prognosis
The likely course of how your disease will go for you is called prognosis. It can be hard to understand what a prognosis means and can sometimes be hard to talk about for everyone involved. Yet, many people want to know their prognosis. For some, having a better understanding of their cancer and what to expect can often be helpful in making decisions. Some decisions you may face include:

- Which treatment is best for you
- If you want treatment
- How best to care for yourself and which side effects you are willing to go through
- Practical planning to address personal affairs

Some factors that affect prognosis include:

- The type of cancer and where it is in your body
- The stage of the cancer, which refers to the size of the cancer and if it has spread to other parts of your body
- The cancer’s grade, which refers to how abnormal the cancer cells look under a microscope. Grade provides clues about how quickly the cancer is likely to grow and spread.
- Certain traits of the cancer cells
- Your age and how healthy you were before cancer
- How you respond to treatment

Some people want to know from their doctor about statistics and chances of surviving or may search for this information on their own. Or, you may find statistics confusing and frightening, and think they are too impersonal to be of value to you. Some people want to talk about the future in terms of possibilities of making it to a special date or event. You may want to know if the cancer is curable (and will never come back) or will treatment slow the cancer and prolong your life, even if it does not disappear completely. It is up to you to decide how much information you want.

If you do decide you want to know more, the doctor who knows the most about your situation is in the best position to discuss your prognosis and provide you the information you feel would be most important for you to prepare for your future.

Resources adapted from websites below

How to better understand your prognosis or possible outcomes
Internet version of this handout with active resource links at: [http://cancer-help.me/prognosis](http://cancer-help.me/prognosis)

**Resources for Additional Information:**
- [NCCN, What is Cancer?](http://nccn.org)
- [NCCN, Understanding a Diagnosis](http://nccn.org)
- [NIH, Understanding Cancer Prognosis](http://nih.gov)
- [NIH, Understanding Cancer](http://nih.gov)
- [NIH, Questions to Ask Your Doctor about Your Diagnosis](http://nih.gov)
- [American Cancer Society, Cancer Facts and Statistics](http://cancer.org)
- [American Cancer Society, 24/7 questions about cancer or need help finding resources, 800-227-2345](http://cancer.org)
- [Cancer.Net, Understanding Statistics Used to Guide Prognosis and Evaluate Treatment](http://cancer.net)

**Información Española**
- [NIH, Instituto Nacional Del Cáncer, El pronóstico del cáncer](http://nih.gov)
- [NIH, Instituto Nacional Del Cáncer, El pronóstico del cáncer - video](http://nih.gov)

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Understanding Your Treatment

There are many types of cancer treatment. The types of treatment that you receive will depend on the type of cancer you have and the stage (the amount of cancer and where it is in the body). Some people with cancer will have only one treatment. But most people have a combination of treatments, such as surgery with chemotherapy and/or radiation therapy. When you need treatment for cancer, you have a lot to learn and think about. It is normal to feel overwhelmed and confused. But, talking with your doctor and learning about the types of treatment you may have can help you feel more in control.

- **Surgery** - When used to treat cancer, surgery is a procedure in which a surgeon removes cancer from your body. Learn the different ways that surgery is used against cancer and what you can expect before, during, and after surgery.

- **Radiation Therapy** - Radiation therapy is a type of cancer treatment that uses high doses of radiation to kill cancer cells and shrink tumors. Learn about the types of radiation, what side effects might occur, which ones you might have, and more.

- **Chemotherapy** - Chemotherapy is a type of cancer treatment that uses drugs to kill cancer cells. Learn how chemotherapy works against cancer, what common side effects may occur, and how it is used with other cancer treatments.

- **Immunotherapy** - Immunotherapy is a type of treatment that helps your immune system fight cancer. Get information about the types of immunotherapy and what might be possible side effects, and how it is used with other cancer treatments.

- **Targeted Therapy** - Targeted therapy is a type of cancer treatment that targets the changes in cancer cells that help them grow, divide, and spread. Learn how targeted therapy works against cancer and about common side effects that may occur.

- **Hormone Therapy** – Hormones are chemicals that are produced in one part of the body and affect another part of the body. Some cancers use hormones to grow and other hormones may be needed to slow or stop the growth of the cancer. Learn about the types of hormone therapy and side effects that may happen.

- **Stem Cell Transplant** - Stem cell transplants are procedures that restore blood-forming stem cells in cancer patients who have had theirs destroyed by very high doses of chemotherapy or radiation therapy. Learn about the types of transplants, side effects that may occur, and how stem cell transplants are used in cancer treatment.

- **Precision Medicine** - Precision medicine helps doctors select treatments that are most likely to help patients based on a understanding the changes in the person’s genes (building blocks of what makes cells). Learn about the role precision medicine plays in cancer treatment, including how genetic changes in a person’s cancer are identified and used to select treatments.

It is most important that you understand basic information of what to expect the treatment will do and how that might affect your outlook (or prognosis) as well as how it might the quality of your life so you can make informed decisions. Also your values and priorities for your care can change and evolve over time, and it is important for you to feel free to discuss this at any time with your care team.

Content adapted from websites below

**Resources for Additional Information:**

- NCCN, Guidelines for Patients, Cancer Treatment
- NCCN, Patient and Caregiver Resources, Clinical Trials
- NIH, Understanding Cancer
- NIH, Types of Cancer Treatment
- Cancer.Net, How Cancer is Treated
- American Cancer Society, Treatment Types
- American Cancer Society, 24/7 questions about cancer or need help finding resources, 800-227-2345

**Información Española**

- NIH, Instituto Nacional Del Cáncer, Tratamiento del cáncer
- NIH, Instituto Nacional Del Cáncer, Preguntas para el doctor acerca del tratamiento
- Chemocare, ¿Por cuánto tiempo se administra la quimioterapia?

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Help discussing and deciding treatment options and what is important to you.

Advance Medical Directives/Living Will/POLST

Having conversations about your care and the future can be an important part of your discussions with your family, friends, caregivers and care team. These conversations can start at diagnosis, and may be revisited through every phase of treatment, and can be very important when the cancer is advanced.

Here are some steps for starting a discussion when you want others to know how you feel about the treatment you are receiving or are offered and what is important to you as you think about your quality of life:

- **Be certain you understand** your illness and the likely course of how your disease will go.
- **Evaluate your quality of life.** Think about what quality of life means to you. Ask yourself how you want to live. What is important for you to continue being able to do throughout treatment or if you become seriously ill? Also think about what is not important to you.
- **Have a conversation with your loved ones.** Discuss your thoughts with the people who would be involved in making decisions for you if you're not able to make them yourself. This will ensure that decisions about your care support your values and priorities.
- **Identify a loved one who can make decisions.** Which person in your life do you trust to understand what are your values and what quality of life means to you? Make sure this person is willing to make decisions for you if needed and that he or she knows what's important to you in your care choices. Don't assume anything.
- **Talk with your health care provider.** Once you have defined your own terms for quality of life and identified someone to carry out your wishes, review all of it with your health care provider. Doing so will inform your doctor about what treatment options you would or wouldn't want down the road, and allows your doctor to provide medical input and perspective.
- **Complete the paperwork.** Completing advance directives is one way for you to make your wishes known about medical treatment before you need such care.

There are three kinds of advance directives:

- **Power of Attorney for Health Care** is a legal document allowing you to designate who can make medical decisions for you (called a proxy or agent), if there is ever a time when you cannot make decisions for yourself.

- **Living Will** is another legal document that states whether you want certain life-saving medical treatments to be used or not used under specific circumstances.

- **POLST Form (Practitioner Orders for Life-Sustaining Treatment)** is a portable medical order signed by you and your doctor that states what kind of medical treatment you want or do not want toward the end of your life.

Content adapted from websites below

**Resources for Additional Information:**

- NIH, Understanding Cancer Prognosis
- NIH, Planning for Advanced Cancer
- NIH, Understanding Healthcare Decisions at the End of Life
- NCI, Coping With Advanced Cancer
- National POLST Paradigm
- Five Wishes, Living Will
- Planning the Transition to End-of-Life Care in Advanced Cancer (PDQ®)
- Cancer.Net, When You and Your Family Differ on Treatment Choices
- Cancer.Net, Putting Your Health Care Wishes in Writing
- Cancer.Net, Completing Your Life

**Información Española**

- American Cancer Society, Tratamiento y apoyo
- [https://www.cancer.net/sites/cancer.net/files/advanced_cancer_care_planning_esp.pdf](https://www.cancer.net/sites/cancer.net/files/advanced_cancer_care_planning_esp.pdf)

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There is a great deal of patient content available from national organizations, such as cancer.net; NCI.gov and specific cancer organizations (i.e. www.lls.org ). The CSOC identified content that did not exist and created additional patient/family/caregiver.

The team also developed a clinician tool on reasons to refer a patient to palliative specialty care or hospice care, that may be used in a conversation with a patient and their caregivers.

Below is the list of CSOC created Cancer Support Resources for Patients. Subsequent pages contain additional information and examples.

1. Community Cancer Support Resource Handout
2. Community Cancer/Treatment Site Cancer Support Resource Brochure
3. Cancer Take Charge Cards - for Patients Receiving Immunotherapy
4. Cancer Take Charge Cards – for Patients Receiving Chemotherapy
5. Planning Ahead for family, practical and logistical considerations; directed to patients/families dealing with a life limiting illness.
6. Reasons to Refer to Palliative or Hospice Care
Providing a variety of resources at no cost that may include:
- Short-term counseling for patients, caregivers, couples, and families
- Support and networking groups for patients and caregivers
- Support groups and classes for children, adolescents, and parents
- Assistance with stress management
- Education and Information programs on topics such as stress management, managing symptoms and side effects, treatment options
- Wellness programs such as massage, acupuncture, reflexology
- Healthy lifestyle and nutrition programs
- Exercise and fitness programs such as yoga, movement or tai chi
- Art/Music therapy and programs
- Survivorship support
- Bereavement support
- Guidance to outside organizations that can help with financial assistance, legal assistance, transportation, wish fulfillment and more

The five comprehensive community organizations offering cancer support resources in the Chicago-land area:

<table>
<thead>
<tr>
<th>Cancer Support Center</th>
<th>North Suburbs</th>
<th>South Suburbs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer Wellness Center</td>
<td>Katie Hull, LCSW Clinical Intake Associate</td>
<td>Kathleen Daly Clinical Program Director</td>
</tr>
<tr>
<td>Gilda’s Club Chicago</td>
<td>630-263-1111</td>
<td>708.798.9171</td>
</tr>
<tr>
<td>Living Well Cancer Resource Center</td>
<td>441 W Williamsburg Ave Geneva, IL 60134</td>
<td>111 North County Line Rd. Hinsdale, Illinois 60521</td>
</tr>
<tr>
<td>The Cancer Support Center</td>
<td>312-464-9900</td>
<td>630-323-5150</td>
</tr>
<tr>
<td>Wellness House</td>
<td>630-263-0000</td>
<td>wellnesshouse.org</td>
</tr>
</tbody>
</table>

Chicagoland Community Cancer Support Resources

Access this interactive map at: http://cancer-help.me/communitycancerresourcecenters

This document may be used as a handout for patients with information about resources for supportive oncology services in the greater Chicagoland, Peoria and Dixon areas.

To access and print copies, download HERE.
Brochures are available as a resource for patients, which include cancer support services at both community support centers and the treating institution.

A template of this brochure is available for customization to individual institutions on the inside flap and to web/phone resources.

Contact CSOC@colemanfoundation.org for more information.
These business size cards are for patients undergoing immunotherapy to help them and their caregivers know when to call the cancer center, by what time, and which number to use.

The goal is to direct patients to care early so they don’t end up in the Emergency Room or hospital with an event that could have been addressed if identified earlier.

Templates of these cards are available. Contact CSOC@colemanfoundation.org for more information.
These business size cards are for patients undergoing chemotherapy to help them and their caregivers know when to call the cancer center, by what time, and which number to use.

The goal is to direct patients to care so they don’t end up in the Emergency Room or hospital with an event that could have been addressed if identified earlier.

Templates of these cards are available. Contact CSOC@colemanfoundation.org for more information.
This patient brochure and a similar caregiver brochure is a resource for organizing aspects of life including personal, logistical, and legal considerations. This brochure is especially useful for patients and caregivers who are experiencing a life limiting form of cancer.

A template of this brochure is available for customization to individual institutions.

Contact
CSOC@colemanfoundation.org for more information.
Multiple studies show that patients who receive palliative care along with treatment for cancer have a better quality of life compared to patients receiving standard of care alone. Palliative care is based on need, not prognosis. Palliative care may be provided by a palliative care specialist or in the absence of one, can be offered alongside standard of care. The CSOC Follow Up Reference Tools or other available palliative training modalities can help guide care considerations.

The lists below can be used as guides by clinicians, with referral capabilities to palliative care specialists, to assess when the patient would most benefit from a palliative care referral. The list includes guides to assist clinicians in identifying/assessing patients who may be best served by a referral to hospice care.

### Outpatient Reasons to Refer to Palliative Specialist

1. Needs someone to support or lead a challenging advance care planning or goals of care discussion
2. Has progressive disease where uncontrolled symptoms interfere with quality of life or performance status
3. Has a cancer diagnosis and has failure to thrive or frailty
4. Patient or family requests a palliative care consult
5. Has a life limiting cancer and poor functional status (ECOG of 3) and the patient or health care agent has declined a hospice referral
6. Has chemotherapy-refractory advanced cancer with a good functional status and is not yet being referred for hospice
7. Has any stage cancer diagnosis, but quality of life and/or survival is limited by debility, has frequent hospitalizations and/or other concurrent chronic medical issues such that prognosis is less than 1 year

### Inpatient Reasons to Refer to Palliative Specialist

1. Needs someone to support or lead a challenging advance care planning or goals of care discussion
2. Has progressive disease where uncontrolled symptoms interfere with quality of life or performance status
3. Has a cancer diagnosis and has failure to thrive or frailty
4. Patient or family requests a palliative care consult
5. Has a life limiting cancer and poor functional status (ECOG of 3) and the patient or health care agent has declined a hospice referral
6. Has chemotherapy-refractory advanced cancer with a good functional status and is not yet being referred for hospice
7. Has any stage cancer diagnosis, but quality of life and/or survival is limited by debility, has frequent hospitalizations and/or other concurrent chronic medical issues such that prognosis is less than 1 year
8. Has a life-limiting oncologic illness and prolonged hospital stay (greater than 7 days) without evidence of clinical improvement
9. Stage IV malignancy or refractory hematologic malignancy in addition to poor functional status
10. Current or past enrolee of hospice program
ICU - Reasons for Referral to Palliative Specialist

1. ICU stay longer than 7 days without evidence of improvement¹
2. Cardiac arrest (either in or out of hospital)¹
3. Multi-system organ failure (3 or more)¹
4. Stage IV malignancy or refractory hematologic malignancy¹
5. Poor neurologic prognosis with low chance of meaningful recovery¹
6. Inability to wean a patient from the ventilator¹
7. Team/family discussing tracheostomy, feeding tube or long term care placement¹
8. Current or past enrollee of hospice program¹
9. There is a family disagreement with the medical team, with the patient’s advance directive, or with each other¹
10. Patient or family requests a palliative care consult¹

Reasons for Referral to Hospice Care

1. The patient is no longer able to come into the oncology clinic for visits due to debility, symptoms etc.²
2. Patient with chemotherapy-refractory metastatic solid tumor malignancy or refractory hematologic malignancy
3. Life expectancy less than 6 months and the patient’s goals of care are focused on comfort⁴
4. Poor performance status (ECOG 2 or more) which inhibits the use of chemotherapy
5. Patient with a cancer diagnosis, other serious chronic comorbidities, debility and/or frequent hospitalizations as well as a life expectancy of less than 6 months²,⁴

⁴ Medicare Guidelines for Hospice eligibility.
Each cancer program has a variety of resources available to support patients. Some resources are available to all patients; others require that the patient is already being seen in another area/department or is in the hospital (in patient). Some resources are only available through external partnerships, referrals or through suggestions to patients. As your organization embarks on optimizing supportive care services, please take an inventory of current resources, identify where gaps exist and how you may address those gaps to fully support your cancer patients.

Below is the list of workflow tools and additional resources that can be found on subsequent pages:

1. Supportive Oncology Resources – Internal, External and Gaps Survey
2. Approaches to Screening and Referrals – Site Examples
3. Quality Metrics to Assess and Evaluate Supportive Oncology Care
4. Approaches to Screening and Referrals – Site Examples
5. Quality Metrics to Assess and Evaluate Supportive Oncology Care
6. Education/Training for Clinical Staff
<table>
<thead>
<tr>
<th>Service / Specialty</th>
<th>Available to Cancer Patients in outpatient clinic</th>
<th>Available at institution through referral to another area</th>
<th>Referred to Externally</th>
<th>Notes on what is needed beyond what exists now</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social Workers</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Support or Networking Groups for patients</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Support or Networking Groups for caregivers / family members</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Support / Networking for patients after treatment is completed</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychologists</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Genetic Assessment</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Palliative Specialist</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Fertility / Reproductive Preservation</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Access to Dental Care</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Financial Navigation / Counseling</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Nutrition</td>
<td></td>
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<td></td>
<td></td>
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<tr>
<td>Physical Therapy</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Oncology Pharmacist</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Immunizations</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pain Specialist</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chaplain</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Others (please note)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
In summary, Standard 3.2 of the Commission on Cancer 2016 Standards Manual requires screening at a minimum of one time at a pivotal medical visit, the validated screening must be reviewed by properly trained medical staff. A member of the team must assess the presence of a physical, psychological, social, spiritual or financial support needs and make the proper referrals to resources on site or external to the site.

While the minimum is one time, the reality is that cancer patients experience a variety of support needs during the course of their cancer care. A patient may have work/financial support in place at the beginning of their care, but that can change over months or years of treatment.

Following are some approaches that CSOC sites have used for screening.

**Example 1: Academic Medical Center A**

**Screening:** This academic medical center uses the Coleman Supportive Oncology Screening tool, which includes the PHQ4 and several other validated instruments to assess all aspects of a patients supportive concerns/needs. The Academic medical center has patients complete the screening tool each time they come in for a medical oncology visit (about once every 3 months). They also provide the patients who are undergoing infusion therapy a screening every 3rd infusion. This site uses a mix of paper screening tools that are filled out by patients in the waiting room and tablet based screening that is filled out by patients while in infusion or when roomed.

**Referrals:** For the patients that use a paper screening questionnaire, the results are entered in the electronic medical record by a medical assistant. The patient’s assigned nurse reviews the results of the screening tool and reviews suggested referrals, based on prompts programmed into the electronic medical record. The nurse suggests referrals to the...
physician and then acts on those that are agreed upon. Automated referrals include social work, palliative care, spiritual care and nutrition at this site.

**Example 2: Community Hospital**

Screening: This community hospital has patients complete a supportive oncology screening once they have been diagnosed with cancer. The screening tool is provided to patients through their assigned patient navigator. The navigator will have the patient re-screened every 3 months when the patient is coming back into see them for a scheduled medical visit.

Referrals: The navigator enters the results of the screening tool into their patient navigator program. In conducting further interaction with the patient, they identify what they are able to support for the patient and what referrals are needed. Many patients at this site see the social worker and many patients are referred to a local community organization for nutritional and social support. The navigators also use the patient handouts created by CSOC to provide patients basic education for the patient on what they can do themselves and what other resources exist.

**Example 3: Safety Net Hospital**

Screening: Every new patient at this safety net hospital is given a screening tool at their first appointment. The patient completes the screening tool in the waiting room or with the help of staff. Each patient is offered a re-screening every 12 weeks when they are in for a medical appointment or infusion.

Referrals: Every new patient is referred to a supportive oncology clinic appointment, the results of each patient’s screening provides a starting point for the clinic to identify resources and staff that should interact with the patient.

**Example 4: Academic Medical Center B**

Screening: This Academic Medical Center sends a supportive screening email to patients prior to their appointment. The intention is for patients to complete the screening questionnaire prior to their appointment. If they have not completed the screening, it is given to the patient when they are roomed during their clinic visit.

Referrals: The results of the screening are available to the clinic team to review and automated referrals are made to social work and other resources based on the results of the screening.
The CSOC has focused on quality improvement. With all quality improvement projects, it is important to collect data to assess the baseline, the point you started, and to collect data at regular intervals to see what the impact of the quality improvement has been. The impact will often be positive but sometimes it will be neutral or negative. Having the data allows your team to get into the details and figure out how to further improve each area.

Also, to support the Commission on Cancer requirements for standard 3.2, data is needed regarding completed screening and referrals. The Coleman Supportive Oncology Collaborative identified metrics, based on ASCO Quality Oncology Practice Initiative metrics associated to supportive care. If you would like a copy of an excel spreadsheet to collect these metrics, please email CSOC@Colemanfoundation.org

Note, the metrics that are bolded below are calculated from the other metrics. There are no measures that will reach 100%, which is built into the expectations.

**What each column in this table represents:**

Column 1: ID that relates to the Excel spreadsheet columns, used for data collection  
Column 2: Description of data/metric  
Column 3: Basis for the measure – the related ASCO QOPI measure  
Column 4: More detail about the data/metric.  
Column 5: Denominator used in the metric calculation in the spreadsheet.

<table>
<thead>
<tr>
<th>ID</th>
<th>Data to Collect</th>
<th>Basis for Measure</th>
<th>Data tracked at patient level / Further Definition or Notes on measure (for Excel File)</th>
<th>Denominator</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Number of patients in population</td>
<td>QOPI CORE 1</td>
<td>A count of the total number of patients in your sample</td>
<td>NA</td>
</tr>
<tr>
<td>1a</td>
<td>Date of Initial Diagnosis</td>
<td></td>
<td></td>
<td>NA</td>
</tr>
<tr>
<td>1b</td>
<td>Date of full diagnosis (full workup completed) - must fill in, use date of diagnosis if not known</td>
<td></td>
<td></td>
<td>NA</td>
</tr>
<tr>
<td>1c</td>
<td>Date of Birth</td>
<td></td>
<td>Month and year, day can be 01</td>
<td>NA</td>
</tr>
<tr>
<td>1c.2</td>
<td>Gender</td>
<td></td>
<td>Male, Female, Indeterminate, Unknown</td>
<td></td>
</tr>
<tr>
<td>1c.3</td>
<td>Type of Cancer</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1d</td>
<td>Date of last active treatment (Chemotherapy or anti-cancer therapy) or move to maintenance phase</td>
<td></td>
<td></td>
<td>NA</td>
</tr>
<tr>
<td>1e</td>
<td>Age (counts 65+ in total)</td>
<td></td>
<td></td>
<td>1.0 %</td>
</tr>
<tr>
<td>1f</td>
<td>Date of death</td>
<td></td>
<td></td>
<td>1.0 %</td>
</tr>
<tr>
<td>1.1</td>
<td>Stage I, II, III solid tumor cancer/ non-refractory hematologic malignancies potentially curative</td>
<td></td>
<td>Date of diagnosis of stage I, II or III solid tumor cancer or non-refractory hematologic malignancy, metric is a count of the patients with the criteria, a subset of ID-1</td>
<td>1.0 %</td>
</tr>
<tr>
<td>ID</td>
<td>Data to Collect</td>
<td>Basis for Measure</td>
<td>Data tracked at patient level / Further Definition or Notes on measure (for Excel File)</td>
<td>Denominator</td>
</tr>
<tr>
<td>-----</td>
<td>-----------------------------------------------------------------------------------------------------------</td>
<td>-----------------------------------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>-------------</td>
</tr>
<tr>
<td>1.2</td>
<td>Stage IV solid tumor cancer/ refractory hematologic malignancies</td>
<td></td>
<td>Date of diagnosis of stage IV solid tumor cancer or refractory hematologic malignancy, metric is a count of the patients with the criteria, a subset of ID-1, note ID-1.1 plus ID-1.2 should add to ID-1</td>
<td>1.0 %</td>
</tr>
<tr>
<td>1.29</td>
<td><strong>Stage (Early-E, Advanced-A)</strong></td>
<td></td>
<td>Calculated based on Stage I, II, III and patients with non-refractory hematologic malignancies are Early (E), Stage IV and refractory or progressive are Advanced (A)</td>
<td>1.0 %</td>
</tr>
<tr>
<td>1.30</td>
<td>Patients on clinical trial</td>
<td></td>
<td></td>
<td>1.0 %</td>
</tr>
<tr>
<td>1.35</td>
<td>Patients on clinical trial 65 and older</td>
<td></td>
<td></td>
<td>1e %</td>
</tr>
<tr>
<td>2.1</td>
<td>Number of patients with a documented discussion on understanding of illness/ treatment expectation/or quality of life within 30 days of full diagnosis date</td>
<td>QOPI Core 2</td>
<td>Date of documented discussion in the medical record (paper or electronic), may be in progress notes or in a specific field.</td>
<td>1.0 %</td>
</tr>
<tr>
<td>2.2</td>
<td>Number of individual patients who were told a prognosis timeframe within 30 days of full diagnosis date</td>
<td>QOPI Core 2 (NQF #0386)</td>
<td>Date of prognosis discussion. Metric is calculated on the excel spreadsheet</td>
<td>1.0 %</td>
</tr>
<tr>
<td>2.25</td>
<td>Number of individual patients who were told prognosis timeframe, within 14 days of full diagnosis date</td>
<td></td>
<td>Calculated on the excel spreadsheet</td>
<td>1.0 %</td>
</tr>
<tr>
<td>2.3</td>
<td>Patients with documented discussion with agent name based on validated health care power of attorney within 90 days of diagnosis date</td>
<td>QOPI Core 25a</td>
<td>Date of documented discussion...</td>
<td>1.0 %</td>
</tr>
<tr>
<td>2.35</td>
<td>If 65 or over, POA within 90 days?</td>
<td></td>
<td></td>
<td>1e %</td>
</tr>
<tr>
<td>2.4</td>
<td>POLST within 90 days</td>
<td></td>
<td>Date of documented POLST, metric calculated</td>
<td>1.0 %</td>
</tr>
<tr>
<td>2.40A</td>
<td>Discussion of POLST Within 90 days if Advanced Cancer</td>
<td></td>
<td></td>
<td>1.2 %</td>
</tr>
<tr>
<td>2.41</td>
<td>Discussion of POLST Within 90 days and 65 or older, regardless of stage</td>
<td></td>
<td></td>
<td>1e %</td>
</tr>
<tr>
<td>2.45</td>
<td>Documented discussion of POLST within 30 days of diagnosis</td>
<td></td>
<td>Metric calculated</td>
<td>1.0 %</td>
</tr>
<tr>
<td>2.45A</td>
<td>Documented discussion of POLST within 30 days if Advanced Cancer</td>
<td></td>
<td>Metric calculated</td>
<td>1.2 %</td>
</tr>
<tr>
<td>2.46</td>
<td>Documented discussion of POLST within 30 days and 65 or older, regardless of stage</td>
<td></td>
<td>Metric calculated</td>
<td>1e %</td>
</tr>
<tr>
<td>2.48</td>
<td>POLST completed more than 30 days before death, regardless of stage</td>
<td></td>
<td>Metric calculated</td>
<td>1f %</td>
</tr>
<tr>
<td>3.1</td>
<td>The number of times patients were offered a supportive oncology screen (can be multiple times for each patient)</td>
<td>QOPI Core 24, Core 3, 4a (NQF #0384), COC 3.2, QOPI Core 6a, 6b</td>
<td>Dates of screening offered to each patient tracked on excel spreadsheet</td>
<td>1.0 %</td>
</tr>
<tr>
<td>3.12</td>
<td>The number of supportive oncology screenings completed by patients in the sample during the data collection time. (can be multiple times for each patient)</td>
<td></td>
<td>Y or N on screening completed by each patient</td>
<td>1.0 %</td>
</tr>
<tr>
<td>3.13</td>
<td>Any supportive screening</td>
<td></td>
<td>Metric calculated</td>
<td>1.0 %</td>
</tr>
<tr>
<td>3.14</td>
<td>The number of patients that were offered a supportive oncology screen but did not complete it</td>
<td></td>
<td>Metric calculated</td>
<td>1.0 %</td>
</tr>
<tr>
<td>ID</td>
<td>Data to Collect</td>
<td>Basis for Measure</td>
<td>Data tracked at patient level / Further Definition or Notes on measure (for Excel File)</td>
<td>Denominator</td>
</tr>
<tr>
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<td>---------------------------------------------------------------------------------</td>
<td>----------------------------------------</td>
<td>---------------------------------------------------------------------------------------</td>
<td>-------------</td>
</tr>
<tr>
<td>3.2</td>
<td>Stage I, II, III solid tumor cancer/ non-refractory hematologic malignancies with at least one supportive oncology screening within 30 days of diagnosis date</td>
<td>Metric calculated</td>
<td></td>
<td>1.1 %</td>
</tr>
<tr>
<td>3.3</td>
<td>Stage IV solid tumor cancer/ refractory hematologic malignancies with at least one supportive oncology screening within 30 days of diagnosis date</td>
<td>Metric calculated</td>
<td></td>
<td>1.2 %</td>
</tr>
<tr>
<td>3.35</td>
<td>Stage IV solid tumor cancer/ refractory hematologic malignancies with at least one supportive oncology screening within 30 days of diagnosis date</td>
<td>Metric calculated</td>
<td></td>
<td>1.2 %</td>
</tr>
<tr>
<td>4</td>
<td>Number of individual patients with one or more actions/referrals identified by supportive oncology screening in the past 12 months in the outpatient setting</td>
<td>QOPI Core 25, Core 5, 6</td>
<td>Calculated for each patient based on 4.1, 4.2, 4.3, 4.4, 4.5, 4.6, 4.7, 4.8</td>
<td>1.0 %</td>
</tr>
<tr>
<td>4.1</td>
<td>Number of patients with distress/emotional/psychosocial action and/or referral identified in the outpatient setting</td>
<td>QOPI Core 25</td>
<td>Date of referral or action suggested, aligns with PHQ-4 portion of CSOC screening tool</td>
<td>1.0 %</td>
</tr>
<tr>
<td>4.15</td>
<td>Number of patients with distress/emotional/psychosocial action and/or referral completed / fulfilled - subset of 4.10, in the outpatient setting</td>
<td>QOPI Core 25</td>
<td>Date of completion/fulfillment of referral or action</td>
<td>4.1 %</td>
</tr>
<tr>
<td>4.2</td>
<td>Number of patients with action/referral identified based on physical function, physical activity or fatigue, in the outpatient setting</td>
<td>QOPI Core 13a?, EOL 43</td>
<td>Date of referral or action suggested, aligns with PROMIS-Fatigue (middle of page 2) and PROMIS-Physical Function (bottom of page 2) portion of CSOC screening tool</td>
<td>1.0 %</td>
</tr>
<tr>
<td>4.25</td>
<td>Number of patients with a physical function, physical activity or fatigue action and/or referral completed/fulfilled. - subset of 4.20, in the outpatient setting</td>
<td>QOPI Core 25</td>
<td>Date of completion/fulfillment of referral or action</td>
<td>4.2 %</td>
</tr>
<tr>
<td>4.3</td>
<td>Number of patients with treatment or care concerns or physical concerns action and/or referral identified, in the outpatient setting</td>
<td>QOPI Core 25</td>
<td>Date of referral or action suggested, aligns with physical concerns (middle right side of page 1) portion of CSOC screening tool</td>
<td>1.0 %</td>
</tr>
<tr>
<td>4.35</td>
<td>Number of patients with treatment or care concerns or physical concern action(s) completed / fulfilled - subset of 4.30, in the outpatient setting</td>
<td>QOPI Core 25</td>
<td>Date of completion/fulfillment of referral or action</td>
<td>4.3 %</td>
</tr>
<tr>
<td>4.4</td>
<td>Number of patients with pain interference and/or pain intensity action and/or referral identified, in the outpatient setting</td>
<td>QOPI Core 6c, 6d, 6e</td>
<td>Date of referral or action suggested, aligns with PROMIS Pain Short Form (top of page 2) portion of CSOC screening tool</td>
<td>1.0 %</td>
</tr>
<tr>
<td>4.45</td>
<td>Number of patients with pain interference and/or pain intensity action(s) completed / fulfilled- subset of 4.40, in the outpatient setting</td>
<td>QOPI Core 25</td>
<td>Date of completion/fulfillment of referral or action</td>
<td>4.4 %</td>
</tr>
<tr>
<td>4.5</td>
<td>Number of patients with practical concern, financial concern and/or family concern action and/or referral identified, in the outpatient setting</td>
<td>QOPI Core 25</td>
<td>Date of referral or action suggested, aligns with practical and family/caregiver concerns (middle left side of page 1) portion of CSOC screening tool</td>
<td>1.0 %</td>
</tr>
<tr>
<td>4.55</td>
<td>Number of patients with practical concern, financial concern and/or family concern action(s) completed / fulfilled - subset of 4.50, in the outpatient setting</td>
<td>QOPI Core 25</td>
<td>Date of completion/fulfillment of referral or action</td>
<td>4.5 %</td>
</tr>
<tr>
<td>ID</td>
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</tr>
<tr>
<td>4.6</td>
<td>Number of patients with spiritual action and/or referral identified, in the outpatient setting</td>
<td></td>
<td>Date of referral or action suggested, aligns with spiritual/faith concerns (bottom right side of page 1) portion of CSOC screening tool</td>
<td>1.0 %</td>
</tr>
<tr>
<td>4.65</td>
<td>Number of patients with spiritual action(s) completed / fulfilled - subset of 4.60, in the outpatient setting</td>
<td></td>
<td>Date of completion/fulfillment of referral or action</td>
<td>4.6 %</td>
</tr>
<tr>
<td>4.7</td>
<td>Number of patients with nutrition concern action(s) identified, in the outpatient setting</td>
<td>QOPI Core 25, Core 5, 6</td>
<td>Date of referral or action suggested, aligns with physical concerns (right side of page 1) portion of CSOC screening tool</td>
<td>1.0 %</td>
</tr>
<tr>
<td>4.75</td>
<td>Number of patients with nutrition concern action(s) completed / fulfilled - subset of 4.70, in the outpatient setting</td>
<td></td>
<td>Date of completion/fulfillment of referral or action</td>
<td>4.7 %</td>
</tr>
<tr>
<td>4.8</td>
<td>Number of patients with treatment or care concern action(s) identified, in the outpatient setting</td>
<td>QOPI Core 11, 13, EOL 43</td>
<td>Date of referral or action suggested, aligns with treatment or care concerns (bottom left side of page 1) portion of CSOC screening tool</td>
<td>1.0 %</td>
</tr>
<tr>
<td>4.85</td>
<td>Number of patients with treatment or care concern action(s) completed / fulfilled - subset of 4.80, in the outpatient setting</td>
<td></td>
<td>Date of completion/fulfillment of referral or action</td>
<td>4.8 %</td>
</tr>
<tr>
<td>5</td>
<td>Number of patients eligible for a survivorship visit, stage I, II and III patients (a proportion of patients from 1.10) who have completed active treatment or moved into maintenance phase [acute to chronic treatment such as endocrine therapy] in the past 12 months.</td>
<td></td>
<td>Date of completion of active therapy (adjuvant, radiation) for patients with curative intent cancer (should be a subset of patients from 1.1)</td>
<td>1.1 (or 1.29(E) %</td>
</tr>
<tr>
<td>5.1</td>
<td>Number of individual stage I, II, III cancer patients (patients with curative intent) that receive a treatment summary and a survivorship care plan, inclusive of a distress screening, within 180 days of completing active treatment or move into maintenance phase [acute to chronic treatment such as endocrine therapy].</td>
<td>QOPI Core 18, 19, 20 COC standard 3.3</td>
<td>Date treatment summary and survivorship care plan are provided to patient, metric calculated</td>
<td>5 %</td>
</tr>
<tr>
<td>5.15</td>
<td>Number of individual stage I, II, III cancer patients (patients with curative intent) that receive a treatment summary and a survivorship care plan, inclusive of a distress screening, within 90 days of completing active treatment or move into maintenance phase [acute to chronic treatment such as endocrine therapy].</td>
<td></td>
<td>Metric calculated based on date in 5.1</td>
<td>5 %</td>
</tr>
<tr>
<td>5.2</td>
<td>The number of patients whose primary care physician were provided a “treatment summary” and a “survivorship care plan” in the past 12 months, as documented in a medical record.</td>
<td></td>
<td>Date, documented in medical record, that PCP received treatment summary and survivorship care plan.</td>
<td>5 %</td>
</tr>
<tr>
<td>6.1</td>
<td>Number of individual stage IV patients solid tumor or refractory hematologic malignancies with any documented palliative care specialist referral in an outpatient setting</td>
<td>QOPI EOL 43, 47, (NQF #0215)</td>
<td>Date of referral (outpatient)</td>
<td>1.2 %</td>
</tr>
<tr>
<td>6.14</td>
<td>Number of individual stage IV patients solid tumor or refractory hematologic malignancies with documented palliative care specialist referral, within 30 days of diagnosis date (subset of 6.1), in an outpatient setting</td>
<td></td>
<td>Calculated based on 6.1 date</td>
<td>1.2 %</td>
</tr>
<tr>
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</tr>
<tr>
<td>6.18</td>
<td>Number of individual stage IV patients solid tumor or refractory hematologic malignancies with documented palliative care specialist referral, within 14 days of diagnosis date, in an outpatient setting (subset of 6.18)</td>
<td>Calculated based on 6.1 date</td>
<td></td>
<td>1.2 %</td>
</tr>
<tr>
<td>6.2</td>
<td>Number of individual stage IV patients solid tumor or refractory hematologic malignancies with documented palliative care specialist referral (from 6.1) that also completed a palliative specialist consult, in an outpatient setting</td>
<td>Date of completion/fulfillment of referral</td>
<td></td>
<td>6.1 %</td>
</tr>
<tr>
<td>6.24</td>
<td>Number of individual stage IV patients solid tumor or refractory hematologic malignancies with documented palliative care specialist referral that also completed a palliative specialist consult within 14 days of referral, in an outpatient setting</td>
<td>Calculated based on 6.2 date</td>
<td></td>
<td>6.1 %</td>
</tr>
<tr>
<td>6.6</td>
<td>Number of individual stage IV patients solid tumor or refractory hematologic malignancies with any documented palliative care specialist referral in an inpatient setting</td>
<td></td>
<td></td>
<td>1.2 %</td>
</tr>
<tr>
<td>6.64</td>
<td>Number of individual stage IV patients solid tumor or refractory hematologic malignancies with documented palliative care specialist referral, within 30 days of diagnosis date (subset of 6.6), in an inpatient setting</td>
<td>Calculated based on 6.6 date</td>
<td></td>
<td>1.2 %</td>
</tr>
<tr>
<td>6.68</td>
<td>Number of individual stage IV patients solid tumor or refractory hematologic malignancies with documented palliative care specialist referral, within 14 days of diagnosis date, in an inpatient setting (subset of 6.64)</td>
<td>Calculated based on 6.6 date</td>
<td></td>
<td>1.2 %</td>
</tr>
<tr>
<td>6.7</td>
<td>Number of individual stage IV patients solid tumor or refractory hematologic malignancies with documented palliative care specialist referral (from 6.6) that also completed a palliative specialist consult, in an inpatient setting</td>
<td>Date of completion/fulfillment of referral</td>
<td></td>
<td>6.6 %</td>
</tr>
<tr>
<td>6.74</td>
<td>Number of individual stage IV patients solid tumor or refractory hematologic malignancies with documented palliative care specialist referral that also completed a palliative specialist consult within 14 days of referral, in an inpatient setting</td>
<td>Calculated based on 6.7 date</td>
<td></td>
<td>6.6 %</td>
</tr>
<tr>
<td>6.80</td>
<td>Documented OUTPATIENT AND/OR INPATIENT palliative care specialist referral</td>
<td>Calculated based on 6.1 and 6.6 date</td>
<td></td>
<td>1.2 %</td>
</tr>
<tr>
<td>6.81</td>
<td>Patient received supportive oncology screening(s) and received palliative referral</td>
<td>Metric calculated</td>
<td></td>
<td>1.2%</td>
</tr>
<tr>
<td>6.84</td>
<td>Documented palliative care specialist referral within 30 days of diagnosis date - either setting</td>
<td>Calculated based on 6.1 and 6.6 date</td>
<td></td>
<td>1.2 %</td>
</tr>
<tr>
<td>6.88</td>
<td>Documented palliative care specialist referral within 14 days of diagnosis date - either setting</td>
<td>Calculated based on 6.1 and 6.6 date</td>
<td></td>
<td>1.2 %</td>
</tr>
<tr>
<td>6.9</td>
<td>Documented OUTPATIENT AND/OR INPATIENT palliative specialist consult completed</td>
<td>Calculated based on 6.2 and 6.7 dates</td>
<td></td>
<td>1.2 %</td>
</tr>
<tr>
<td>6.91</td>
<td>Earliest date of palliative specialist consult (either in or outpatient)</td>
<td>Metric, should be same result as 6.9, data used to calculate other metrics</td>
<td></td>
<td>1.2%</td>
</tr>
<tr>
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<td>------------</td>
</tr>
<tr>
<td>6.94</td>
<td><strong>Palliative Consult completed within 14 days of referral - either setting</strong></td>
<td>Calculated based on 6.2 and 6.7 dates</td>
<td>1.2 %</td>
<td></td>
</tr>
<tr>
<td>7.1</td>
<td>Number of stage IV patients solid tumor or refractory hematologic malignancies with documented hospice referral at least 14 days prior to death, in an <strong>outpatient setting</strong></td>
<td>Date of hospice referral (outpatient), metric calculated based on that</td>
<td>1f %</td>
<td></td>
</tr>
<tr>
<td>7.12</td>
<td>Number of stage IV patients solid tumor or refractory hematologic malignancies with documented hospice referral at least 30 days prior to death, in an outpatient setting</td>
<td>Calculated based on 7.1 date</td>
<td>1f %</td>
<td></td>
</tr>
<tr>
<td>7.16</td>
<td>Number of stage IV patients solid tumor or refractory hematologic malignancies with documented hospice referral at least 60 days prior to death, in an outpatient setting</td>
<td>Calculated based on 7.1 date</td>
<td>1f %</td>
<td></td>
</tr>
<tr>
<td>7.2</td>
<td>Number of stage IV patients solid tumor or refractory hematologic malignancies with documented hospice referral at least 14 days prior to death, in an <strong>inpatient setting</strong></td>
<td>Date of hospice referral (inpatient), metric calculated based on that</td>
<td>1f %</td>
<td></td>
</tr>
<tr>
<td>7.22</td>
<td>Number of stage IV patients solid tumor or refractory hematologic malignancies with documented hospice referral at least 30 days prior to death, in an inpatient setting</td>
<td>Calculated based on 7.3 date</td>
<td>1f %</td>
<td></td>
</tr>
<tr>
<td>7.26</td>
<td>Number of stage IV patients solid tumor or refractory hematologic malignancies with documented hospice referral at least 60 days prior to death, in an inpatient setting</td>
<td>Calculated based on 7.3 date</td>
<td>1f %</td>
<td></td>
</tr>
<tr>
<td>7.3</td>
<td><strong>Documented OUTPATIENT And/or INPATIENT hospice referral</strong></td>
<td>Calculated based on 7.3 date</td>
<td>1f %</td>
<td></td>
</tr>
<tr>
<td>7.31</td>
<td><strong>Hospice Referral at least 14 days before death, either setting</strong></td>
<td>Calculated based on 7.3 date</td>
<td>1f %</td>
<td></td>
</tr>
<tr>
<td>7.32</td>
<td><strong>Hospice Referral at least 30 days before death, either setting</strong></td>
<td>Calculated based on 7.3 date</td>
<td>1f %</td>
<td></td>
</tr>
<tr>
<td>7.36</td>
<td><strong>Hospice Referral at least 60 days before death, either setting</strong></td>
<td>Calculated based on 7.3 date</td>
<td>1f %</td>
<td></td>
</tr>
<tr>
<td>7.4</td>
<td>Number of patients enrolled in hospice</td>
<td>Date patient is enrolled in hospice, date patient expires</td>
<td>1f %</td>
<td></td>
</tr>
<tr>
<td>7.41</td>
<td>Number of patients enrolled in hospice 3 or more days before death</td>
<td>Calculated based on 7.4 dates</td>
<td>1f %</td>
<td></td>
</tr>
<tr>
<td>7.42</td>
<td>Number of patients enrolled in hospice 7 or more days before death</td>
<td>Calculated based on 7.4 dates</td>
<td>1f %</td>
<td></td>
</tr>
<tr>
<td>7.45</td>
<td>Number of patients enrolled in hospice 30 or more days before death</td>
<td>Calculated based on 7.4 dates</td>
<td>1f %</td>
<td></td>
</tr>
<tr>
<td>7.46</td>
<td>Number of patients enrolled in hospice 60 or more days before death</td>
<td>Calculated based on 7.4 dates</td>
<td>1f %</td>
<td></td>
</tr>
<tr>
<td>7.48</td>
<td>Patients with receipt of Palliative Care and Hospice Enrollment</td>
<td>Metric calculated</td>
<td>6.9%</td>
<td></td>
</tr>
<tr>
<td>7.5</td>
<td>Number of patients who received anti-cancer therapy within 30 days of death that were not enrolled in a clinical trial</td>
<td>Date of last anti-cancer non-clinical trial therapy, metric calculated from that date and from 7.4 date patient expires</td>
<td>1f %</td>
<td></td>
</tr>
<tr>
<td>7.6</td>
<td>Number of clinical trial enrolled patients who received anti-cancer therapy within 30 days of death.</td>
<td>Date of last anti-cancer clinical trial therapy, metric calculated from that date and from 7.4 date patient expires</td>
<td>1f %</td>
<td></td>
</tr>
<tr>
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</tr>
<tr>
<td>7.55</td>
<td>Received anti-cancer therapy within 14 days of death not on clinical trial</td>
<td>Metric calculated from that date and from 7.4 date patient expires</td>
<td>1f %</td>
<td></td>
</tr>
<tr>
<td>7.65</td>
<td>Number of clinical trial patients that received anti-cancer therapy within 14 days of death</td>
<td>Metric calculated from that date and from 7.4 date patient expires</td>
<td>1f %</td>
<td></td>
</tr>
<tr>
<td>7.7</td>
<td>Length of Hospice Stay</td>
<td>Date of death (1f) – date of hospice enrollment (7.4)</td>
<td>1f average</td>
<td></td>
</tr>
<tr>
<td>8.1</td>
<td>Date of FIRST hospital admission (other than for planned procedure)</td>
<td>Date entering hospital</td>
<td>NA</td>
<td></td>
</tr>
<tr>
<td>8.11</td>
<td>Date leaving hospital after FIRST unplanned admission</td>
<td>Date of discharge</td>
<td>NA</td>
<td></td>
</tr>
<tr>
<td>8.12</td>
<td>Number of days in ICU during FIRST admission</td>
<td>Total Days in ICU for this admission</td>
<td>NA</td>
<td></td>
</tr>
<tr>
<td>8.2</td>
<td>Date of SECOND hospital admission (other than for planned procedure)</td>
<td>Date entering hospital</td>
<td>NA</td>
<td></td>
</tr>
<tr>
<td>8.21</td>
<td>Date leaving hospital after SECOND unplanned admission</td>
<td>Date of discharge</td>
<td>NA</td>
<td></td>
</tr>
<tr>
<td>8.22</td>
<td>Number of days in ICU during SECOND admission</td>
<td>Total Days in ICU for this admission</td>
<td>NA</td>
<td></td>
</tr>
<tr>
<td>8.3</td>
<td>Date of THIRD hospital admission (other than for planned procedure)</td>
<td>Date entering hospital</td>
<td>NA</td>
<td></td>
</tr>
<tr>
<td>8.31</td>
<td>Date leaving hospital after THIRD unplanned admission</td>
<td>Date of discharge</td>
<td>NA</td>
<td></td>
</tr>
<tr>
<td>8.32</td>
<td>Number of days in ICU during THIRD admission</td>
<td>Total Days in ICU for this admission</td>
<td>NA</td>
<td></td>
</tr>
<tr>
<td>8.4</td>
<td>Date of FORTH hospital admission (other than for planned procedure)</td>
<td>Date entering hospital</td>
<td>NA</td>
<td></td>
</tr>
<tr>
<td>8.41</td>
<td>Date leaving hospital after FORTH unplanned admission</td>
<td>Date of discharge</td>
<td>NA</td>
<td></td>
</tr>
<tr>
<td>8.42</td>
<td>Number of days in ICU during FORTH admission</td>
<td>Total Days in ICU for this admission</td>
<td>NA</td>
<td></td>
</tr>
<tr>
<td>8.5</td>
<td>Date of FIFTH hospital admission (other than for planned procedure)</td>
<td>Date entering hospital</td>
<td>NA</td>
<td></td>
</tr>
<tr>
<td>8.51</td>
<td>Date leaving hospital after FIFITH unplanned admission</td>
<td>Date of discharge</td>
<td>NA</td>
<td></td>
</tr>
<tr>
<td>8.52</td>
<td>Number of days in ICU during FIFTH admission</td>
<td>Total Days in ICU for this admission</td>
<td>NA</td>
<td></td>
</tr>
<tr>
<td>8.6</td>
<td>After the 5th unplanned admission, Additional number of unplanned admission</td>
<td>Total days hospitalized (after 5th unplanned admission)</td>
<td>NA</td>
<td></td>
</tr>
<tr>
<td>8.62</td>
<td>After 5th unplanned admission, additional total number of days in ICU</td>
<td>Total days in ICU (after 5th unplanned admission)</td>
<td>NA</td>
<td></td>
</tr>
<tr>
<td>8.8</td>
<td>Number of unplanned hospitalization days per patient</td>
<td>CMS OCM Model</td>
<td>Calculated by summing the data regarding hospitalizations</td>
<td>1.0 average</td>
</tr>
<tr>
<td>8.805</td>
<td>Number of hospital days for patients with supportive screening</td>
<td>Calculated</td>
<td>1.0 average</td>
<td></td>
</tr>
<tr>
<td>8.807</td>
<td>Number of hospital days after Palliative Receipt</td>
<td>Calculated</td>
<td>6.9 average</td>
<td></td>
</tr>
<tr>
<td>8.81</td>
<td>Number of Unplanned Hospitalizations</td>
<td>Calculated by counting number of hospitalizations</td>
<td>1.0 average</td>
<td></td>
</tr>
<tr>
<td>8.82</td>
<td>Stay 1 and 2 within 30 days of each other</td>
<td>Calculated: 8.2-8.11</td>
<td>1.0 average</td>
<td></td>
</tr>
<tr>
<td>8.83</td>
<td>Stay 2 and 3 within 30 days of each other</td>
<td>Calculated: 8.3-8.21</td>
<td>1.0 average</td>
<td></td>
</tr>
<tr>
<td>8.84</td>
<td>Stay 3 and 4 within 30 days of each other</td>
<td>Calculated: 8.4-8.31</td>
<td>1.0 average</td>
<td></td>
</tr>
<tr>
<td>8.85</td>
<td>Stay 4 and 5 within 30 days of each other</td>
<td>Calculated: 8.5-8.41</td>
<td>1.0 average</td>
<td></td>
</tr>
<tr>
<td>8.87</td>
<td>Number of stays within 30 days of each other</td>
<td>Count of “Y” (8.82:8.85)</td>
<td>1.0 average</td>
<td></td>
</tr>
<tr>
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</tr>
<tr>
<td>8.9</td>
<td>Number of unplanned ICU days per patient</td>
<td>CMS OCM Model</td>
<td>Calculated by summing ICU data</td>
<td>1.0 average</td>
</tr>
<tr>
<td>9.10</td>
<td>Number of known Emergency Department visits per patient</td>
<td>CMS OCM Model</td>
<td></td>
<td>1.0 average</td>
</tr>
<tr>
<td>9.105</td>
<td>ER visits for patients with supportive screening</td>
<td></td>
<td></td>
<td>3.13 average</td>
</tr>
<tr>
<td>9.11</td>
<td>Percentage of Emergency room visits at patient’s treating facility</td>
<td>CMS OCM Model</td>
<td></td>
<td>9.10 %</td>
</tr>
<tr>
<td>9.12</td>
<td>Percentage of Emergency room visits that end up with hospital admission</td>
<td>CMS OCM Model</td>
<td></td>
<td>9.10 %</td>
</tr>
</tbody>
</table>
The Coleman Supportive Oncology Collaborative developed courses on different aspects of supportive oncology. These courses are available at NCCN’s education portal. These courses were created by the clinicians of the collaborative and have been vetted by NCCN’s scientific review committee.

There are 14 courses (26 modules) available at no cost with CME for Physicians & Nurses. They are available on-line, on-demand. Each learner will need to setup their own login to access the training. The courses may be reached via the Supportive Oncology Collaborative website, or search in Google: “NCCN Supportive Oncology”

A certificate is generated upon completion. Log into https://education.nccn.org/, go to my account, select my activities, then can save a pdf of completed activities that may be submitted to licensing body. Physician, Nurse and Physician Assistant credit automatically available.

Course Titles and descriptions on the following 2 pages.
<table>
<thead>
<tr>
<th>Course Title</th>
<th>Modules Within</th>
<th>Objectives</th>
</tr>
</thead>
</table>
| Supportive oncology care and documenting patient’s supportive needs        | What is Supportive Oncology Care?                                               | 1. Define supportive oncology care and describe its role  
2. Explain the appropriate timing of supportive oncology care services, with a focus on distress screening  
3. Describe factors that may impact the needs of specific patient populations |
|                                                                            | Documenting Supportive Care needs and Referrals in a Patient’s Medical Records | 1. Explain the key components of supportive oncology care that should be tracked in medical records  
2. Contrast how care sites have implemented supportive oncology screening, results and referrals in Epic electronic health records.  
3. Describe how care sites have implemented and documented advance care planning in Cerner electronic health records |
| Distress: impact on care, screening for distress and addressing distress   | The Impact of Distress on Patient Care                                           | 1. Define stress, distress and depression  
2. Identify sources of distress and why it warrants screening  
3. Explain the impact of distress on cancer treatment and quality of life, and how to treat this distress |
|                                                                            | How to conduct a Supportive Oncology Screening (Including Distress)             | 1. Explain which guidelines and instruments inform various sections of the supportive oncology screening (distress) tool  
2. Describe the appropriate timing and frequency of the supportive oncology (distress) screening tool  
3. Discuss examples of how different healthcare organizations have used the supportive oncology (distress) screening tool |
|                                                                            | How to Address Patient Distress: Mild, Moderate and Severe, Using the Example of PHQ-4 Results | 1. Explain how to score and interpret distress screening, using the PHQ-4, in real time  
2. Identify the follow-up process for patients scoring with mild, moderate or severe depression and/or anxiety  
3. Employ urgent care needs for patients indicating immediate risk of harming them self or others |
| Patient’s practical and family concerns                                    | How to Discuss Practical and Family Concerns with Patients and Families          | 1. Communicate with patients and family members about common practical and family concerns  
2. Share and discuss resources available to patients reporting mild, moderate and severe levels of distress  
3. Describe the documentation needed to communicate your follow-up efforts |
| Cancer survivorship defined, identification of patient needs at survivorship visit and Commission on Cancer’s requirements for Survivorship Care Plans | What is survivorship?                                                           | 1. Define who is a cancer survivor  
2. Describe what is survivorship care  
3. Discuss trends of the survivorship population |
|                                                                            | How to Conduct a Screening of Patient Concerns and Distress at a Survivorship Appointment | 1. Describe which guidelines and instruments form the basis for the various sections of the Survivorship Appointment Tool  
2. Describe the appropriate timing for the administration of the Survivorship Appointment Tool  
3. Discuss examples of how the tool is being used and its impact on the survivorship appointment visit |
|                                                                            | Commission on Cancer Requirements for Survivorship Care Plan                    | 1. Identify the minimal data elements required by CoC Program Standard 3.3 to be included in cancer survivorship care plans  
2. Describe the process requirements of a survivorship care plan  
3. Summarize the timeline by which CoC-accredited institutions need to provide comprehensive care summaries and follow-up plans |
| Cancer survivor care                                                        | Comprehensive Care for Cancer Survivors                                           | 1. Explain what is comprehensive follow-up care for cancer survivors  
2. Describe common models of survivorship care  
3. Identify challenges of survivorship care |
|Survivorship factors: lifestyle and behavior, common psychosocial challenges and common late and long term effects | Lifestyle and Behavioral Factors                                                | 1. Explain why it is important for cancer survivors to achieve and maintain a healthy lifestyle following active treatment for cancer  
2. Restate what constitutes healthy lifestyle habits for survivorship  
3. Describe the benefits/risks of engaging in healthy lifestyle behaviors as part of cancer survivorship |
|                                                                            | Common Psychosocial Challenges of Survivors/Psychosocial Sequelae of Cancer     | 1. Identify common psychosocial experiences and concerns of cancer patients and survivors  
2. Understand experiences of depression, emotional distress and fear of cancer recurrence  
3. Recognize financial concerns and return to work and/or other roles |
|                                                                            | Common Late and Long Term Effects                                               | 1. Discuss the definition of late and long-term complication and effects of cancer treatments  
2. Describe the major categories in which the complications fall  
3. Explain common late and long-term complications |
|                                                                            | Prevention and Cancer Screening                                                 | 1. Discuss appropriate cancer screening  
2. Identify cancer prevention strategies |
<table>
<thead>
<tr>
<th>Course Title</th>
<th>Modules Within</th>
<th>Objectives</th>
</tr>
</thead>
</table>
| Cancer survivor screening and prevention strategies and genetic testing for  | Genetic Testing for Patients, Families and Survivors                            | 1. Identify the reasons for genetic counseling in a cancer survivor  
2. Describe the impact of a BRCA mutation on medical management of a cancer survivor  
3. Describe the impact of Lynch Syndrome on medical management of a cancer survivor |
| patients, families and survivors                                           |                                                                                |                                                                                                                                              |
| Pain assessment: the basics                                                | Pain Assessment: The Basics                                                    | 1. Differentiate different types of cancer pain  
2. Complete a thorough assessment of pain  
3. Identify and manage opioid side effects |
| Pain management: beyond the basics                                          | Pain Management: Beyond the Basics                                             | 1. Explain treatment options for pain management, including opioids and adjuvant pain medications  
2. Describe opioid pharmacology  
3. Discuss optimal dosing of opioids  
4. Convert from one opioid to another |
| How to communicate prognosis                                               | How to Communicate Prognosis                                                    | 1. Prepare for a conversation about prognosis by identifying and addressing important steps  
2. Identify barriers in communication of prognosis to patients and families  
3. Describe how to best communicate a prognosis, responding to patients’ understanding of their illness and identifying what is most important to them |
| Goals of care and advance care planning over time                          | Goals of Care                                                                  | 1. Define goals of care  
2. Adapt conversations and recommendations for a goals of care plan to a patient’s individual wishes and preferences, even when barriers exist  
3. Explain how and when to broach the subject of hospice care within a goals of care discussion |
| Advance Care Planning Over Time                                            | Advance Care Planning Over Time                                                | 1. Explain the components of an advance care planning discussion tailored to stages of health  
2. Describe the elements of an advance care plan based on a model of stages of change for health behaviors |
| POLST: Physician Orders for Life Sustaining Treatment Paradigm             | POLST Paradigm – Physician Orders for Life Sustaining Treatment Paradigm        | 1. Distinguish the relationship between an advance directive and the POLST (Practitioner Orders for Life- Sustaining Treatment) Form  
2. Identify patients who are appropriate to initiate a discussion about POLST  
3. Use the POLST form for creating actionable medical orders for ensuring seriously ill patient’s decisions about life-sustaining treatments are respected across settings of care (outpatient to hospital; hospital to home or nursing home) |
| Addressing symptoms that impact quality of life: nausea/vomiting,         | Nausea/Vomiting                                                                | 1. Identify common etiologies of nausea and vomiting in oncology patients  
2. Discuss how to prevent nausea and vomiting in patients prior to receiving high risk emetic chemotherapy  
3. Describe and evaluate etiology of nausea and vomiting  
4. Use pharmacologic and non-pharmacologic methods for managing nausea and vomiting |
| constipation, dyspnea & shortness of breath                                |                                                                                |                                                                                                                                              |
| Dyspnea & Shortness of Breath                                              |                                                                                | 1. Assess constipation in cancer patients  
2. Initiate treatment of constipation in cancer patients |
| Primary palliative care vs. specialized palliative care and reasons to     | Primary Palliative Care vs. Specialized Palliative Care                        | 1. Differentiate between supportive care, palliative care and hospice care  
2. Identify primary oncology team practices that are considered “primary palliative care”  
3. Compare palliative care provided by a primary oncology team to care provided by a palliative medicine specialist |
| refer to hospice and palliative care                                       |                                                                                |                                                                                                                                              |
| Reasons to refer to Hospice and Palliative Care                            | Reasons to refer to Hospice and Palliative Care                                | 1. Describe the basics of what a palliative care program provides  
2. Differentiate how an outpatient palliative care program differs from hospice  
3. Identify when to make an inpatient or outpatient palliative care or hospice referral  
4. Explain the basics of what hospice provides and when a patient is eligible for hospice care |
The CSOC and participating cancer centers identified the need for additional resources, identified reimbursement codes to support some supportive care encounters and also created templates for documenting specific aspects of care in their respective medical record systems.

Below is the list of included administrative resources that can be found on subsequent pages:

1. Sample Business Cases
   a) Social Workers
   b) Palliative Care Nurse
2. Reimbursement Codes
3. Care Plan Documentation Template
4. Oncology Nutrition Documentation Template
5. Advanced Care Planning and POLST Documentation Template
6. Accreditation Considerations
COC Accreditation Requirement for distress screening and provision of psychosocial care:

XXX is accredited by the Commission on Cancer (COC) as an Academic Comprehensive Cancer Program. As of January 1, 2015, COC standard 3.2 requires “on-site” psychosocial distress screening and referral for the provision of psychosocial care. Menhert, A., et al. (JCO 2014) found that 31.8% of cancer patients “met strict diagnostic criteria for mental disorders”.

Presently XXX is not in compliance with COC’s distress screening accreditation requirement—placing the valuable COC accreditation at risk.

XXX are piloting a distress screening protocol, and have increased referrals to Social Work services by XX%. This increase in Social Work service demand will continue to increase as distress screening is expanded to the rest of XXX Cancer Center patients and XXX achieves compliance with the COC accreditation standard.

The Role of Social Workers in Cancer Care:

Our under-resourced and vulnerable patient population has a high need for access to psychosocial support services, much higher than the 31.8% found by Menhert. Per the results of the Breast and Gyn pilot screening projects, approximately 63% of patients require Social Work intervention. Psychosocial services help alleviate patient distress, remove barriers to treatment, and increase patient compliance to their treatment plans.

Between the inpatient unit (8W) and outpatient MedOnc, SurgOnc, and RadOnc clinics, there are an insufficient 0.0 FTE XXX Social Workers shared among this high-needs population. These Social Workers provide in-depth psychosocial evaluation of patients identified as distressed; and then deliver cancer-specific resources, care coordination, and emotional counseling to the patient and their family throughout their lengthy cancer experience.

As it stands, our patients have limited access to onsite Social Workers and no access to Health Psychologists to provide critical short-term, solution-focused mental health care necessitated by the trauma of their cancer diagnosis. The high caseloads of our current XXX Social Workers inhibit their ability to deliver these types of individual and group therapies—though they are licensed and trained to do so. Recent cuts to the XXX eliminated this resource, and the limited number of insurance policies accepted at XXX Psychiatry nullifies this option for many. Currently most patients needing ongoing emotional support to enhance their ability to cope with cancer are referred to community mental health clinics. But this is not a solution as they face wait times of X-X months, and both state and federal cuts to these services are rising.

Our estimate is that there is a need for a total of X FTE of XXX Licensed Clinical Social Workers to provide this critical resource to XXX cancer patients, in order to adequately support their complex needs at pivotal points in care (e.g. diagnosis, treatment, survivorship or end of life).

Proposal:

We propose XXX hire X additional FTE Licensed Clinical Social Workers (LCSWs). These professionals hold masters degrees, are trained to provide therapeutic interventions, and can bill for their services. One or both of these new hires will be bilingual to meet the needs of XXX’s Spanish-only speaking population. Together this
A team of X LCSWs will ensure the XXX Cancer Center meets COC standards, and develop programming to ensure patients are properly supported in a cost efficient manner.

This is the model that many COC accredited cancer centers have successfully adopted, including some of our competitors. This type of care results in better patient outcomes, satisfaction scores, and reduces costly readmissions and failed appointments. The cost of these new LCSWs will require an annual investment of $Xk, which will be XX% recouped through billable revenue each year. The current XXX outpatient cancer Social Workers would also begin billing for their services to generate revenue that can further be used toward self-sustainability of these new LCSW positions.

**Direct Revenue:**

- There are between X to X new XXX cancer patients per year
- The rate of patients that need basic LCSW consult, using pilot data, is X% This consult can be billed as an assessment CPT96150, and required follow-up screenings at “pivotal points” can be billed as re-assessments under CPT96151.
- Estimate that half of the XX% (X% of total population) need intensive ongoing psychosocial services like individual therapy or crisis work. These can be billed under psych CPT90791, 90832-90849.
- With additional LCSWs we will have time to conduct support groups (billable as CPT96153 or 90853), so an additional number of both ‘basic’ and ‘intensive’ needs patients would generate this revenue as well.

**Total Net Savings:** There will be an approximate net loss each year of $X to hire X additional LCSWs (see appendix 1). However, this small loss will be more than made up for by indirect revenue from other outcomes positively associated with increased psychosocial support including:

- Improving clinical outcomes and patient experience
- Improving patient access to necessary mental health support services
- Reduction of readmissions
- Increased referrals to XXX’s outpatient palliative care clinic and/or other appropriate services
- Generating new patient referrals via word of mouth from satisfied patients
- A guarantee that XXX will maintain its COC accreditation and reputation as an Academic Comprehensive Cancer Program

**Appendix 1**

**Total Net Savings** = -$X

($18.19 x # of cancer patients x X% needing social work) for initial distress screening
+ 2($17.46 x # of cancer patients x X% needing social work) for f/u distress screenings
+ 2(10 x 12 x $21.46) for group therapies
+ 50% x (# of patients needing intensive therapy or crisis work x $16.37 + 5 x $16.73) for model group 1 in which pts receive 5 H&B interventions and 1/3 of the pts received an additional H&B intervention with family present
+ 50% x ((# of patients needing intensive therapy or crisis work x $113.86 + 1 x $109.13 + 5 x $72.75) for model group 2 in which ½ of pts receive 1 psych crisis intervention, and all pts receive a psych assessment for dx of “adjustment disorder” and 5 f/u psych therapy sessions
- $X cost of X LCSWs

*Based on 2016 CMS reimbursement rates for Health and Behavior (H&B) and Psych CPT codes
Sample Business Case for Palliative Care Nurse

Background

XXXX is rapidly adapting to meet the needs of our patients and changing financial incentives and quality reporting requirements. IN YYY, the ZZZZ team was launched to provide palliative care services to our hospitalized patients. It has been well received by staff, patients and hospital administration. An analysis of its impact in XXXX showed that by reducing readmissions, reducing in patient deaths and increasing hospice referrals the inpatient palliative team efforts have resulted in cost savings of $XXXX to the hospital with an operating cost of $XXXX.

According to a study by Banarto, et al. in 2004, 30% of all Medicare expenditures are attributed to the 5% of Medicare beneficiaries that die each year. 1/3 of this cost is during the last month of life. This is further described in a Forbes article from 2013: https://www.forbes.com/sites/michaelbell/2013/01/10/why-5-of-patients-create-50-of-health-care-costs/#6d7a502128d7

This is not sustainable for payors and thus they are now shifting much of this financial burden to hospital systems with various penalties and capitated payment arrangements. With continued changes in our payor mix, particularly the increasing number of patients with Medicaid Managed Care plans, the distinction between inpatient and outpatient encounters is blurring. Providing patients with access to high quality palliative support in outpatient settings, in addition to inpatient settings, is essential for our institution to thrive in the new healthcare environment.

The Role of Palliative Care:

Patient with high symptom burden and patients approaching end-of-life utilize a disproportionate percentage of resources, often with little benefit to the patients. The driving force for this unfortunate “overtreatment” of patients is largely a communication gap. Palliative care specialists offer a solution by taking extra time to fill this communication game. They assist patients in reaching acceptance and empowering patients to learn about alternative options that can enable them to optimize their quality of life.

Contrary to popular belief, providing palliative care services can actually prolong patients’ lives. This was illustrated with a randomized study published in 2010 in the New England Journal of Medicine (Temmel et al). Patients who were randomized to see a palliative care clinician early after being diagnosed with Stage IV lung cancer lived 2.7 months longer than those randomized to usual care. In the usual care arm of the study, patients received a palliative care visit later in their disease – closer to end of life. The early palliative group also had less depression, reported high quality of life, and received less aggressive end of life care.
Outpatient Palliative Care Need at XXX

Providing access to clinic-based palliative care is now a standard of care as per the World Health Organization and The National Comprehensive Cancer Network. It is also a requirement for all Comprehensive Cancer Centers. XXXX was providing limited palliative care consults (YY per week) in an outpatient setting, but had to stop this due to the hospital’s inpatient demand.

Proposal

Hire a palliative care nurse (or APN, or physician, or other) to join the supportive care team and provide palliative care consultations in an outpatient clinic. This resource will work closely with the inpatient palliative care team to ensure consistency in practice and to identify ways to support patients so they don’t end up inpatient. Suggest rotating this new resource every two weeks with a similar level inpatient resource to reduce burnout of both resources and to further ensure consistency of practice. The anticipated salary for this resource is between $xxx and $xxx annually, depending on years of service.

Direct Revenue:

A full time APN (fill in resource here) can do approximately 15 patient visits per week, billing 85% of what a physician can bill X 47 weeks or 705 patient visits per year. This would result in approximately $XXX,XXX per year in professional fees.

Cost Savings:

An outpatient nurse will impact a patient’s goal of care, including discussions about advance directives. It is anticipated that X% of patients will change their status from full code to DNR/DNI and Y% will decide to enroll in hospice. This reflects the impact that our inpatient palliative service has had on patients, with a similar expectation in the outpatient setting. These changes in a patient’s goals will lead to fewer readmissions and fewer full codes.

Total Net Savings:

Billing Rev + Cost Savings – Salary =
Reimbursement Codes

Background

With the shifting reimbursement and philanthropic landscape, it is important that cancer treatment sites receive reimbursement for essential supportive services. Our team has identified a set of billing codes (CPT / HCPCS) codes relevant to many essential supportive oncology care services. These codes were identified in partnership with The Coleman Supportive Oncology Collaborative (CSOC), input from experts in the area of reimbursement, and publicly available sources. Unfortunately some of these relevant, available codes may not be on your site’s current charge master. The following document will share information about each code, the source, any rules that we found and for some a template for medical record documentation of the care associated with the code. As you use this document and identify edits, additions, improvements please share with csoc@colemanfoundation.org. This document should be used for guidance only. Your site is responsible to follow the most current rules and regulations associated with billing and claims.

<table>
<thead>
<tr>
<th>HCPCS or CPT Code</th>
<th>Description</th>
<th>Estimated private payer payment, subject to each organization’s contract</th>
</tr>
</thead>
<tbody>
<tr>
<td>S0353</td>
<td>Treatment planning and care coordination management for cancer initial treatment</td>
<td>$ 277.00</td>
</tr>
</tbody>
</table>

| IL Medicaid*      | N/A                                                                            |
| Medicare, RVU; National Payment - Facility Price | Not in physician fee schedule                                                 |
| Scope of Practice | N/A                                                                            |

Additional Information: A treatment plan is a detailed outline of care composed of a list of problems including the cancer details, treatment goals, methods and estimated time necessary to achieve those goals. It may also include treatment side effects and the names and addresses of individual providers. The care coordination involves the organization and monitoring of the different treatment types or services outlined in the treatment plan.

Source: ** Physician’s Quality Reporting System tab on Optum360

Related Codes?: S0354, Treatment planning and care coordination management for cancer established patient with a change of regimen, estimated private payer payment $42

Medical Record documentation: See care plan documentation template that aligns with National Academy of Medicine’s IOM Care plan checklist, which is required by Medicare’s Oncology Care Model (OCM)
### Health Risk Assessment (Supportive Oncology Screening) Code

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<thead>
<tr>
<th>HCPCS or CPT Code</th>
<th>96160</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Description</strong></td>
<td>Administration and interpretation of health risk assessment instrument (e.g., health hazard appraisal) (Replaces 99420)</td>
</tr>
<tr>
<td><strong>Estimated private payer payment</strong>, subject to each organization's contract</td>
<td>$7.38</td>
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<tr>
<td><strong>IL Medicaid</strong> max rate, no 2.7% reduction</td>
<td>$14.60</td>
</tr>
<tr>
<td><strong>Medicare, RVU; National Payment - Facility Price</strong></td>
<td>Work RVU - 0, Transitioned non-FAC PE RVU 0.13; $4.67</td>
</tr>
<tr>
<td><strong>Scope of Practice</strong></td>
<td>Health Risk Assessment (HRA)</td>
</tr>
<tr>
<td><strong>What is the required documentation?</strong></td>
<td>A provision in the Patient Protection and Affordable Care Act of 2010 (ACA) established a Medicare Wellness Visit, which included a Health Risk Assessment (HRA) and customized wellness or prevention plan. HRAs are typically completed by a patient or caregiver prior to the encounter with a physician or other qualified health care professional, but can involve the assistance of the clinician and/or staff members. The HRA tool is purposefully designed to be brief, straightforward, and easy to comprehend with questions such as patient demographic information, personal and/or family history, a self-assessment of how the patient interprets his/her health to be, risk factors, biometric measurements, and compliance. Completion of the HRA tool takes approximately 20 minutes and may be done via the internet or on a paper-based document. Code includes scoring and documentation of the assessment tool.</td>
</tr>
<tr>
<td><strong>Source</strong></td>
<td>Optum 360</td>
</tr>
<tr>
<td><strong>Related Codes?</strong></td>
<td>96161, health risk assessment tool is given to the caregiver for the benefit of the patient, $7.38 estimated private payer; $0 Medicaid; Medicare: Work RVU - 0, Transitioned non-FAC PE RVU 0.13; $4.67</td>
</tr>
<tr>
<td><strong>Medical Record documentation</strong></td>
<td>See screening tool, which may be setup as an EMR form/template or scanned into EMR after patient completes</td>
</tr>
<tr>
<td>HCPCS or CPT Code</td>
<td>97802</td>
</tr>
<tr>
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</tr>
<tr>
<td><strong>Description</strong></td>
<td>Medical nutrition therapy; initial assessment and intervention, individual, face-to-face with the patient, each 15 minutes</td>
</tr>
<tr>
<td><strong>Estimated private payer payment</strong>, subject to each organization’s contract</td>
<td>$39.25</td>
</tr>
<tr>
<td><strong>IL Medicaid</strong> max rate, no 2.7% reduction</td>
<td>listed, no value</td>
</tr>
<tr>
<td><strong>Medicare, RVU; National Payment - Facility Price</strong></td>
<td>Work RVU - 0.53; $33.02 - note for Medicare may only work for patients that have diabetes</td>
</tr>
<tr>
<td><strong>Scope of Practice</strong></td>
<td>RN Service, LPN Service, CHIROPRACTIC SERVICES, NUTRITIONIST, CERTIFIED DIABETIC EDUCATOR, CERTIFIED NURSE PRACTITIONER, CERTIFIED NURSE SPECIALIST</td>
</tr>
<tr>
<td><strong>What is the required documentation?</strong></td>
<td>NOTE - FOR CMS, this code IS ONLY for patients with diabetes, renal disease, or kidney transplant (in previous 3 years).</td>
</tr>
<tr>
<td><strong>Additional Information</strong></td>
<td>&quot;Physicians and other qualified health care professionals who may report evaluation and management services should use the appropriate evaluation and management codes.&quot; (Professional Edition CPT Current Procedural Terminology 2017, 671) Excludes medical nutrition therapy assessment/intervention provided by physician or other qualified health care provider; use appropriate E&amp;M codes</td>
</tr>
<tr>
<td><strong>Source</strong></td>
<td>Optum 360 &amp; CPT</td>
</tr>
<tr>
<td><strong>Related Codes?</strong></td>
<td>97803, Medical nutrition therapy; re-assessment and intervention, individual, face-to-face with the patient, each 15 minutes. Estimated private payers $34.15, $31.37 Mod 26; no value for Medicaid; Medicare Work RVU -.45, $27.99</td>
</tr>
<tr>
<td><strong>Medical Record documentation</strong></td>
<td><em>Nutrition documentation template</em> that aligns with American Dietetic Association Oncology Tool Kit</td>
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<tr>
<td><strong>Nutrition Code</strong></td>
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<tr>
<td><strong>HCPCS or CPT Code</strong></td>
<td>97804</td>
</tr>
<tr>
<td><strong>Description</strong></td>
<td>Medical nutrition therapy; group (2 or more individual(s)), each 30 minutes</td>
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<tr>
<td><strong>Estimated private payer payment, subject to each organization’s contract</strong></td>
<td>$18.05, $17.25 -mod 26</td>
</tr>
<tr>
<td><strong>IL Medicaid</strong></td>
<td>max rate, no 2.7% reduction</td>
</tr>
<tr>
<td><strong>Medicare, RVU; National Payment - Facility Price</strong></td>
<td>Work RVU - 0.25; $15.43</td>
</tr>
<tr>
<td><strong>Scope of Practice</strong></td>
<td>RN Service, LPN Service, CHIROPRACTIC SERVICES, NUTRITIONIST, CERTIFIED DIABETIC EDUCATOR, CERTIFIED NURSE PRACTITIONER, CERTIFIED NURSE SPECIALIST</td>
</tr>
<tr>
<td><strong>What is the required documentation?</strong></td>
<td>NOTE - FOR CMS, this code IS ONLY for patients with diabetes, renal disease, or kidney transplant (in previous 3 years).</td>
</tr>
<tr>
<td><strong>Additional Information</strong></td>
<td>&quot;Physicians and other qualified health care professionals who may report evaluation and management services should use the appropriate evaluation and management codes.&quot; (Professional Edition CPT Current Procedural Terminology 2017, 671)</td>
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<tr>
<td><strong>Source</strong></td>
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<td><strong>Related Codes?</strong></td>
<td>Nutrition documentation that aligns with American Dietetic Association Oncology Tool Kit</td>
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<tr>
<td><strong>Medical Record documentation</strong></td>
<td></td>
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</tbody>
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## Nutrition Codes

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<th>HCPCS or CPT Code</th>
<th>S9470</th>
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</thead>
<tbody>
<tr>
<td><strong>Description</strong></td>
<td>Nutritional counseling, dietitian visit</td>
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<tr>
<td><strong>Estimated private payer payment</strong></td>
<td>$100 Flat Amount</td>
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<tr>
<td><strong>IL Medicaid</strong></td>
<td>max rate, no 2.7% reduction</td>
</tr>
<tr>
<td><strong>Medicare, RVU; National Payment - Facility Price</strong></td>
<td>not in physician fee schedule</td>
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<tr>
<td><strong>Scope of Practice</strong></td>
<td>NUTRITIONIST, CERTIFIED DIABETIC EDUCATOR, CERTIFIED NURSE PRACTITIONER IL, CERTIFIED NURSE SPECIALIST</td>
</tr>
<tr>
<td><strong>Medical Record documentation</strong></td>
<td>Nutrition documentation template that aligns with American Dietetic Association Oncology Tool Kit</td>
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</tbody>
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<table>
<thead>
<tr>
<th>HCPCS or CPT Code</th>
<th>G0270</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Description</strong></td>
<td>Medical nutrition therapy; reassessment and subsequent intervention(s) following second referral in same year for change in diagnosis, medical condition or treatment regimen (including additional hours needed for renal disease), individual, face to face with the patient, each 15 minutes</td>
</tr>
<tr>
<td><strong>Estimated private payer payment</strong></td>
<td>$34.15, $31.37 -Mod 26</td>
</tr>
<tr>
<td><strong>IL Medicaid</strong></td>
<td>listed, no value</td>
</tr>
<tr>
<td><strong>Medicare, RVU; National Payment - Facility Price</strong></td>
<td>0.45 Work RVUs; $27.99</td>
</tr>
<tr>
<td><strong>Scope of Practice</strong></td>
<td>CHIROPRACTIC SERVICES, Certified Nurse Practitioner, Certified Nurse Specialist</td>
</tr>
<tr>
<td><strong>What is the required documentation?</strong></td>
<td>NOTE - FOR CMS, this code IS ONLY for patients with diabetes, renal disease, or kidney transplant (in previous 3 years).</td>
</tr>
<tr>
<td><strong>Additional Information</strong></td>
<td>&quot;The G codes are used to identify professional health care procedures and services that would otherwise be coded in CPT but for which there are no CPT codes. Please refer to your CPT book for possible alternate code(s).&quot; (2017 HCPCS Level II, 41)</td>
</tr>
<tr>
<td><strong>Source</strong></td>
<td>HCPCS Level II</td>
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<td><strong>Related Codes?</strong></td>
<td>G0271, Medical nutrition therapy, reassessment and subsequent intervention(s) following second referral in same year for change in diagnosis, medical condition, or treatment regimen (including additional hours needed for renal disease), group (2 or more individuals), each 30 minutes. Private Payer: $18.05, $17.25 -Mod 26; Medicaid: listed, no value; Medicare: 0.25 Work RVUs; $15.43</td>
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<tr>
<td><strong>Medical Record documentation</strong></td>
<td>See Appendix 3 for documentation template that aligns with American Dietetic Association Oncology Tool Kit</td>
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<td>HCPCS or CPT Code</td>
<td>98960</td>
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<tr>
<td>-------------------</td>
<td>------</td>
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<tr>
<td>Description</td>
<td>Education and training for patient self-management by a qualified, non-physician health care professional using a standardized curriculum, face-to-face with the patient (could include caregiver/family) each 30 minutes; individual patient</td>
</tr>
<tr>
<td>Estimated private payer payment, subject to each organization’s contract</td>
<td>$ 32.93</td>
</tr>
<tr>
<td>IL Medicaid*</td>
<td>NA</td>
</tr>
<tr>
<td>Medicare, RVU; National Payment - Facility Price</td>
<td>not in physician fee schedule</td>
</tr>
<tr>
<td>Scope of Practice</td>
<td>REGISTERED PHYSICAL THERAPY PROCEDURE, CHIROPRACTIC SERVICES, NUTRITIONIST, CERTIFIED DIABETIC EDUCATOR, CERTIFIED NURSE PRACTITIONER, CERTIFIED NURSE SPECIALIST</td>
</tr>
<tr>
<td>What is the required documentation?</td>
<td>&quot;Education and training for patient self-management may be reported with these codes only when using a standardized curriculum. This curriculum may be modified as necessary for the clinical needs, cultural norms and health literacy of the individual patient(s).&quot; (Professional Edition CPT Current Procedural Terminology 2016, 660)</td>
</tr>
<tr>
<td>Additional Information</td>
<td>INCLUDES: Education/training services: Prescribed by a physician or other qualified health care professional Provided by a qualified non-physician health care provider Standardized curriculum that may be modified as necessary for: Clinical needs Cultural norms Health literacy Teaching the patient how to manage the illness/delay the comorbidity(s) EXCLUDES: Genetic counseling education services (96040, 98961-98962) Health/behavior assessment (96150-96155) Medical nutrition therapy (97802-97804) The following services: Counseling/education to a group (99078) Counseling/education to individuals (99201-99215, 99217-99223 [99224, 99225, 99226], 99231-99233, 99241-99255, 99281-99285, 99304-99318, 99324-99337, 99341-99350, 99401-99429) Counseling/risk factor reduction without symptoms/established disease (99401-99412)</td>
</tr>
</tbody>
</table>
Office Consultation New or Established Patient Code - requires 3 key components

<table>
<thead>
<tr>
<th>HCPCS or CPT Code</th>
<th>99241</th>
</tr>
</thead>
<tbody>
<tr>
<td>Description</td>
<td>Office consultation for a new or established patient, which requires these 3 key components: <strong>Counseling and/or coordination of care</strong> with other physicians, other qualified health care professionals, or agencies are provided consistent with the nature of the problem(s) and the patient's and/or family's needs. Typically, 15 minutes are spent face-to-face with the patient and/or family.</td>
</tr>
<tr>
<td>Estimated private payer payment, subject to each organization's contract</td>
<td>$47.19 $29.24 -mod 26</td>
</tr>
<tr>
<td>IL Medicaid* max rate, no 2.7% reduction</td>
<td>32.15; add on adult 7.04</td>
</tr>
<tr>
<td>Medicare, RVU; National Payment - Facility Price</td>
<td>not in physician fee schedule</td>
</tr>
<tr>
<td>Scope of Practice</td>
<td>CHIROPRACTIC SERVICES, Managed Care Psych, NUTRITIONIST, CERTIFIED NURSE MIDWIFE, CERTIFIED NURSE PRACTITIONER, CERTIFIED NURSE SPECIALIST</td>
</tr>
<tr>
<td>What is the required documentation?</td>
<td>N/A</td>
</tr>
<tr>
<td>INCLUDED:</td>
<td>A third-party mandated consultation</td>
</tr>
<tr>
<td></td>
<td>All outpatient consultations provided in the office, outpatient or other ambulatory facility, domiciliary/rest home, emergency department, patient's home, and hospital observation</td>
</tr>
<tr>
<td></td>
<td>Documentation of a request for a consultation from an appropriate source</td>
</tr>
<tr>
<td></td>
<td>Documentation of the need for consultation in the patient’s medical record</td>
</tr>
<tr>
<td></td>
<td>One consultation per consultant</td>
</tr>
<tr>
<td></td>
<td>Provision by a physician or qualified non-physician practitioner (consultant) whose advice, opinion, recommendation, suggestion, direction, or counsel, etc., is requested for evaluating/treating a patient since said individual’s expertise in a specific medical area is beyond the scope of knowledge of the requesting physician.</td>
</tr>
<tr>
<td></td>
<td>Provision of a written report of findings/recommendations from the consultant to the referring physician.</td>
</tr>
<tr>
<td>EXCLUDED:</td>
<td>Another appropriately requested and documented consultation pertaining to the same/new problem; repeat use of consultation codes.</td>
</tr>
<tr>
<td></td>
<td>Any distinctly recognizable procedure/service provided on or following the consultation.</td>
</tr>
<tr>
<td></td>
<td>Assumption of care (all or partial); report subsequent codes as appropriate for the place of service (99211-99215, 99334-99337, 99347-99350)</td>
</tr>
<tr>
<td></td>
<td>Consultation prompted by the patient/family; report codes for office, domiciliary/rest home, or home visits instead (99201-99215, 99324-99337, 99341-99350)</td>
</tr>
<tr>
<td></td>
<td>Services provided to Medicare patients; E&amp;M code as appropriate for the place of service or HCPCS code (99221-99223, 99231-99233, G0406-G0408, G0425-G0427)</td>
</tr>
</tbody>
</table>

Source CMS.gov & Optum 360

Related Codes? 99492 for 30 minutes: private payer $80.09, $56.63 – mod 26; Medicaid 40.20, add on adult 32.71; Medicare not on physician fee schedule. 99243 – 40 minutes; 99244 – 60 minutes; 99245 – 80 minutes.
## Advance Care Planning Code

<table>
<thead>
<tr>
<th>HCPCS or CPT Code</th>
<th>99497</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Description</strong></td>
<td>Advance care planning including the explanation and discussion of advance directives such as standard forms (with completion of such forms, when performed), by the physician or other qualified health care professional; first 30 minutes, face-to-face with the patient, family member(s), and/or surrogate</td>
</tr>
<tr>
<td><strong>Estimated private payer payment</strong>, subject to each organization's contract</td>
<td>$50.00</td>
</tr>
<tr>
<td><strong>IL Medicaid</strong> max rate, no 2.7% reduction</td>
<td>NA</td>
</tr>
<tr>
<td><strong>Medicare, RVU; National Payment - Facility Price</strong></td>
<td>1.5 Work RVUs; $77.88</td>
</tr>
<tr>
<td><strong>Scope of Practice</strong></td>
<td>Physician (MD/DO), Certified Nurse Practitioner, Certified Nurse Specialist</td>
</tr>
<tr>
<td><strong>What is the required documentation?</strong></td>
<td>Suggested by P. Rodgers: document brief summary of the voluntary conversation; reflect and justify length/complexity of conversation; who was present including patient; start/stop time or total time in minutes; note if forms were completed, no diagnosis requirements, but if serious illness is in documentation, it should be reported in claim.</td>
</tr>
<tr>
<td><strong>Additional Information</strong></td>
<td>Excludes Critical care services (99291-99292, 99468-99469, 99471-99472, 99475-99476, 99477-99480)</td>
</tr>
<tr>
<td></td>
<td>Excludes Treatment/management for an active problem (see appropriate E&amp;M service)</td>
</tr>
<tr>
<td></td>
<td>We have a ppt from AAPHM with more detail: &quot;may include: discussion of goals and preferences for care; complex medical decision making regarding life-threatening or life-limiting illness; explanation of relevant advance directives - including but not requiring completion of advance directives; Engaging patients, family members and/or surrogate decision makers as clinical situation requires&quot; - from AAPHM presentation from Phil Rodgers MD FAAHPM U of Michigan</td>
</tr>
<tr>
<td><strong>Source</strong></td>
<td>Optum 360</td>
</tr>
<tr>
<td><strong>Related Codes?</strong></td>
<td>99498 for each additional 30 minutes (List separately in addition to code for primary procedure): private payer $40, $40 mod 26; Medicaid NA; Medicare 1.4 Work RVUs, $72.50</td>
</tr>
<tr>
<td><strong>Medical Record documentation</strong></td>
<td>See documentation template for Advance Care Planning and POLST</td>
</tr>
<tr>
<td>HCPCS or CPT Code</td>
<td>G0337</td>
</tr>
<tr>
<td>------------------</td>
<td>-------</td>
</tr>
<tr>
<td><strong>Description</strong></td>
<td>HOSPICE EVALUATION AND COUNSELING SERVICES, PRE-ELECTION</td>
</tr>
<tr>
<td><strong>Estimated private payer payment, subject to each organization’s contract</strong></td>
<td>$93.06</td>
</tr>
<tr>
<td><em><em>IL Medicaid</em> max rate, no 2.7% reduction</em>*</td>
<td>N/A</td>
</tr>
<tr>
<td><strong>Medicare, RVU; National Payment - Facility Price</strong></td>
<td>not in physician fee schedule</td>
</tr>
<tr>
<td><strong>Scope of Practice</strong></td>
<td>RN Service, Certified Nurse Practitioner, Certified Nurse Specialist</td>
</tr>
<tr>
<td><strong>What is the required documentation?</strong></td>
<td>N/A</td>
</tr>
<tr>
<td><strong>Additional Information</strong></td>
<td>Excludes Critical care services (99291-99292, 99468-99469, 99471-99472, 99475-99476, 99477-99480) Excludes Treatment/management for an active problem (see appropriate E&amp;M service)</td>
</tr>
<tr>
<td><strong>Source</strong></td>
<td>Optum 360</td>
</tr>
<tr>
<td><strong>Related Codes?</strong></td>
<td>Medical Record documentation</td>
</tr>
<tr>
<td><strong>Medical Record documentation</strong></td>
<td>You may want to use template in Appendix 4; minimally the section reviewing patient’s wishes</td>
</tr>
</tbody>
</table>
## Care Coordination Medical Conference – Interdisciplinary with Managed Care Psych Code

<table>
<thead>
<tr>
<th>HCPCS or CPT Code</th>
<th>S0220</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Description</strong></td>
<td>Medical conference by a physician with interdisciplinary team of health professionals or representatives of community agencies to coordinate activities of patient care (patient is present); approximately 30 minutes</td>
</tr>
<tr>
<td><strong>Estimated private payer payment</strong></td>
<td>$62.63 $61.12 -Mod 26</td>
</tr>
<tr>
<td>subject to each organization’s contract</td>
<td></td>
</tr>
<tr>
<td><strong>IL Medicaid</strong></td>
<td>N/A</td>
</tr>
<tr>
<td>max rate, no 2.7% reduction</td>
<td></td>
</tr>
<tr>
<td><strong>Medicare, RVU; National Payment</strong></td>
<td>not in physician fee schedule</td>
</tr>
<tr>
<td>- Facility Price</td>
<td></td>
</tr>
<tr>
<td><strong>Scope of Practice</strong></td>
<td>Managed Care Psych</td>
</tr>
<tr>
<td><strong>What is the required documentation?</strong></td>
<td>N/A</td>
</tr>
<tr>
<td><strong>Additional Information</strong></td>
<td>&quot;The S codes are used by the Blue Cross/Blue Shield Association (BCBSA) and the Health Insurance Association of America (HIAA) to report drugs, services, and supplies for which there are no national codes but for which codes are needed by the private sector to implement policies, programs, or claims processing. They are for the purpose of meeting the particular needs of the private sector. These codes are also used by the Medicaid program, but they are not payable by Medicare.&quot; (2017 HCPCS Level II, 135)</td>
</tr>
<tr>
<td><strong>Source</strong></td>
<td>HCPCS Level II</td>
</tr>
<tr>
<td><strong>Related Codes?</strong></td>
<td>S0221 for approximately 60 minutes, Private payer $82.49</td>
</tr>
<tr>
<td><strong>Medical Record documentation</strong></td>
<td></td>
</tr>
</tbody>
</table>
### Licensed Clinical Social Work Counseling – Individual Code

<table>
<thead>
<tr>
<th>HCPCS or CPT Code</th>
<th>CPT 90791, 90832-90849.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Description</strong></td>
<td>Individual therapy or crisis work can be billed under psych</td>
</tr>
<tr>
<td><strong>Estimated private payer payment</strong>, subject to each organization’s contract</td>
<td>?</td>
</tr>
<tr>
<td><strong>IL Medicaid</strong> max rate, no 2.7% reduction</td>
<td>90791- $70; 90832- $29.48; 90833-$24.62; 90834- $88.40; 90836- $40.24; 90837- 133.42; 90838- $64.64; 90839- $66.71; 90847- $61.20; 90849- $61.20</td>
</tr>
<tr>
<td><strong>Medicare, RVU; National Payment - Facility Price</strong></td>
<td>90791- ~$124; 90832- ~$63; 90833- ~$66; 90834- ~$84.70; 90836- ~$83.62; 90837- 127.40; 90838- $110.54; 90839- $132.79; 90847- $106.59; 90849- $31.58</td>
</tr>
</tbody>
</table>

### Scope of Practice

**What is the required documentation?**

**Additional Information**

<table>
<thead>
<tr>
<th><strong>Source</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Related Codes?</strong></td>
<td>Medical Record documentation</td>
</tr>
<tr>
<td><strong>Medical Record documentation</strong></td>
<td></td>
</tr>
</tbody>
</table>

### Licensed Clinical Social Work Counseling – Group Therapy Code

<table>
<thead>
<tr>
<th>HCPCS or CPT Code</th>
<th>96153 or 90853</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Description</strong></td>
<td>Group psychotherapy</td>
</tr>
<tr>
<td><strong>Estimated private payer payment</strong>, subject to each organization’s contract</td>
<td>?</td>
</tr>
<tr>
<td><strong>IL Medicaid</strong> max rate, no 2.7% reduction</td>
<td>Not listed for 96143, $33.70 for 90853</td>
</tr>
<tr>
<td><strong>Medicare, RVU; National Payment - Facility Price</strong></td>
<td>$4.67 96153, $25.48 for 90853</td>
</tr>
</tbody>
</table>
## Care Plan Documentation Template

<table>
<thead>
<tr>
<th>Date: <em>(calendar)</em></th>
<th>Cancer Type <em>(link to ICD10 – list)</em></th>
<th>Cancer Stage <em>(create drop down)</em></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Molecular/Biological Information</strong> <em>(free text field that can be imported into note)</em></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chemotherapy Consent signed</td>
<td>☐ Yes → <em>select the date</em></td>
<td>☐ No</td>
</tr>
<tr>
<td>Prognosis</td>
<td>☐ <em>Days to Weeks</em></td>
<td>☐ <em>Weeks to Months</em></td>
</tr>
<tr>
<td>All Planned Treatment for Patient</td>
<td>Type of Treatment</td>
<td>Physician Name</td>
</tr>
<tr>
<td>☐ <em>Chemotherapy</em></td>
<td></td>
<td></td>
</tr>
<tr>
<td>☐ <em>Chemoradiotherapy</em></td>
<td></td>
<td></td>
</tr>
<tr>
<td>☐ <em>Radiation therapy</em></td>
<td></td>
<td></td>
</tr>
<tr>
<td>☐ <em>Surgery</em></td>
<td></td>
<td></td>
</tr>
<tr>
<td>☐ <em>Endocrine Therapy</em></td>
<td></td>
<td></td>
</tr>
<tr>
<td>☐ <em>Immunotherapy</em></td>
<td></td>
<td></td>
</tr>
<tr>
<td>☐ <em>Psychosocial</em></td>
<td></td>
<td></td>
</tr>
<tr>
<td>☐ <em>Other 1 (free text field)</em></td>
<td></td>
<td></td>
</tr>
<tr>
<td>☐ <em>Other 2 (free text field)</em></td>
<td></td>
<td></td>
</tr>
<tr>
<td>☐ <em>Other 3 (free text field)</em></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Treatment Benefits and Harms</strong> <em>(free text field that can be imported into note)</em></td>
<td></td>
<td></td>
</tr>
<tr>
<td>common and rare toxicities and how to manage these toxicities, as well as short-term and late effects of treatment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Quality of Life Discussed</td>
<td>☐ Yes</td>
<td>☐ No</td>
</tr>
<tr>
<td>Does Treatment Conform to National Guidelines or is Treatment on a Clinical Trial</td>
<td>☐ Yes</td>
<td>☐ No</td>
</tr>
<tr>
<td>Expected Response to Therapy</td>
<td>☐ <em>n/a -Adjuvant or Neoadjuvant Therapy</em></td>
<td>☐ <em>Complete Response</em></td>
</tr>
<tr>
<td>Advance Care Plans Discussed</td>
<td>☐ <em>Yes, Advanced Care Plan Note Completed</em></td>
<td>☐ <em>Yes, Advanced Care Plan Note in EMR</em></td>
</tr>
<tr>
<td>Health Care Power of Attorney Documented</td>
<td>☐ <em>Yes, copy in EMR [need standard place to track]</em></td>
<td>☐ <em>Yes, patient shared verbally and documented in EMR</em></td>
</tr>
<tr>
<td>Plan to address psychosocial health needs in place? <em>(psychological, vocational, disability, legal or financial concerns and their management)</em></td>
<td>☐ Yes</td>
<td>☐ No</td>
</tr>
</tbody>
</table>
Note: this is adapted from the ©2010 American Dietetic Association Oncology Toolkit

Date: ____________________

Patient MRN: ______________

Patient DOB: ______________

Start time _____ Stop Time _____ Total time _____

Who participated in appointment, in addition to patient:

**Assessment**

Patient concern or complaint (Info provided by patient, family, or other)

Patient Height_______ Weight_____ Usual Weight ______ Body Mass Index_______

**Patient symptoms / concerns**

<table>
<thead>
<tr>
<th>Concern?</th>
<th>Concern / Symptom:</th>
<th>Text to pull in:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Dry Mouth (xerostomia)</td>
<td>Amount of saliva, how much water / fluid daily?, daily tooth brushing, flossing, oral thrush</td>
</tr>
<tr>
<td></td>
<td>Weight Loss</td>
<td>Weight before diagnosis: Current weight: % current weight/weight before</td>
</tr>
<tr>
<td></td>
<td>Anorexia</td>
<td>Taste issues, feeling full / early satiety, nausea, depression</td>
</tr>
<tr>
<td></td>
<td>Nausea</td>
<td>When happens, what triggers nausea, how often, for how long</td>
</tr>
<tr>
<td></td>
<td>Vomiting</td>
<td>Taking any anti-nausea medications? How often</td>
</tr>
<tr>
<td></td>
<td>Diarrhea</td>
<td># of watery stools / day, describe stools</td>
</tr>
<tr>
<td></td>
<td>Hyperglycemia</td>
<td>Cause: steroids, other medications</td>
</tr>
<tr>
<td></td>
<td>Dysphagia</td>
<td>Swallow evaluation done? Solid foods vs. beverages</td>
</tr>
<tr>
<td></td>
<td>Constipation</td>
<td>History of diet, amount of fiber, supplements, fluid daily? Medications</td>
</tr>
<tr>
<td></td>
<td>Esophagitis</td>
<td>Related to radiation treatment field? Mediastinal nodes?</td>
</tr>
<tr>
<td></td>
<td>Heartburn</td>
<td>Location of tumor/pressure, size of meals, frequency, position after eating</td>
</tr>
<tr>
<td></td>
<td>Stomatitis / Mucositis</td>
<td>Pain meds currently being taken, cause</td>
</tr>
<tr>
<td></td>
<td>Taste Changes</td>
<td>When did they start, seasonal allergies / sinus problems, history of alcohol use, possible zinc deficiency</td>
</tr>
</tbody>
</table>
**Relevant Medical History**
PEG tube – if placed, what date? Pre-treatment (yes or no)
Relevant surgeries, and dates.
Physical findings related to nutrition: muscle mass, functional activity, dental status
Relevant labs, tests, procedures, date, results
Current medications: name, dosage, reason for med
Dietary or Herbal supplements, Homeopathic medications: names, amount/day, purpose, within limits

**Nutritional and Support**
Patient living situation: lives alone, lives with family, skilled nursing facility, assisted living, other: 
________

TEXT: usual eating pattern: cooking, dining out, ________________, who shops for 
groceries______________, prepares meals______________, fills 
prescriptions______________________________  
Does cost of food impact food choices? ________________, food assistance needed? ________________  
Level of physical activity and type of work: ________________________________
Estimated nutritional needs: Total energy expenditure (TEE): _______ (RMR x PhNysical Activity Level); 
Protein ______________g; Fluid ________________ml
Nutrient intake: oral, enteral, parenteral
Calorie intake: _____kcal (not enough, appropriate, too much)
Protein intake: _______g (not enough, appropriate, too much)
Fluid intake: _____ml (not enough, appropriate, too much)
% fat intake: _______% (not enough, appropriate, too much)
Medical food supplements: Name______, % of intake
Nutrition Diagnosis: intake, clinical, behavioral-environmental with details ________ related to (etiology) 
________as evidenced by _____ (symptoms, concerns)

**Plan**
What do you recommend or plan to do to address the nutrition diagnoses?
Recommend change in food-nutrient delivery (supplement, change in diet, nutrition support, vitamin-mineral supplement) (NI)
Nutrition education (E)
Nutrition counseling (C)
Coordination of nutrition care (RC)
Monitoring and evaluation (follow up plan):
Materials provided to patient:
What will you monitor to determine if the nutrition intervention was successful?
Advanced Care Planning and POLST Documentation Template

<table>
<thead>
<tr>
<th>Date:</th>
<th>Start Time:</th>
<th>Stop Time:</th>
<th>Total time spent:</th>
</tr>
</thead>
</table>

**Who was present at encounter/discussion:**

- **Name**
  - Patient
  - Physician
  - Social Worker
  - Chaplain
  - APN/PA/Mid Level Provider
  - RN
  - House Staff
  - Family member(s) and relationship to patient
  - Other

---

If not decisional, move to Section 2 to invoke IL Health Care Surrogate Act or Section 3 for existing advance directive

**Section 1- Patient is decisional**

Patient designated decision maker for future healthcare decisions when patient unable to make decision

Name ______________________________ Phone _______________________________
Address ______________________________ Email _______________________________
Relationship to patient _____________________________________________________________

(q) Power of attorney for healthcare form completed? __________________________________________

(q) Verbal decision as noted above

_Upon completing Section 1 - skip to section 3 Advance care planning discussion_

**Section 2- Patient is not decisional, invoking IL Health Care Surrogate Act**

This section is completed when a patient lacks decisional capacity. The following information is required to be completed under the Illinois Health Care Surrogate Act and in accordance with hospital policy.

Patient needs to meet one of these conditions:  
- [ ] Terminal
- [ ] Permanent Unconsciousness
- [ ] Irreversible

(q) I have determined the patient is not decisional

(q) The patient does not have an applicable advance care directive

(q) The following physician has also determined that the patient lacks decision-making capacity:  XXXXX

(q) I have informed the patient of their lack of capacity to make decisions and the designation of a surrogate to make decisions and to the extent of the surrogate’s authority to make decisions:  Note if any objections by patient XXXXX

(q) Identify appropriate surrogate in accordance with following priority order

- [ ] Patient’s guardian
- [ ] Patient’s spouse or partner of a registered civil union
- [ ] Adult child
- [ ] Parent
- [ ] Adult sibling
- [ ] A close friend of the patient (complete Affidavit)
- [ ] Adult grandchild
- [ ] The patient’s guardian of the estate

(q) (Surrogate name: Relationship; address; phone number): __________________________________
Section 3- Advance Care Plan Discussion

- Patient/Legal Representative understanding of illness (including prognostic understanding):

- Prior experience with serious illness with family or friends:

- Patient’s hopes or important goals or upcoming events to achieve for their remaining time or legal representative's hopes/goals for patient:

- Patient’s worries or fears about the future or legal representative’s concerns for the patient [Uncontrolled pain or suffering, burdening family, loss of control/being dependent, finances, other]

- Information provided to patient/legal representative about prognosis: ___yes ____ no ___declined
  FREE TEXT; Hours to days, days to weeks, weeks to months, months to years, years plus, uncertain

Section 4- Code Status: Practitioner Orders for Life-Sustaining Treatment (POLST)

- POLST Form reviewed ___ yes ___ no
- POLST Form completed ___ yes ___ no
- Copy of POLST Form retained for EMR ___ yes ___ no
- Practitioner Orders for Life-Sustaining Treatment (based on patient/legal representative understanding and clarification of gaps in understanding and prognosis). Below reflects Section A and Section B of POLST Form:
  - Full Code –Attempt CPR, including Full Treatment (intubation) to prolong life, including all life-sustaining interventions
  - DNR –Full Treatment-(Intubation will occur in the event of respiratory failure, but chest compressions will not be performed in the event of cardiac arrest).
  - DNR-Selective Treatment (No Intubation, but accepts selected interventions: IV fluids and IV medications (may include antibiotics or vasopressors) as medically appropriate; less invasive airway support, (CPAP, BiPAP); dialysis or blood products, as indicated.
  - DNR-Comfort-focused Treatment–Relieve pain and suffering through the use of medication by any route as needed, and oxygen as relates to comfort.
- Optional Additional Orders: (i.e. indicate if time-limited trial of intubation or if accepts tracheostomy and long term ventilation).
  - ________________________________

- Medically Administered (Artificial) Nutrition: (Optional to complete) Offer food by mouth as feasible and desired
  - Long-term medically administered (artificial) nutrition by tube, as indicated
  - Trial period of medically administered (artificial) nutrition by tube
  - No medically administered (artificial) nutrition by tube
  - Not addressed
Accreditation Considerations

Making improvements in supportive oncology is wonderful for your patients and for your organization. It results in higher quality and literature shows that providing proper supportive care may lead to cost reductions. Many sites that participate in the Coleman Supportive Oncology Collaborative have conducted quality improvement projects, that support their accreditation requirements, using content from this tool kit. To qualify for an accreditation quality improvement, there must be evidence of an issue using data, an improvement made and then evidence of the impact of the improvement, using data.

Here are a few examples.

- Implementing improvements to supportive oncology and distress screening, using the Coleman Supportive Oncology Screening Tool (CSOC-ST). Site tracked their screening rate; expanded screening using the CSOC-ST, and tracked improved screening rate.
- Implementing improved referrals using the follow up reference documents. This site tracked their current referral rates to several supportive services: Social Work, Nutrition, Palliative Care, spiritual care, and physical therapy. Then they implemented an improved process based on follow up reference documents. They tracked the results and associated impact on references to supportive services.
- Improving supportive services screening through training the workforce. This site wanted to increase their rate of screening, they measured their current screening rate. Then they required the cancer center staff to take specific Coleman NCCN courses to increase their understanding of why supportive screening is needed and what the process is. After the education was done, they put expanded supportive services screening in place. The staff at this site insisted that all patients receive supportive screening, as they learned about the importance of this during the training. The site measured the improvement in screening rate.

Appreciation

Thank you to the over 200 healthcare professionals who contributed to the creation, development, and testing of tools and resources for service delivery to help improve cancer care and help patients achieve the best possible outcome.