Palliative Care
Family Caregiver
Education

City of Hope
# Palliative Care Family Caregiver Education
## Table of Contents

## I. Domain 1: Physical Well Being: Family Caregivers

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction</td>
<td>D1/CG-3</td>
</tr>
<tr>
<td>Distress Thermometer</td>
<td>D1/CG-4</td>
</tr>
<tr>
<td>List of Symptoms</td>
<td>D1/CG-4</td>
</tr>
<tr>
<td>General Information on Caring for the Patient’s Physical Symptoms</td>
<td>D1/CG-5</td>
</tr>
<tr>
<td>Breathing Problems and Cough</td>
<td>D1/CG-7</td>
</tr>
<tr>
<td>Pain</td>
<td>D1/CG-8</td>
</tr>
<tr>
<td>Constipation</td>
<td>D1/CG-9</td>
</tr>
<tr>
<td>Fatigue</td>
<td>D1/CG-9</td>
</tr>
<tr>
<td>Sleep Problems</td>
<td>D1/CG-10</td>
</tr>
<tr>
<td>Nausea and Vomiting</td>
<td>D1/CG-10</td>
</tr>
<tr>
<td>Appetite Problems/Weight Loss</td>
<td>D1/CG-11</td>
</tr>
<tr>
<td>Skin, Nail, Hair Changes</td>
<td>D1/CG-11</td>
</tr>
<tr>
<td>Diarrhea</td>
<td>D1/CG-12</td>
</tr>
<tr>
<td>Information on How to Quit Smoking</td>
<td>D1/CG-13</td>
</tr>
<tr>
<td>Physical Well Being Self-Care Plan</td>
<td>D1/CG-14</td>
</tr>
<tr>
<td>Caring for Your Own Health Needs</td>
<td>D1/CG-13</td>
</tr>
<tr>
<td>Developing a Self-Care Plan</td>
<td>D1/CG-17</td>
</tr>
<tr>
<td>Resources for Physical Well Being</td>
<td>D1/CG-19</td>
</tr>
<tr>
<td>Foods that are High in Calories or Protein</td>
<td>D1/CG-19</td>
</tr>
<tr>
<td>Foods that are Easy on a Sore Mouth</td>
<td>D1/CG-20</td>
</tr>
<tr>
<td>Liquid Foods</td>
<td>D1/CG-21</td>
</tr>
<tr>
<td>Foods and Drinks that are Easy on the Stomach</td>
<td>D1/CG-23</td>
</tr>
<tr>
<td>Yakima Fruit Paste Recipe</td>
<td>D1/CG-24</td>
</tr>
<tr>
<td>Pursed Lip Breathing</td>
<td>D1/CG-25</td>
</tr>
<tr>
<td>Breathing: Relaxation Exercises</td>
<td>D1/CG-26</td>
</tr>
<tr>
<td>Bowel Regimen for Constipation</td>
<td>D1/CG-27</td>
</tr>
</tbody>
</table>

## II. Domain 2: Psychological Well Being: Family Caregivers

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction</td>
<td>D2/CG-2</td>
</tr>
<tr>
<td>Distress Thermometer</td>
<td>D2/CG-3</td>
</tr>
<tr>
<td>List of Topics</td>
<td>D2/CG-3</td>
</tr>
<tr>
<td>General Information on Caring for the Patient’s Emotional Needs</td>
<td>D2/CG-4</td>
</tr>
<tr>
<td>Worry and Fear</td>
<td>D2/CG-6</td>
</tr>
<tr>
<td>Depression</td>
<td>D2/CG-6</td>
</tr>
<tr>
<td>Anger</td>
<td>D2/CG-7</td>
</tr>
<tr>
<td>Cognitive Changes</td>
<td>D2/CG-7</td>
</tr>
<tr>
<td>Psychological Well Being Self-Care Plan</td>
<td>D2/CG-7</td>
</tr>
<tr>
<td>Caring for Your Own Emotional Needs</td>
<td>D2/CG-8</td>
</tr>
<tr>
<td>Refining Your Self-Care Plan</td>
<td>D2/CG-10</td>
</tr>
<tr>
<td>Resources</td>
<td>D2/CG-12</td>
</tr>
<tr>
<td>Relaxation Techniques and Mind/Body Practices</td>
<td>D2/CG-12</td>
</tr>
</tbody>
</table>
III. Domain 3: Social Well Being: Family Caregivers

Introduction.........................................................................................................D3/CG-2
Distress Thermometer ......................................................................................D3/CG-3
List of Topics ......................................................................................................D3/CG-3
General Information on Caring for the Patient’s Social Concerns ..............D3/CG-4
Changes with Relationships ............................................................................D3/CG-5
Communication ..................................................................................................D3/CG-6
Sexual Changes ..................................................................................................D3/CG-6
Social Support .....................................................................................................D3/CG-7
Financial Burdens ..............................................................................................D3/CG-7
Healthcare Planning ..........................................................................................D3/CG-8
Social Well Being Self-Care Plan ....................................................................D3/CG-9
Caring for Your Own Social Needs .................................................................D3/CG-9
Refining Your Self-Care Plan ..........................................................................D3/CG-11
Resources ............................................................................................................D3/CG-13
Cancer Resource List .........................................................................................D3/CG-18

IV. Domain 4: Spiritual Well Being: Family Caregivers

Introduction.........................................................................................................D4/CG-2
Distress Thermometer ......................................................................................D4/CG-3
List of Topics ......................................................................................................D4/CG-3
General Information on Caring for the Patient’s Spiritual Concerns ..........D4/CG-4
Purpose and Meaning in Life ...........................................................................D4/CG-6
Hope ....................................................................................................................D4/CG-6
Redefining Self and Priorities in Life ...............................................................D4/CG-7
Inner Strength ....................................................................................................D4/CG-7
Uncertainty ..........................................................................................................D4/CG-8
Positive Changes ...............................................................................................D4/CG-8
Spiritual Well Being Self-Care Plan .................................................................D4/CG-9
Caring for Your Own Spiritual Needs .............................................................D4/CG-9
Refining Your Self-Care Plan ..........................................................................D4/CG-11
Resources ............................................................................................................D4/CG-14
List of Books and Websites ..............................................................................D4/CG-14

V. Guide for Patients & Families.............................................................................R1
Domain 1- Physical Well Being: Family Caregiver
# Domain 1- Physical Well Being: Family Caregiver

## Table of Contents for Domain 1- Physical Well Being

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>I. Introduction</td>
<td>D1CG-3</td>
</tr>
<tr>
<td>II. Distress Thermometer</td>
<td>D1CG-4</td>
</tr>
<tr>
<td>III. List of Symptoms</td>
<td>D1CG-4</td>
</tr>
<tr>
<td>IV. General Information on Caring for the Patient’s Physical Symptoms</td>
<td>D1CG-5</td>
</tr>
<tr>
<td>V. Breathing Problems and Cough</td>
<td>D1CG-7</td>
</tr>
<tr>
<td>VI. Pain</td>
<td>D1CG-8</td>
</tr>
<tr>
<td>VII. Constipation</td>
<td>D1CG-9</td>
</tr>
<tr>
<td>VIII. Fatigue</td>
<td>D1CG-9</td>
</tr>
<tr>
<td>IX. Sleep Problems</td>
<td>D1CG-10</td>
</tr>
<tr>
<td>X. Nausea and Vomiting</td>
<td>D1CG-10</td>
</tr>
<tr>
<td>XI. Appetite Problems/Weight Loss</td>
<td>D1CG-11</td>
</tr>
<tr>
<td>XII. Skin, Nail, Hair Changes</td>
<td>D1CG-11</td>
</tr>
<tr>
<td>XIII. Diarrhea</td>
<td>D1CG-12</td>
</tr>
<tr>
<td>XIV. Information on How to Quit Smoking</td>
<td>D1CG-13</td>
</tr>
<tr>
<td>XV. Self-Care Plan</td>
<td>D1CG-14</td>
</tr>
<tr>
<td>XVI. Foods/Drinks High in Calories or Protein</td>
<td>D1CG-19</td>
</tr>
<tr>
<td>XVII. Foods That Are Easy on a Sore Mouth</td>
<td>D1CG-20</td>
</tr>
<tr>
<td>XVIII. Liquid Foods</td>
<td>D1CG-21</td>
</tr>
<tr>
<td>XIX. Foods/Drinks That Are Easy on the Stomach</td>
<td>D1CG-23</td>
</tr>
<tr>
<td>XX. Yakima Fruit Paste Recipe</td>
<td>D1CG-24</td>
</tr>
<tr>
<td>XXI. Pursed Lip Breathing</td>
<td>D1CG-25</td>
</tr>
</tbody>
</table>
XXII. Breathing: Relaxation Exercises .................................................................D1CG-26

XXIII. Bowel Regimen for Constipation .............................................................D1CG-27
Domain 1- Physical Well Being: Family Caregiver

Domain 1 Introduction

People with lung cancer often have symptoms that are a result of their cancer and/or treatments. Physical well-being and quality of life are affected by the physical symptoms that your loved one experiences. This session is also about how your physical needs affect your quality of life as a cancer caregiver. Some of your physical health needs as a caregiver may be new, and some you may have had for a longer time. It is important to make sure that all of your physical needs are addressed so that you are able to take part fully in your activities as a caregiver.

In this session, we will review some of the more common physical symptoms faced by your loved one with lung cancer. We will talk about how you can help your loved one manage his/her physical symptoms. We will also talk about common physical health needs that you may experience as a cancer caregiver. We will talk about developing a self-care plan so that you can take good care of yourself too. At the end of the session, we will give you some resources that can help you be better prepared to care for you and your loved one’s health needs. In each of our next sessions, we will continue to work together to develop your own comprehensive self-care plan.

In each of our sessions we will begin by asking you to give us some information about how you and your loved one are coping with lung cancer. Over the last two weeks ---

1. Have you noticed any changes in your loved one’s ability to function?
   - Bathing
   - Dressing
   - Walking
   - Mental status

2. Are you providing more or less personal care for your loved one?
   - More
   - Less
   - Same

3. What are the current goals of care or treatment plan for your loved one?
Domain 1 - Physical Well Being: Family Caregiver

Next, we would like you to rate your level of distress as a caregiver. This helps us to know overall how you are coping with your loved one’s lung cancer and your role as a caregiver. Using the thermometer below, please rate the number (0=no distress, 10=extreme distress) that best describes the overall distress you are feeling now.

![Thermometer Image]

My overall distress _______

It would be helpful if you would tell us what physical well-being topics you would like to learn about during today’s session. We find that asking you to identify which physical topics are most important makes the teaching more relevant to your personal needs as a cancer caregiver.

Below is a list of physical well-being topics that are common for patients who face lung cancer. Please pick three topics that you would like to learn about in today’s session. Your choices will help guide the content that we will cover for this session.

- [ ] Breathing Problems and Cough (pg. 7)
- [ ] Pain (pg. 8)
- [ ] Constipation (pg. 9)
- [ ] Fatigue (pg. 9)
- [ ] Sleep Problems (pg. 10)
- [ ] Nausea and Vomiting (pg. 10)
- [ ] Appetite Problems/Weight Loss (pg. 11)
- [ ] Skin, Nail, Hair Changes (pg. 11)
Domain 1- Physical Well Being: Family Caregiver

GENERAL INFORMATION ON CARING FOR THE PATIENT’S PHYSICAL SYMPTOMS

Key things to know:
- As a family caregiver, you may find yourself working closely with the health care team, doing things like:
  - Managing medicines
  - Managing side effects
  - Reporting physical problems
  - Helping to coordinate your loved one’s care
  - Keeping track of prescriptions, know which tests are to be done, and make sure all involved doctors know what is going on
  - Learning how to provide proper physical care

Tips to help care for your loved one’s physical symptoms:
- Help your loved one keep track of his/her symptoms. Call the doctor/nurse practitioner if:
  - The symptom is new or getting worse
  - The symptom keeps your loved one from doing his/her everyday activities
- Keep track of the following:
  - When the symptom started
  - What makes the symptom better/worse
  - How long the symptom lasts
- Report the following right away to the doctor/nurse practitioner if your loved one experiences the following:
  - Hasn’t been able to eat or drink for the last 24 hours
  - Has a change in mental status, such as sleeping more or more restless
  - Develops a fever of greater than 101° or 38.5°, or chills
  - Has diarrhea or loose stools for more than 24 hours
  - Has no bowel movement or stool for more than 3 days
  - Has extreme fatigue or inability to get out of bed for the last 24 hours
  - Begins bleeding, especially bright red that is uncontrolled
- Help your loved one keep track of his/her medicines. Call the doctor/nurse practitioner if you:
  - Have questions about how your loved one should take his/her medicine
  - Have problems getting your loved one’s medicine
- Keep a calendar or notebook that includes all your loved one’s medical appointments, test results, medications and dosages, symptoms and side effects, new questions between appointments, and names and numbers for resources
- Help with medicine management. Refill all medicines before the last dose to avoid running out
Domain 1- Physical Well Being: Family Caregiver

- Monitor your loved one for any changes in condition, such as worsening physical (i.e. increase in pain) or functional status (i.e. decreased ability to care for self)
- When your loved one is struggling with severe symptoms, do not leave him or her alone. Try to stay calm and contact the doctor right away
- Take an active role in your loved one’s medical care. If possible, go with them to medical appointments
- Coach and support prescribed diet, activity level, sleep, and any supportive therapies such as pursed lip breathing or relaxation
- Maintain a clean and safe home environment. Call your doctor/nurse practitioner if you need any assistive devices, such as a walker at home
- If your loved one requires physical care—such as bathing, dressing, feeding, using the toilet, and grooming—consider talking to your doctor/nurse practitioner.
- Allow plenty of time for daily activities. Plan ahead. Do not rush yourself or your loved one
- Support your loved one’s treatment decisions, even if you may be in a position to share decision-making
- Think about finding support in your role as a caregiver. These include outside resources, such as friends, other family members, or paying for outside help.
Domain 1- Physical Well Being: Family Caregiver

BREATHING PROBLEMS AND COUGH

Caregiver tips:

❖ Supportive care professionals that can help:
  • Pulmonary rehabilitation doctor
  • Physical/occupational therapist
  • Palliative care team
  • Your oncologist

❖ Help your loved one keep track of his/her breathing problems or cough. Call the doctor/nurse practitioner if:
  • The symptoms are new or getting worse
  • The symptoms keep your loved one from doing his/her everyday activities

❖ When your loved one is struggling with severe breathing problems or cough, do not leave him or her alone. Try to stay calm and contact the doctor right away

❖ Help your loved one practice breathing techniques, such as pursed lip breathing (pg. 37) or relaxation exercises (pg. 38)

❖ Help your loved one keep track of his/her medicines. Refill all medicines before the last dose to avoid running out

❖ Use cough medicine if prescribed. Be aware that medications with codeine may cause constipation or nausea

❖ Use oxygen if prescribed

❖ Encourage your loved one drink enough fluids

❖ Elevate head off bed

❖ Use a humidifier

❖ Use a fan
Domain 1- Physical Well Being: Family Caregiver

PAIN

Caregiver tips:

- Supportive care professionals that can help:
  - Palliative care team
- Help your loved one keep track of his/her pain and pain medicines. Call the doctor/nurse practitioner if:
  - Pain is new or getting worse
  - Pain keeps your loved one from doing his/her everyday activities
- Encourage your loved one to communicate their pain with you and others by rating it using a 0-10 scale (0 = no pain to 10 = worst pain)
- If your loved one is taking opioids (morphine-like medicines), help them with the following:
  - Do not stop taking opioids suddenly (may cause withdrawal symptoms like agitation, anxiety, sweating, vomiting, diarrhea)
  - Take pain medicines as prescribed.
  - Help your loved one keep track of common side effects of opioids, such as constipation or feeling sleepy. Make sure that your loved one is taking stool softeners and/or laxatives daily
  - Physical therapy may be able to help if the pain is musculoskeletal by nature when stretching or strengthening can help

Help with medicine management. Refill all medicines before the last dose to avoid running out. Please note: opioids (morphine-like medicines) cannot be called in to the pharmacy. Allow 3-4 days for the prescription to be mailed to your home.
Domain 1- Physical Well Being: Family Caregiver

CONSTIPATION

Caregiver tips:
- Supportive care professionals that can help:
  - Palliative care team
- Help your loved one keep track of his/her constipation. Call the doctor/nurse practitioner practitioner if:
  - Constipation is new, getting worse, or is associated with nausea, vomiting, or belly pain
- Make sure that your loved one is using a bowel regimen (stool softener or laxative) on a daily basis (see patient notebook)
- Encourage your loved one to drink enough fluids and eat foods high in fiber (see patient notebook)
- Encourage your loved one to stay as active as possible. Go on walks with your loved one on a daily basis if you are both able to
- Help your loved one keep track of his/her medicines. Refill all medicines before the last dose to avoid running out

FATIGUE

Caregiver tips:
- Supportive care professionals that can help:
  - Physical/occupational therapist
  - Psychologist/Psychiatrist
  - Dietitian
  - Palliative care team
- Help your loved one keep track of his/her fatigue. Call the doctor/nurse practitioner if:
  - Fatigue is new or getting worse
  - Fatigue keeps your loved one from doing his/her everyday activities
- Encourage your loved one to communicate their fatigue with you by rating it using a 0-10 scale (0 = no fatigue to 10 = worst fatigue)
- Help your loved one to conserve energy by prioritizing daily activities
- Encourage your loved one to stay active and eat well
Domain 1- Physical Well Being: Family Caregiver

SLEEP PROBLEMS

Caregiver tips:
- Supportive care professionals that can help:
  - Physical therapist
  - Psychologist/Psychiatrist
  - Palliative care team
- Help your loved one keep track of his/her sleep problems. Call the doctor/nurse practitioner if:
  - Sleep problems are new or getting worse
  - Sleep problems keep your loved one from doing his/her everyday activities
- Encourage your loved one to stay active
- Encourage your loved one to use the bed only for sleeping
- Help your loved one keep track of his/her medicines. Refill all medicines before the last dose to avoid running out

NAUSEA AND VOMITING

Caregiver tips:
- Supportive care professionals that can help:
  - Dietitian
  - Palliative care team
- Help your loved one keep track of his/her nausea and vomiting. Call the doctor/nurse practitioner if:
  - Nausea/vomiting is new or getting worse despite taking medications
  - Nausea/vomiting keeps your loved one from doing his/her everyday activities
- Take medications as prescribed
  - Taking medication on a schedule helps to prevent nausea from getting out of control
- Help your loved one follow nutrition tips, like eating small, frequent meals, drinking enough fluids, and eating foods that are easy on the stomach
- Help your loved one keep track of his/her medicines. Refill all medicines before the last dose to avoid running out
- Please see resource page (see patient notebook) for foods easy on the stomach
Domain 1- Physical Well Being: Family Caregiver

APPETITE PROBLEMS/WEIGHT LOSS

Caregiver tips:
- Supportive care professionals that can help:
  • Dietitian
  • Psychologist/Psychiatrist
  • Palliative care team
- Help your loved one keep track of his/her appetite problems or weight loss. Call the doctor/nurse practitioner if:
  • Appetite problems are new or getting worse
  • Appetite problems keep your loved one from doing his/her everyday activities
- Help your loved one keep their weight stable, especially if he/she is receiving chemotherapy
- Encourage your loved one to stay active. Small amount of physical activity before meals can help increase appetite (i.e. walking)
- Help your loved one with cooking and nutrition tips, such as eating small frequent meals
- Help your loved one keep track of his/her medicines. Refill all medicines before the last dose to avoid running out

SKIN, NAIL, HAIR CHANGES

Caregiver tips:
- Supportive care professionals that can help
- Look Good Feel Better
  American Cancer Society
  (800) 227-2345
  http://lookgoodfeelbetter.org/
- Help your loved one keep track of his/her skin/nail problems. Call the doctor/nurse practitioner if:
  • Skin/nail problems are new or getting worse such as rashes or thinning nails
  • Skin/nail problems keep your loved one from doing his/her everyday activities
- Help your loved one keep track of his/her medicines. Refill all medicines before the last dose to avoid running out
Domain 1- Physical Well Being: Family Caregiver

DIARRHEA

Caregiver tips:

- Supportive care professionals that can help:
  - Palliative care team
- Help your loved one keep track of his/her diarrhea. Call the doctor/nurse practitioner practitioner if:
  - Diarrhea is new, getting worse, or is associated with a puffy or bloated abdomen.
- Check with the doctor before using any over the counter medicine. Many of these may contain compounds that are like aspirin, which can worsen bleeding problems.
- Encourage your loved one to eat frequent small meals, avoiding spicy foods and citrus drinks as they may stimulate/irritate the digestive tract.
- Help your loved one keep track of his/her medicines. Refill all medicines before the last dose to avoid running out.
- Notify the doctor if your loved one has a fever.
- If you are providing personal care, make sure the anal area is kept clean and a water-repellent cream, such as A&D ointment can be applied to the area.
Domain 1- Physical Well Being: Family Caregiver

Information on How to Quit Smoking

What to do if you would like to quit smoking:

❖ Resources for quitting:
  • http://smokefree.gov/
  • http://women.smokefree.gov/
  • Kaiser Permanente Wellness Coaching- Quitting Smoking (866) 862-4295 https://healthy.kaiserpermanente.org

The Research Nurse can provide these materials to you
Domain 1- Physical Well Being: Family Caregiver

CARING FOR YOUR OWN HEALTH NEEDS

Key things to know:

- You may find yourself so busy and concerned about your loved one that you don't pay attention to your own physical health
- It is very important that you take care of your health. Taking care of yourself will give you strength to help others
- Here are some changes caregivers often have:
  - Fatigue (feeling excessively tired)
  - Weaker immune system (poor ability to fight off illness)
  - Sleep problems
  - Higher blood pressure
  - Changes in appetite or weight
  - Frequent headaches
- New stresses and daily demands often add to any health problems you may already have. And if you are sick or have an injury, it's even more important that you take care of yourself
- If you have medical conditions, such as heart disease, it is very important for you to see your doctor regularly for check-ups and to take any medicines as prescribed
- Even if you have no medical conditions, it is important to follow routine medical and dental follow-ups
- The stress of caregiving can lead some people to develop or increase unhealthy habits, such as smoking, or drinking too much alcohol
- Maintaining a healthy lifestyle, such as exercising, eating a healthy diet, and getting enough sleep, can help you with completing your tasks as a cancer caregiver. The benefits of exercise and a good diet include the following:
  - Improves your mood, relationships, and social activities
  - Improves your quality of life
  - Increases energy
  - Improves heart health, blood pressure, physical function, and balance
  - Improves attention and focus
  - Improves your ability to manage stress
  - Improves immune system
  - Improves blood sugar control
  - Increases bone strength
  - Improves sleep quality

How to talk about your own health needs:

- Make sure that any medical conditions that you may have are being followed by a doctor. Call your doctor if:
  - You have any symptoms that are new or getting worse
  - You have any symptoms that are keeping you from doing your activities as a caregiver
Domain 1 - Physical Well Being: Family Caregiver

- You have any symptoms that are bothering you
- If you cannot make it to a doctor’s appointment, call your doctor’s office and re-schedule the appointment.

Self-care tips:

- Make sure that you keep track of your medicines. Follow directions when taking any medicines. Call your doctor if you:
  - Have questions about how you should take your medicine
  - Have problems getting your medicines
- Keep a calendar or notebook that includes all your medical appointments, test results, medications and dosages, new questions between appointments, and names and numbers for resources
- Stay as active as possible
  - Talk to your doctor before starting any exercise regimen
  - Identify an activity that you enjoy, such as bicycling or swimming
  - Design an individualized exercise plan. Set reasonable goals to achieve everyday, and build on those goals. For example, start with 5-10 minutes three times a week then gradually increase as your time and stamina allow
  - Work at your own pace. Only do what you can. Never push beyond your limits
  - Think about doing your exercise activity with a friend or pet
- Maintain a healthy diet
  - Try to get your nutrients from foods instead of from supplements
  - Check with your doctor for any food or diet restrictions
  - Choose a variety of foods from all the food groups. Try to eat at least 5 to 7 servings a day of fruits and vegetables, including citrus fruits and dark-green and deep-yellow vegetables
- Make sure you get enough sleep. Use the following tips below to help:
  - Sleep hygiene methods:
    - No coffee, tea, chocolate, or soft drinks before bed
    - No exercising 2-4 hours before bed
    - Sleep in dark, cool, quiet, and relaxing rooms
    - Use bedtime rituals that comfort you (i.e. warm milk before bed, warm baths, soothing music)
    - Use bed only for sleep and intimacy
    - Try to go to bed at the same time each night
- Recognize the signs of stress:
  - Continual exhaustion or fatigue
  - Frequent sickness
  - Inadequate sleep
  - Impatience
  - Irritability
  - Forgetfulness
Domain 1- Physical Well Being: Family Caregiver

- Inability to enjoy activities
- Withdrawing from people
- Maintain routine medical follow-ups
  - Yearly physical exams
  - All recommended cancer screening tests, such as colonoscopy, mammograms
  - Dental exam
  - Vision exam
- Make time for yourself and other relationships. Spending time doing something you enjoy can help give you a much-needed break so you can remain an effective caregiver. It is also important to spend time with other people who are important to you so that you can maintain those supportive relationships
- Reduce stress by using meditation and relaxation
- Consider quitting smoking. Seek help from smoking cessation programs (see pg. 21)
- Ask family/friends for help if you have trouble doing your everyday activities
- Maintain a clean and safe home environment
- Allow plenty of time for daily activities. Plan ahead. Do not rush yourself
- Think about finding support as a caregiver. These include outside resources, such as friends, other family members, or paying for outside help
- Join a caregiver support group
Domain 1- Physical Well Being: Family Caregiver

DEVELOPING A SELF-CARE PLAN

Key things to know:
- As a caregiver you need to balance caring for your loved one while keeping up with the needs of family and your own needs
- The patient’s needs are important; however it is essential for you to stay in tune with the things you need to maintain your health and quality of life
- One of the ways to take care of yourself is to make a self-care plan
- Using your self-care plan will help improve your ability to cope as you deal with the many responsibilities in your caregiving role

Designing your own self-care plan:
- In today’s session, we will begin to design an individualized self-care plan for you as a caregiver for an individual with lung cancer. We will start today by focusing on your physical well-being. In the next three sessions we will discuss the other three quality of life domains, which include psychological, social, and spiritual well-being. We will have time during each session to revise and refine your self-care plan as needed

Assessment:
- To begin, let’s do some simple assessments
- First, let’s review some of the common potential physical stressors for cancer caregivers

<table>
<thead>
<tr>
<th>Potential Caregiver Stressors:</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Physical Well Being</strong></td>
</tr>
<tr>
<td>• Fatigue/lack of sleep</td>
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<tr>
<td>• Physical stress</td>
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<tr>
<td>• Neglecting your own health needs</td>
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<tr>
<td>• Not eating/poor nutrition</td>
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<tr>
<td>• Other</td>
</tr>
</tbody>
</table>

- Next, let’s discuss some of the strengths that you bring to your role as a caregiver. What are some of your personal strengths related to caring for your loved one’s physical symptoms?
- Now, let’s explore your current coping strategies. What types of strategies have worked for you in the past to help address your own physical/medical conditions?
- Let’s also discuss your current self-care strategies for meeting your physical/medical needs. What have you done successfully in the past to take care of yourself physically?

Intention statement:
- Before beginning to write your self-care plan, let’s work on writing an intention statement about what you want to achieve and what is important to you
Domain 1 - Physical Well Being: Family Caregiver

- This is more like a “goal statement” about self-care
- Example of an intention statement: “I want to stay healthy, have more energy, and feel calmer so that I can continue with my caregiving responsibilities”

**Your physical well-being self-care plan:**
- Using the information that we talked about today during this session, write at least one strategy you will use in the next week to help manage your physical health needs
- Include how often you will do it, and what support or resources you will need in order to do it
- Make it a realistic strategy, and be as specific as you can
- Physical well-being strategies: sleeping, walking, stretching, getting a massage, yoga, gardening, diet, schedule an annual physical with your doctor
## Domain 1- Physical Well Being: Family Caregiver

### Foods and Drinks That Are High in Calories or Protein

<table>
<thead>
<tr>
<th>Type</th>
<th>Examples</th>
</tr>
</thead>
</table>
| **Soups**                     | Cream soups  
|                               | Soups with lentils, dried peas, or beans (such as pinto, black, red,  
|                               | or kidney)                                                               |
| **Drinks**                    | Instant breakfast drinks  
|                               | Milkshakes  
|                               | Smoothies  
|                               | Whole milk                                                               |
| **Main meals and other**      | Beef  
| foods                         | Butter, margarine, or oil added to your food  
|                               | Cheese  
|                               | Chicken  
|                               | Cooked dried peas and beans (such as pinto, black, red, or kidney)  
|                               | Cottage cheese  
|                               | Cream cheese  
|                               | Croissants  
|                               | Deviled ham  
|                               | Eggs  
|                               | Fish  
|                               | Nuts, seeds, and wheat germ  
|                               | Peanut butter  
|                               | Sour cream                                                               |
| **Sweets**                    | Custards (soft or baked)  
|                               | Frozen yogurt  
|                               | Ice cream  
|                               | Muffins  
|                               | Pudding  
|                               | Yogurt (plain or vanilla)                                                |
| **Replacements and**          | Liquid meal replacements  
| supplements                   | Powdered milk added to foods such as pudding, milkshakes, and  
|                               | scrambled eggs                                                           |
## Domain 1 - Physical Well Being: Family Caregiver

### Foods That Are Easy on a Sore Mouth

<table>
<thead>
<tr>
<th>Type</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Main meals and other foods</td>
<td>Baby food</td>
</tr>
<tr>
<td></td>
<td>Cooked refined cereals</td>
</tr>
<tr>
<td></td>
<td>Cottage cheese</td>
</tr>
<tr>
<td></td>
<td>Eggs (scrambled)</td>
</tr>
<tr>
<td></td>
<td>Macaroni and cheese</td>
</tr>
<tr>
<td></td>
<td>Mashed potatoes</td>
</tr>
<tr>
<td></td>
<td>Pureed cooked foods</td>
</tr>
<tr>
<td></td>
<td>Soups</td>
</tr>
<tr>
<td></td>
<td>All foods softened with gravies or sauces</td>
</tr>
<tr>
<td>Sweets</td>
<td>Custards</td>
</tr>
<tr>
<td></td>
<td>Fruit (pureed or baby food)</td>
</tr>
<tr>
<td></td>
<td>Gelatin</td>
</tr>
<tr>
<td></td>
<td>Ice cream</td>
</tr>
<tr>
<td></td>
<td>Milkshakes</td>
</tr>
<tr>
<td></td>
<td>Puddings</td>
</tr>
<tr>
<td></td>
<td>Smoothies</td>
</tr>
<tr>
<td></td>
<td>Soft fruits (bananas and applesauce)</td>
</tr>
<tr>
<td></td>
<td>Yogurt (plain or vanilla)</td>
</tr>
<tr>
<td>Type</td>
<td>Examples</td>
</tr>
<tr>
<td>--------------------------</td>
<td>--------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Soups</td>
<td>Cheese soup</td>
</tr>
<tr>
<td></td>
<td>Soup that has been strained or put through a blender</td>
</tr>
<tr>
<td></td>
<td>Soup with pureed potatoes</td>
</tr>
<tr>
<td></td>
<td>Tomato soup</td>
</tr>
<tr>
<td>Drinks</td>
<td>Eggnog (pasteurized and alcohol free)</td>
</tr>
<tr>
<td></td>
<td>Fruit juices</td>
</tr>
<tr>
<td></td>
<td>Milk (all types)</td>
</tr>
<tr>
<td></td>
<td>Milkshakes</td>
</tr>
<tr>
<td></td>
<td>Smoothies</td>
</tr>
<tr>
<td>Fats</td>
<td>Butter</td>
</tr>
<tr>
<td></td>
<td>Cream</td>
</tr>
<tr>
<td></td>
<td>Margarine</td>
</tr>
<tr>
<td></td>
<td>Oil</td>
</tr>
<tr>
<td></td>
<td>Sour cream</td>
</tr>
<tr>
<td>Sweets</td>
<td>Custard (soft or baked)</td>
</tr>
<tr>
<td></td>
<td>Frozen yogurt</td>
</tr>
<tr>
<td></td>
<td>Ice cream with no chunks (such as nuts or cookie pieces)</td>
</tr>
<tr>
<td></td>
<td>Ice milk</td>
</tr>
<tr>
<td></td>
<td>Pudding</td>
</tr>
<tr>
<td></td>
<td>Yogurt (plain or vanilla)</td>
</tr>
<tr>
<td>Replacements and supplements</td>
<td>Instant breakfast drinks</td>
</tr>
<tr>
<td></td>
<td>Liquid meal replacements</td>
</tr>
</tbody>
</table>
Domain 1- Physical Well Being: Family Caregiver

These items may also be helpful if you have nausea or diarrhea, but they are not high in nutrients:
- Bouillon
- Broth
- Carbonated beverages
- Coffee
- Fruit drinks
- Fruit punch
- Fruit purees that are watered down
- Gelatin
- Honey
- Jelly
- Sports drinks
- Syrup
- Tea
- Water
### Domain 1- Physical Well Being: Family Caregiver

#### Foods and Drinks That Are Easy on the Stomach

<table>
<thead>
<tr>
<th>Type</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Soups</strong></td>
<td>Clear broth, such as chicken, vegetable, or beef</td>
</tr>
<tr>
<td><strong>Drinks</strong></td>
<td>Clear carbonated beverages that have lost their fizz</td>
</tr>
<tr>
<td></td>
<td>Cranberry or grape juice</td>
</tr>
<tr>
<td></td>
<td>Fruit-flavored drinks</td>
</tr>
<tr>
<td></td>
<td>Fruit punch</td>
</tr>
<tr>
<td></td>
<td>Sports drinks</td>
</tr>
<tr>
<td></td>
<td>Tea</td>
</tr>
<tr>
<td></td>
<td>Water</td>
</tr>
<tr>
<td><strong>Main meals and other foods</strong></td>
<td>Cheese</td>
</tr>
<tr>
<td></td>
<td>Chicken (broiled or baked without its skin)</td>
</tr>
<tr>
<td></td>
<td>Cream of rice</td>
</tr>
<tr>
<td></td>
<td>Eggs</td>
</tr>
<tr>
<td></td>
<td>Fish (poached or broiled)</td>
</tr>
<tr>
<td></td>
<td>Instant oatmeal</td>
</tr>
<tr>
<td></td>
<td>Noodles</td>
</tr>
<tr>
<td></td>
<td>Peanut butter (creamy)</td>
</tr>
<tr>
<td></td>
<td>Potatoes (boiled without skins)</td>
</tr>
<tr>
<td></td>
<td>Pretzels</td>
</tr>
<tr>
<td></td>
<td>Refined cold cereals (e.g. Rice Krispies)</td>
</tr>
<tr>
<td></td>
<td>Saltine crackers</td>
</tr>
<tr>
<td></td>
<td>White rice</td>
</tr>
<tr>
<td></td>
<td>White toast</td>
</tr>
<tr>
<td><strong>Sweets</strong></td>
<td>Angel food cake</td>
</tr>
<tr>
<td></td>
<td>Bananas</td>
</tr>
<tr>
<td></td>
<td>Canned fruit, such as applesauce, peaches, and pears</td>
</tr>
<tr>
<td></td>
<td>Custard</td>
</tr>
<tr>
<td></td>
<td>Gelatin</td>
</tr>
<tr>
<td></td>
<td>Ice cream</td>
</tr>
<tr>
<td></td>
<td>Ice milk</td>
</tr>
<tr>
<td></td>
<td>Popsicles</td>
</tr>
<tr>
<td></td>
<td>Sherbet or sorbet</td>
</tr>
<tr>
<td></td>
<td>Yogurt (plain or vanilla)</td>
</tr>
</tbody>
</table>
Domain 1- Physical Well Being: Family Caregiver

Yakima Fruit Paste Recipe

Dose: 1-2 tablespoons per day

1 pound prunes
1 pound raisins
1 pound figs-pitted
4 oz. senna tea
1 cup brown sugar
1 cup lemon juice

1. Prepare tea-use about 2½ cups boiled water added to tea and steep 5 minutes
2. Strain tea to remove tea leaves and add only 1 pint tea to a large pot, then add fruit
3. Boil fruit and tea for 5 minutes
4. Remove from heat and add sugar & lemon juice. Allow to cool.
5. Use hand mixer of food processor to turn fruit mixture into smooth paste
6. Place in plastic container and place in freezer. (Paste will not freeze but will keep forever in freezer).
7. Spoon out what you require each day.

Enjoy eating fruit paste straight off the spoon.
Spread it on toast or add hot water and make a drink.
- If the fruit paste is not working (no bowel movements) then increase the amount of fruit paste each day.
- If the fruit paste induces very loose stools, cut down on the amount of fruit paste intake. Consider taking it every other day in some cases.
- For questions or problems with the fruit paste, contact your home care or hospice nurse.

Caution-Dietary changes, including fruit paste, could potentially lead to alteration of electrolytes. For example, it is possible that a patient with underlying renal insufficiency could develop hyperkalemia when dietary changes are made.
Domain 1- Physical Well Being: Family Caregiver

Pursed Lip Breathing

Pursed lip breathing is one of the easiest ways to control shortness of breath. It is a quick and easy way to slow your pace of breathing, making each breath more effective.

Use this technique during the hard part of any activity, such as bending, lifting or stair climbing. Practice 4-5 times a day at first so you can do the technique correctly.

Technique

1. Relax your neck and shoulder muscles.

2. Breathe in (inhale) slowly through your nose for two counts, keeping your mouth closed. Don't take a deep breath; a normal breath will do. It may help to count to yourself: inhale, one, two.

3. Pucker or "purse" your lips as if you were going to whistle or gently flicker the flame of a candle.

4. Breathe out (exhale) slowly and gently through your pursed lips while counting to four. It may help to count to yourself: exhale, one, two, three, four.

5. Breathing while bending forward can help you breathe better. Lean forward at the waist, and keep your back straight. People often use a table or the back of a chair for this. You can also use this breathing method while you are sitting down.
Domain 1- Physical Well Being: Family Caregiver

Breathing: Relaxation Exercises

The following relaxation techniques can help with the tension and anxiety that may be caused by your breathing problems. By learning to relax your mind and body, you may feel better.

☐ To begin, lie down on a comfortable surface and place pillows under your head and knees. If you are more comfortable on your side, use pillows under your head and between your knees.

☐ Relax

☐ Lie quietly in a comfortable position. Take a slow deep breath through your nose. Hold the breath for several seconds; purse your lips, and slowly exhale. Relax.

☐ Take another deep, slow breath through your nose. Hold your breath and pull your toes towards your head and tighten your leg muscles (no longer than a count to 3). Feel the tension. Purse your lips, exhale slowly and relax your legs. Relax.

☐ Take another deep slow breath through your nose. Hold your breath and make a fist with both hands and tighten your arm muscles. Feel the tension. Purse your lips, exhale slowly and relax your arms and hands. Relax

☐ Take another slow, deep breath through your nose. Hold the breath and bite down as hard as you can and tighten your jaw muscles. Feel the tension. Purse your lips, exhale slowly, and relax your jaws. Relax.

☐ Take a slow deep breath through your nose. Hold your breath and lift up your head and tighten your neck muscles. Feel the tension. Purse your lips, exhale slowly, let your head rest back on the pillow, and relax your neck muscles.

☐ Lie still and enjoy the relaxed feeling you are experiencing. You should do this relaxation technique several times a day, even if you simply do it while sitting in a chair.
Domain 1- Physical Well Being: Family Caregiver

Bowel Regimen for Constipation

Start with Senokot S (laxative) – 2 tablets at bedtime

If you have bowel movement:
Take Senokot S – 2 tablets at bedtime on a regular basis when you are taking morphine-like pain medicines. If you start having loose stools, call your doctor/nurse practitioner

If no bowel movement on day 1:
Take your pain medicine in addition to Senokot S - 2 tablets twice a day.

If no bowel movement on day 2:
Take your pain medicine in addition to Senokot S - 3-4 tablets twice a day or three times a day.

If no bowel movement on day 3:
Call your doctor/nurse practitioner
Domain 2- Psychological Well Being: Family Caregivers
Domain 2- Psychological Well Being: Family Caregivers

Table of Contents for Domain 2- Psychological Well Being

I. Introduction ........................................................................................................ D2CG-2
II. Distress Thermometer .......................................................................................... D2CG-3
III. List of Symptoms ................................................................................................ D2CG-3
IV. General Information on Caring for the Patient’s Psychological Concerns .......... D2CG-4
V. Worry and Fear ..................................................................................................... D2CG-6
VI. Depression .......................................................................................................... D2CG-6
VII. Anger ................................................................................................................. D2CG-7
VIII. Cognitive Changes ............................................................................................ D2CG-7
IX. Psychological Well Being Self-Care Plan .......................................................... D2CG-8
X. Relaxation Techniques and Mind/Body Practices ................................................. D2CG-12
XI. Positive Self-Talk: Creating and Using Positive Affirmations ............................. D2CG-14
Domain 2 - Psychological Well Being: Family Caregivers

Domain 2 Introduction

One of the most important—but often forgotten—tasks for caregivers is caring for themselves emotionally. A caregiver's emotional health is very important to the well-being of the person who has cancer. You've probably felt a range of feelings since your loved one’s lung cancer diagnosis. You may have had these feelings at other times in your life, too, but they may be more intense now.

People with lung cancer often have emotional issues that are a result of their cancer and/or treatments. Psychological well-being is focused on how the emotional issues that your loved one experiences affects his or her quality of life and everyday activities. This session is also about how your emotional needs affect your quality of life as a cancer caregiver. It is important to make sure that your emotional needs are addressed so that you are able to take part fully in your activities as a caregiver.

Giving yourself an outlet for your own thoughts and feelings is important. In this session, we will review some of the more common emotional symptoms faced by your loved one with lung cancer. We will talk about how you can help your loved one manage his/her emotional symptoms. We will also talk about common emotional needs that you may experience as a cancer caregiver, and give you some self-care tips that can be used to manage your emotional needs. We will continue working on developing your individualized self-care plan. In each session, we will work together to develop your comprehensive self-care plan. We will discuss some resources that can help you be better prepared to care for you and your loved one’s emotional needs.

In each of our sessions we begin by asking you to give us some information about how you and your loved one are coping with lung cancer. Over the last two weeks ---

1. Have you noticed any changes in your loved one’s ability to function?
   - Bathing
   - Dressing
   - Walking
   - Mental status

2. Are you providing more or less personal care for your loved one?
   - More
   - Less
   - Same

3. What are the current goals of care or treatment plan for your loved one?
Domain 2 - Psychological Well Being: Family Caregivers

Next, we would like you to rate your level of distress as a caregiver. This helps us to know overall how you are coping with your loved one’s lung cancer and your role as a caregiver. Using the thermometer below, please rate the number (0=no distress, 10=extreme distress) that best describes the overall distress you are feeling now.

![Thermometer Image]

My overall distress _______

It would be helpful if you would tell us what psychological well-being topics you would like to learn about during today’s session. We find that asking you to identify which emotional topics are most important makes the teaching more relevant to your personal needs as a cancer caregiver.

Below is a list of psychological well-being topics that are common for patients who face lung cancer. Please pick three topics that you would like to learn about in today’s session. Your choices will help guide the content that we will cover for this session.

_____ Worry and Fear (pg. 6)
_____ Depression (pg. 6)
_____ Anger (pg. 7)
_____ Cognitive Changes (pg. 7)
Domain 2- Psychological Well Being: Family Caregivers

GENERAL INFORMATION ON CARING FOR THE PATIENT’S EMOTIONAL NEEDS

Key things to know:
- Beyond caring for the physical needs of your loved one, caregiving can also mean giving emotional support and encouragement.
- You may be helping your loved one with lung cancer cope and work through the many feelings that come up.
- Keep in mind that taking care of your emotional health makes you a more effective caregiver, which ultimately helps the person who is ill.

Tips to help care for your loved one’s emotional needs:
- Help your loved one keep track of his/her emotional symptoms. Call the doctor/nurse practitioner if:
  - The symptom is new or getting worse
  - The symptom keeps your loved one from doing his/her everyday activities
  - The symptom bothers your loved one
- Keep track of the following:
  - When the symptom started
  - What makes the symptom better/worse
  - How long the symptom lasts
- Report the following right away to the doctor/nurse practitioner if your loved one experiences the following:
  - Change in mental status, such as sleeping more or more restless
  - Extreme fatigue or inability to get out of bed for the last 24 hours
  - Excessive worrying
  - Sleep problems
  - Hasn’t been able to eat or drink for the last 24 hours
  - Has no interest in things that he/she used to enjoy
- Help your loved one keep track of his/her medicines that are used to treat emotional symptoms. Call the doctor/nurse practitioner if you:
  - Have questions about how your loved one should take his/her medicine
  - Have problems getting your loved one’s medicine
- If your loved one’s emotional symptoms are caused by uncontrolled symptoms such as pain or difficulty breathing (dyspnea), talk to your loved one’s doctor/nurse practitioner about better physical symptom management.
- Keep a journal that includes all your loved one’s medical appointments, test results, medications and dosages, symptoms and side effects, new questions between appointments, and names and numbers for resources.
- Help with medicine management. Refill all medicines before the last dose to avoid running out.
Domain 2- Psychological Well Being: Family Caregivers

- When your loved one is struggling with severe emotional distress, do not leave him or her alone. Try to stay calm and contact the doctor right away.
- Take an active role in your loved one’s emotional care. If possible, go with them to medical appointments.
- Coach and support prescribed diet, activity level, sleep, and any supportive therapies.
- Provide a calm, safe, comforting environment and your calm presence.
- If anger or worry is the problem, wait until the emotions have lessened and encourage your loved one to talk about any concerns that may be distressing them.
- Allow your loved one to express their feelings openly. Listen without judging or “cheerleading”.
- Think about how you have helped each other feel better during a difficult time in the past. Do whatever works for you both and don’t be afraid to try something new.
- Support your loved one’s treatment decisions, even if you may be in a position to share decision-making. Your support in their decisions will help him/her feel a sense of control.
- Allow plenty of time for daily activities. Plan ahead. Do not rush yourself or your loved one.
- Think about finding support as a caregiver. These include outside resources, such as friends, other family members, or paying for outside help.
- Help him/her live as normal a life as possible. To do this you might start by helping him/her decide what activities are most important. He/she may need to put aside those that are less important in order to do the things he/she enjoys most.
- Let your loved one know that you are available, but don’t press issues. Let your loved one decide when he/she need assistance.
- Respect your loved one’s need to be alone. Sometimes, we all need time alone -- even you.
- If you get the feeling that your loved one isn’t talking to you because he/she wants to spare your feelings, make sure he/she knows that you are open to listening, even about difficult topics.
Domain 2- Psychological Well Being: Family Caregivers

WORRY AND FEAR

Caregiver tips:
- Supportive care professionals that can help:
  - Psychologist/Psychiatrist
  - Social worker
  - Spiritual counselors (chaplains)
  - Palliative care team
- Help your loved one keep track of his/her worry or fear. Call the doctor/nurse practitioner if:
  - Worry or fear is new or getting worse
  - Worry or fear keeps your loved one from doing his/her everyday activities
- Encourage your loved one to keep a journal or notebook of his/her feelings and experiences. Encourage him/her to join a support group
- Encourage your loved one to stay active and do activities that he/she enjoys
- Encourage your loved one to use methods that may have helped him/her in the past, such as relaxation, prayer, and meditation
- Help your loved one identify what they are most concerned about. Fear can often decrease when we address the cause of our concern
- Help your loved one keep track of his/her medicines. Refill all medicines before the last dose to avoid running out

DEPRESSION

Caregiver tips:
- Supportive care professionals that can help:
  - Psychologist/Psychiatrist
  - Social worker
  - Spiritual counselors (chaplains)
  - Palliative care team
- Call your doctor/nurse practitioner if:
  - Depression is new or getting worse
  - If you fear that your loved one may hurt him or herself
  - Depression keeps your loved one from doing his/her everyday activities
- Encourage your loved one to keep a journal or notebook of his/her feelings and experiences. Encourage him/her to join a support group
- Encourage your loved one to use methods that may have helped him/her in the past, such as relaxation, prayer, and meditation
- Help your loved one keep track of his/her medicines. Refill all medicines before the last dose to avoid running out
Domain 2 - Psychological Well Being: Family Caregivers

ANGER

Caregiver tips:
- Supportive care professionals that can help:
  - Psychologist/Psychiatrist
  - Social worker
  - Spiritual counselors (chaplains)
- Call the doctor/nurse practitioner if your loved one’s anger is out of control or you feel that they need a counselor
- Encourage your loved one to keep a journal of his/her feelings and experiences.
- Encourage him/her to join a support group
- Encourage your loved one to stay active and do activities that they enjoy
- Encourage your loved one to use methods that may have helped him/her in the past, such as relaxation, prayer, and meditation
- Help your loved one keep track of his/her medicines. Refill all medicines before the last dose to avoid running out

COGNITIVE CHANGES

Caregiver tips:
- Supportive care professionals that can help:
  - Psychologist/Psychiatrist
  - Neurologist
  - Social worker
  - Call the doctor/nurse practitioner if your loved one’s cognitive changes are new or getting worse
- Call the doctor/nurse practitioner if your loved one has trouble with the following:
  - Remembering (i.e. names, dates, events)
  - Concentrating (“spacing out”)
  - Short-term memory loss
  - Forgetting things easily
  - Finding the right words to finish a sentence
  - Seizures
- Encourage your loved one to stay active
- Encourage your loved one to get enough rest and sleep
- Help your loved one set up and follow routines, and encourage them to try and keep the same daily schedules as much as possible
- Help your loved one keep track of his/her medicines. Refill all medicines before the last dose to avoid running out
Domain 2- Psychological Well Being: Family Caregivers

**CARING FOR YOUR OWN EMOTIONAL NEEDS**

**Key things to know:**
- You may also experience periods of stress, anxiety, depression, and frustration
- You've probably felt a range of feelings as you care for your loved one with lung cancer
- These feelings can be quite strong and will likely come and go in strength as you go through treatment with the patient
- It may feel like your emotions are on a “rollercoaster”
- You may feel sad, afraid, angry, guilty, and worried
- There is no right or wrong way to feel or react. **These feelings are all normal**
- You may be tempted to put your own feelings aside while helping your loved one cope with his/her own feelings
- But it's very important that you take care of your emotional health, too. Taking care of yourself will give you strength to help others
- The stress of caregiving can lead some people to develop psychological issues or increase unhealthy habits, such as smoking, or drinking too much alcohol

**How to talk about your own emotional needs:**
- Make sure that any medical or emotional condition that you may have are being followed by a doctor. Call your doctor if:
  - You have any symptoms that are new or getting worse
  - You have any symptoms that are keeping you from doing your activities as a caregiver
  - You have any symptoms that are bothering you
- If you cannot make it to a doctor’s appointment, call your doctor’s office and re-schedule the appointment

**Self-care tips:**
- Make sure that you keep track of your medicines. Follow directions when taking any medicines. Call your doctor if you:
  - Have questions about how you should take your medicine
  - Have problems getting your medicines
- One of the first steps to coping with feelings is to recognize that they exist and that having them is normal. Give yourself time to sort out your feelings
- Stay as active as possible
- Maintain a healthy diet
- Make sure you get enough sleep
- Recognize the signs of stress
- Maintain routine medical follow-ups
- Make time for yourself and other relationships. Spending time doing something you enjoy can help give you a much-needed break so you can remain an effective caregiver. It
Domain 2- Psychological Well Being: Family Caregivers

- is also important to spend time with other people who are important to you so that you can maintain those supportive relationships
- If you can, try to keep doing some of your regular activities
- Be willing to change your routines. You may have to do things at a different time of day or for less time than you do normally
- Write in a journal or notebook. Writing or journaling can help express your thoughts and feelings
- Be kind and patient with yourself. Many caregivers experience occasional bouts of anger or frustration and then feel guilty for having these feelings. Try to find positive ways of coping with these difficult feelings, such as talking with supportive friends and exercising
- Once a day, think about something that you find rewarding about caregiving, such as gratitude you've received, or extra support from a health care provider
- Ask family/friends for help if you have trouble doing your everyday activities
- Maintain a clean and safe home environment
- Allow plenty of time for daily activities. Plan ahead. Do not rush yourself
- Think about finding support as a caregiver. These include outside resources, such as friends, other family members, or paying for outside help
- Join a caregiver support group
- Focus on the things you feel are worth your time and energy. Let the other things go for now. For example, don't fold the clothes when you're tired. Go ahead and take time to rest.
Domain 2- Psychological Well Being: Family Caregivers

REFINING YOUR SELF-CARE PLAN

Key things to know:
- As a caregiver you need to strike a balance as you care for your loved one while keeping up with the needs of your family and your own needs
- Your loved one’s needs are important; however it is essential for you to stay in tune with the things you need to maintain your health and quality of life
- One of the ways to take care of yourself is to use your self-care plan
- Using your self-care plan will help improve your ability to cope as you deal with the many responsibilities in your caregiving role

Refining your self-care plan:
- In today’s session, we will continue to develop your individualized self-care plan. Before we begin, have you been able to use the strategies that you chose during the last session to care for your physical/medical needs? Were there any activities that just didn’t fit or work right now? We can think about making revisions to your plan.
- For today, we will focus on your emotional well-being. In the next two sessions we will discuss the other two quality of life domains, which include social and spiritual well-being. We will also have time during the next sessions to further revise and refine your self-care plan.

Assessment:
- To begin, let’s do some simple assessments
- First, let’s review some of the common potential psychological stressors for cancer caregivers

Potential Caregiver Stressors:

<table>
<thead>
<tr>
<th>Psychological Well Being</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Depression</td>
</tr>
<tr>
<td>• Worry/anxiety/fears</td>
</tr>
<tr>
<td>• Making decisions</td>
</tr>
<tr>
<td>• Knowing how to get and give support</td>
</tr>
<tr>
<td>• Dealing with your loved one’s emotions</td>
</tr>
</tbody>
</table>

- Next, let’s discuss some of the strengths that you bring to your role as a caregiver. What are some of your personal strengths related to caring for your loved one’s emotional symptoms?
- Now, let’s assess your current coping strategies. What types of strategies have worked for you in the past to help improve your own emotional well-being?
- Let’s also assess your current self-care strategies for meeting your emotional needs. What have you done in the past to take care of yourself emotionally?
Domain 2- Psychological Well Being: Family Caregivers

**Intention statement:**
- Before beginning to write your self-care plan, let’s review the intention statement that you created during our last session. Has there been any change in how you want to define your goals for taking care of yourself?

**Your emotional well-being self-care plan:**
- Using the information that we talked about today during this session, write at least one strategy you will use in the next week to help manage your emotional needs
- Include how often you will do it, and what support or resources you will need in order to do it
- Make it a realistic strategy, and be as specific as you can
- Emotional well-being strategies: journaling, talking with close friends, positive affirmations, support groups
Domain 2- Psychological Well Being: Family Caregivers

Relaxation Techniques and Mind/Body Practices

How They Can Help You Cope With Cancer

Cancer and its treatment can be stressful for people with cancer and their caregivers. Relaxation techniques and other mind/body practices can help calm your mind and sharpen your ability to focus. These techniques offer creative ways to reduce stress caused by cancer and to maintain inner peace. For example, some people use these techniques to help them relax as they wait for treatments or test results.

Here are some techniques that can help you cope with the challenges of cancer:

Deep Breathing Exercises:
At the core of life is breath. Laughing and sighing are the body’s natural ways of getting us to breathe deeply. That is why we often feel calmer or rejuvenated after these experiences. Anxiety and stress can make us take short, shallow breaths. Shallow breathing, which does not allow enough oxygen to enter our bodies, can make us even more anxious.

Try this four-step breathing exercise. It can be done anywhere, anytime:

1. Take in a deep breath from your diaphragm (this is the muscle between your lungs and abdomen).
2. Hold the breath for several seconds – however long is comfortable for you – and then exhale slowly.
3. Repeat steps 1 and 2 two more times.
4. Afterwards, relax for a moment and let yourself feel the experience of being calm.

Meditation
Repetitive prayers are a form of meditation. Two other traditional forms of meditation include “one-pointed” and “two-pointed” meditation.

One-pointed meditation focuses on a word or sound called a mantra. Many people create their own mantra from an affirming word, such as “peace,” “love” or “hope.” The goal is to relax the mind, which has a natural tendency to jump from one idea to the next – and from one worry to the next. Do not try to force your mind back to your mantra when you notice it has wandered. Simply guide it back gently, accepting that it will stray again.

Two-pointed meditation is also called “mindful” or “insight” meditation. With this technique, you relax your mind by focusing on your breath. As your mind jumps around, practice “non-judgmental awareness” – simply observe the pattern of your thoughts and gently guide them back to focus on your breath. Non-judgmental awareness allows you to separate yourself from
Domain 2- Psychological Well Being: Family Caregivers

emotions and sensations rather than getting pulled into them. One benefit of this type of meditation is that you can practice it while seated quietly or when doing daily activities.

**Guided Imagery**
This stress-reducing technique combines deep breathing and meditation. As you practice deep breathing, imagine a peaceful scene or setting, perhaps from a memory. Once you are relaxed, you can create a “wakeful dream” in which, for example, you envision pain being washed away or your body becoming stronger.

Many people practice guided imagery exercises while listening to recordings of “ambient” sounds. These are usually music or sounds from nature, such as waterfalls or ocean waves. Sometimes just listening to ambient sounds is enough to relax your mind and briefly transport you emotionally to a place in which you feel safer and more secure.
Domain 2- Psychological Well Being: Family Caregivers

Positive Self-Talk: Creating and Using Affirmations

An affirmation is a statement you make about yourself. It can be positive or negative. Often the negative is easier to repeat (e.g. “I can’t possibly do this”) because of deep issues from our past. The positive (e.g. “we can get through this”) is sometimes harder to affirm. However, when you affirm the positive, you open up a new awareness or understanding within yourself to ways to get what you need. Below are some examples of positive and negative affirmations:

**Negative:** I can’t deal with all this stress; I’m just going to give up.
**Positive:** This is so difficult, but I can do it. I’ll need more support, and I’ll have to focus on the basics; but I’ve pulled through tough times before and I’ll do it again.

**Negative:** I can’t watch my loved one suffer.
**Positive:** I know it is going to be difficult; I can’t take the suffering away; but I can help by being present and showing I care.

**Negative:** No one understands what our family is going through.
**Positive:** Even though others may not fully understand what we are going through, they want to help us. I am so glad to have their support.

I encourage you to write some of your negative thoughts and reframe them as positive affirmations:

**Negative:**
**Positive:**

**Negative:**
**Positive:**

**Negative:**
**Positive:**

**Negative:**
**Positive:**
Use positive affirmations:
- I am learning to accept responsibility for my own happiness
- I do the best I can to make each day count
- I have what I need to cope with today’s challenges
- I have the courage and strength to do what I really need to do
- I am learning to identify things I cannot change
- I am learning to live within my limitations
- I am focusing my energy on what I can do, rather than on what I can no longer do
- I will forgive whoever I need to today, not for their sake, but for mine.
Domain 3- Social Well Being: Family Caregivers
Domain 3- Social Well Being: Family Caregivers

Table of Contents for Domain 3- Social Well Being

I. Introduction .................................................................................................................. D3CG-2
II. Distress Thermometer ............................................................................................... D3CG-3
III. List of Symptoms ...................................................................................................... D3CG-3
IV. General Information on Caring for the Patient’s Social Concerns ...................... D3CG-4
V. Changes in Relationships .......................................................................................... D3CG-5
VI. Communication ........................................................................................................ D3CG-6
VII. Sexual Changes ....................................................................................................... D3CG-6
VIII. Social Support ........................................................................................................ D3CG-7
IX. Financial Burdens ..................................................................................................... D3CG-7
X. Healthcare Planning .................................................................................................. D3CG-8
XI. Social Well Being Self-Care Plan .......................................................................... D3CG-9
XII. California Advance Health Care Directive ............................................................. D3CG-13
XIII. Cancer Resource List ............................................................................................. D3CG-18
Domain 3- Social Well Being: Family Caregivers

Domain 3 Introduction

Social well-being refers to how people carry on relationships with family, friends, colleagues at work, and the general community. This session is also about how your social needs affect your quality of life as a cancer caregiver. Lung cancer doesn't affect just one person. It affects couples, families, and friends. Lung cancer changes roles in relationships, often in unexpected ways. Lung cancer also causes changes in responsibilities, such as chores and/or your job. As a caregiver, your social needs are very important to the well-being of the person who has cancer. It is also important to make sure that your social needs are met so that you are able to take part fully in your activities as a caregiver.

In this session, we will review some of the more common social concerns faced by your loved one with lung cancer. We will talk about how you can help your loved one manage his/her social concerns. We will also talk about social needs that you may experience as a cancer caregiver, and give you some self-care tips that can be used to manage your social needs. We will continue working on developing your individualized self-care plan. In the next session, we will continue to work on designing and refining your self-care plan. At the end of this session, we will give you some resources that can help you be better prepared to meet you and your loved one’s social needs.

In each of our sessions we will begin by asking you to give us some information about how you and your loved one are coping with lung cancer. Over the last two weeks ---

1. Have you noticed any changes in your loved one’s ability to function?
   - Bathing
   - Dressing
   - Walking
   - Mental status

2. Are you providing more or less personal care for your loved one?
   - More
   - Less
   - Same

3. What are the current goals of care or treatment plan for your loved one?
Domain 3- Social Well Being: Family Caregivers

Next, we would like to rate your level of distress as a caregiver. This helps us to know overall how you are coping with your loved one’s lung cancer and your role as a caregiver. Using the thermometer below, please rate the number (0=no distress, 10=extreme distress) that best describes the overall distress you are feeling now.

![Thermometer Image]

My overall distress ______

It would be helpful if you would tell us what social well-being topic you would like to learn about during today’s session. We find that asking you to identify which social topics are most important makes the teaching more relevant to your personal needs as a cancer caregiver.

Below is a list of social well-being topics that are common for patients who face lung cancer. Please pick three topics that you would like to learn about in today’s session. Your choices will help guide the content that we will cover for this session.

_____ Changes in Relationships (pg. 5)
_____ Communication (pg. 6)
_____ Sexual Changes (pg. 6)
_____ Social Support (pg. 7)
_____ Financial Burdens (pg. 7)
_____ Healthcare Planning (pg. 8)
Domain 3- Social Well Being: Family Caregivers

GENERAL INFORMATION ON CARING FOR THE PATIENT’S SOCIAL CONCERNS

Key things to know:
- You may be helping your loved one with lung cancer cope with his/her social concerns.
- Keep in mind that taking care of your social needs makes you a more effective caregiver, which ultimately helps the person who is ill.

How to talk about your loved one’s social concerns:
- Since the lung cancer diagnosis, have you noticed any social concerns that your loved one has or has not discussed with you?
- It is important for both partners to communicate their needs.
- Keep in mind your children’s or grandchildren’s ages and give them truthful and correct information they can understand. Your social worker can help you think about your family’s special needs.

Tips to help care for your loved one’s social concerns:
- Report the following right away to the doctor/nurse if your loved one experiences the following:
  - Extreme fatigue or inability to get out of bed for the last 24 hours
  - Has no interest in things that he/she used to enjoy
- If your loved one’s social concerns are caused by uncontrolled symptoms such as pain or dyspnea, talk to your loved one’s doctor about better physical symptom management.
- Help your loved one maintain family and social connections and activities.
- When your loved one is struggling with coping with social concerns, do not leave him or her alone. Try to stay calm.
- Take an active role in your loved one’s social needs.
- Coach and support prescribed activity level.
- Provide a calm, safe, comforting environment and your own calm presence.
- Allow your loved one to express his/her feelings openly. Listen without judging or “cheerleading”.
- Think about how you have helped each other feel better during a difficult time in the past. Do whatever works for you both and don’t be afraid to try something new.
- Allow plenty of time for daily activities. Plan ahead. Do not rush yourself or your loved one.
- Think about finding support as a caregiver. These include outside resources, such as friends, other family members, or paying for outside help.
- Help him/her live as normal a life as possible. To do this you might start by helping him/her decide what activities are most important. He/she may need to put aside those that are less important in order to do the things he/she enjoys most.
- Let your loved one know that you are available, but don’t press issues. Let your loved one decide when he/she needs assistance.
- Respect the need to be alone. Sometimes, we all need time alone -- even you.
Domain 3- Social Well Being: Family Caregivers

- If you get the feeling that your loved one isn't talking to you because he/she wants to spare your feelings, make sure he/she knows that you are always open to listening, even about tough topics
- Remember that people communicate in different ways. Take your cues from the person with cancer. Some people are very private while others will talk more about what they are going through

Be realistic and flexible about what you hope to talk about and agree on. You may need or want to talk, only to find that your loved one does not want to do it at this time

Changes with Relationships

Caregiver tips:
- Supportive care professionals that can help:
  - Psychologist/psychiatrist
  - Social worker
  - Spiritual counselors (chaplains)
- Since your loved one’s lung cancer diagnosis, what kind of changes in your relationships have you noticed?
- Encourage your loved one to accept outside help from family/friends
- Work together with your loved one to meet short-term goals, such as finishing cancer treatment
- Encourage your loved one to join a support group
Domain 3- Social Well Being: Family Caregivers

COMMUNICATION

Caregiver tips:
❖ Supportive care professionals that can help:
  • Psychologist/psychiatrist
  • Social worker
  • Spiritual counselor (chaplain)
❖ Since your loved one’s lung cancer diagnosis, have you noticed changes in the way you talk with your family/friends?
❖ Remind your loved one that it is important for him/her to communicate his/her needs
❖ Let your loved one take the lead in talking. Let him/her know that it's okay for them to talk about their lung cancer
❖ Don't always expect that you will be able to answer all your loved one’s questions; your loved one may just want someone who will listen and who will understand his/her feelings
❖ Encourage your loved one to accept outside help from family/friends
❖ Encourage your loved one to join a support group

SEXUAL CHANGES

Partner tips:
❖ Supportive care professionals that can help:
  • Psychologist/psychiatrist
  • Social worker
❖ Since your loved one’s lung cancer diagnosis, have you noticed any sexuality changes?
❖ Remind your loved one that it is important for him/her to communicate his/her needs
❖ Sexuality is much more than intercourse. Intimacy and closeness through touch and spending quiet time together are very important
❖ Do not push your loved one. Wait until he/she feels ready for sexual activity
❖ Try other things if your usual sexual activities are uncomfortable for your loved one
❖ Both partners may need extra reassurance that they are still needed and loved. You may think your loved one knows how much you love him or her, but he or she may need to hear it more often now
Domain 3- Social Well Being: Family Caregivers

SOCIAL SUPPORT

Caregiver tips:

- Social support systems can include:
  - Family members
  - Friends
  - Other people who have cancer
  - Support groups
  - Spiritual/church groups
  - Health care professionals
- Your loved one may have already identified social systems that have been helpful to him/her since their diagnosis. What types of social support does your loved one find helpful?
- If your loved one hasn’t identified social systems for support, what types of support would he/she like to have?
- Help your loved one build a team of caregivers
- Help your loved one maintain close contact with friends, family, and social groups
- Encourage your loved one to accept outside help from family/friends
- Encourage your loved one to join a support group

FINANCIAL BURDENS

Caregiver tips:

- Supportive care professionals that can help:
  - Hospital financial counselors
  - Social worker
  - Case managers
- Since your loved one’s lung cancer diagnosis, has she/he had problems with managing money and finances?
- Access financial services professionals to help your loved one manage financial burdens
- Help your loved one develop a plan to cope with changing financial needs for daily expenses (i.e. medicines, housing, rent/mortgage, transportation, insurance, groceries)
- Help your loved one organize a financial record-keeping system
- Encourage your loved one to join a support group
Domain 3- Social Well Being: Family Caregivers

HEALTHCARE PLANNING

Caregiver tips:
- Sometimes family members and doctors may need to make medical decisions if the patient cannot
- Supportive care professionals that can help:
  - Hospital financial counselors
  - Social worker
  - Spiritual counselors (chaplains)
- Since your loved one’s lung cancer diagnosis, has he/she thought about medical care preferences if they cannot decide for themselves?
- For more information on Advance Directives, please ask to speak with a Social Worker
Domain 3- Social Well Being: Family Caregivers

CARING FOR YOUR OWN SOCIAL NEEDS

Key things to know:
- You may be tempted to put your own social needs aside while helping your loved one cope with their own social concerns
- But it's very important that you take care of your social health, too. Taking care of yourself will give you strength to help others
- The stress of caregiving can lead some people to have unmet social needs or increase unhealthy habits, such as smoking, or drinking too much alcohol

How to talk about your own social needs:
- Make sure that any medical or emotional conditions that you may have are being followed by a doctor. Call your doctor if:
  - You have any symptoms that are new or getting worse
  - You have any symptoms that are keeping you from doing your activities as a caregiver
  - You have any symptoms that are bothering you
- Share your feelings with your loved one about both the good and difficult parts about caregiving. Let your loved one do the same
- Speak frankly about feelings using “I” messages such as “I feel loved when you share your feelings or thoughts with me”
- Speak openly, honestly about how you are managing your role as the caregiver
- Find ways to say thank you

Self-care tips:
- Make sure that you keep track of your medicines. Follow directions when taking any medicines. Call your doctor if you:
  - Have questions about how you should take your medicine
  - Have problems getting your medicines
- Stay as active as possible
- Maintain a healthy diet
- Make sure you get enough sleep
- Recognize the signs of stress
- Maintain routine medical follow-ups
- Make time for yourself and other relationships
- Be willing to change your routines as needed
- Write in a journal or notebook
- Try to find someone you can really open up to about your feelings or fears
- Tips on bringing up hard topics with your loved one:
  - Practice what you'll say in advance
  - Know that your loved one may not want to hear what you have to say
  - Find a quiet time and ask if it's okay to talk
  - Be clear on what your goals are
  - Speak from your heart
Domain 3- Social Well Being: Family Caregivers

- Allow time for your loved one to talk. Listen and try not to interrupt
- Tips on finding ways to be intimate
  - Intimacy isn't just physical. It also involves feelings, and there are many different ways to be intimate with each other
  - Talk about ways to be intimate
  - Try not to judge
  - Protect your time together. Turn off the phone and TV
  - Take it slow
  - Talk to a therapist or counselor
- Ask family/friends for help if you have trouble doing your everyday activities
- Allow plenty of time for daily activities. Plan ahead. Do not rush
- Think about finding support as a caregiver. These include outside resources, such as friends, other family members, or paying for outside help
- Join a caregiver support group
Domain 3- Social Well Being: Family Caregivers

REFINING YOUR SELF-CARE PLAN

**Key things to know:**
- As a caregiver you need to balance caring for your loved one while keeping up with the needs of family and your own needs.
- Your loved one’s needs are important; however it is essential for you to stay in tune with the things you need to maintain your health and quality of life.
- One of the ways to take care of yourself is to use your self-care plan.
- Using your self-care plan will help improve your ability to cope as you deal with the many responsibilities in your caregiving role.

**Refining your self-care plan:**
- In today’s session, we will continue to develop your individualized self-care plan. Before we begin, have you been able to use the strategies that you chose during the last session to care for your emotional needs? Were there any activities that just don’t fit or work right now? We can think about making revisions to your plan.
- For today, we will focus on your social well-being. In the next session we will discuss the last quality of life domain, which is spiritual well-being. We will have time during the next session to further revise and refine your self-care plan.

**Assessment:**
- To begin, let’s do some simple assessments.
- First, let’s review some of the common potential social stressors for cancer caregivers.

**Potential Caregiver Stressors:**

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<th>Social</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Financial Stress</td>
</tr>
<tr>
<td>• Relationships</td>
</tr>
<tr>
<td>• Changing roles</td>
</tr>
<tr>
<td>• Not feeling connected socially</td>
</tr>
<tr>
<td>• Juggling multiple roles</td>
</tr>
<tr>
<td>• Changing social life</td>
</tr>
<tr>
<td>• Changing daily routine</td>
</tr>
<tr>
<td>• How to communicate with your loved one, family/friends, health-care providers</td>
</tr>
</tbody>
</table>

- Next, let’s discuss some of the strengths that you bring to your role as a caregiver. What are some of your personal strengths related to caring for your loved one’s social concerns?
- Now, let’s assess your current coping strategies. What types of strategies have worked for you in the past to help you meet your social needs?
- Let’s also assess your current self-care strategies for meeting your social needs. What have you done in the past to take care of yourself socially?
Domain 3- Social Well Being: Family Caregivers

Intention statement:
❖ Before beginning to write your self-care plan, let’s review the intention statement that you created during our first session. Has there been any change in how you want to define your goals for taking care of yourself?

Your social well-being self-care plan:
❖ Using the information that we talked about today during this session, write at least one strategy you will use in the next week to help meet your social needs
❖ Include how often you will do it, and what support or resources you will need in order to do it
❖ Make it a realistic strategy, and be as specific as you can
❖ Social well-being example: meeting friends for lunch, family picnic, going to a movie with friend/family
Domain 3- Social Well Being: Family Caregivers

CALIFORNIA ADVANCE HEALTH CARE DIRECTIVE
Including Power of Attorney for Health Care

PART 1 - APPOINTING AN AGENT TO MAKE HEALTH CARE DECISIONS
NOTE: You should discuss your wishes in detail with your designated agent(s).

My name is: ___________________________ Date of Birth: ___________
My address is: __________________________

In this document I appoint an agent. That agent will make health care decisions for me in the future, if and when I no longer have the mental capacity to make my own health care decisions.

Optional: I want my agent to make my health care decisions now, even though I currently have the mental capacity to make my own health care decisions. ________ (Do not initial here if you want to continue making your own health decisions for as long as you are able.)

The following persons cannot be selected as your agent or alternate agent:

- Your primary physician
- An employee of the health care institution or residential care facility where you receive care (unless you are related to that person or you are co-workers).

PRIMARY AGENT:
Agent’s Name: ___________________________
Address: _______________________________

(Phone numbers – indicate home, work, pager, and cellular phone)

1st ALTERNATE AGENT (If Agent is not willing, able, or reasonably available to serve.)
Name of first alternate agent: ___________________________
Address: _______________________________

(Phone numbers – indicate home, work, pager, and cellular phone)

2nd ALTERNATE AGENT (If Agent and 1st Alternate are unavailable or unwilling to serve.)
Name of second alternate agent: ___________________________
Address: _______________________________

(Phone numbers – indicate home, work, pager, and cellular phone)
WHAT MY AGENT MAY DO
My agent will be allowed to make health care decisions for me just as I can presently make my own. For example, I give my agent my trust to make decisions (1) to accept or refuse treatment for me, including accepting or discontinuing food and fluid that is given through a tube into my stomach or into a vein; (2) to choose for me a particular physician or health care facility; and (3) to receive or review my medical information and records, or to permit release of my records for others’ review. _______(initial here)

WHAT MY AGENT MUST DO
My agent shall make health care decisions for me by considering what I have written here, and by considering my other wishes. My agent will try to find out as much as he/she can about my wishes. If my agent does not know my wishes, he/she shall consider my personal values as much as possible and make decisions that he/she thinks are in my best interest. I ask that when my agent is trying to consider my values and prior wishes, that he/she talk to other loved ones who know me and care about me. _______(initial here)

The following individual(s) are to be EXCLUDED from any part of health care decision-making for me:

☐ No Exclusions  _______(initial here)

AFTER MY DEATH
My agent will be able to authorize an autopsy, donate all or part of my body, and/or determine the disposition of my remains. If I have written a will or made funeral arrangements, my agent should follow those instructions on what happens to my body after my death or other arrangements I have made. **If I want to make exceptions to this authority, I write them here or in an attachment to this form:**

☐ No Exceptions  _______(initial here)

(Sign and date the attached pages when this document is witnessed.)

PART 2: HEALTH CARE INSTRUCTIONS  (Cross out the sections that do not apply)
I have made additional written instructions to my agent and attached them. _______(initial here)

(Sign and date the attached pages when this document is witnessed.)

TRUST IN AGENT: The instructions I give to my agent are guidelines to assist him/her in making the best medical decisions for me. The subject of unacceptable treatments is a complex one. Whether I would or would not want a particular medical intervention might depend on context. At some point there might be a conflict between treatment instructions I have given and what my agent thinks best in circumstances that I could not have predicted. I trust that my agent will honor my goals and values. _______(initial here)

PERSONAL CARE DECISIONS: By my initials here I direct that my agent(s) named above authorize personal care on my behalf including, but not limited to, choice of residence, clothing, receipt of my mail, care for my personal belongings, care for my pet(s) if any, and all other decisions of a personal nature not included in the description of health care. _______(initial here)

DNR ORDER: I have completed a Prehospital Do Not Resuscitate Form. _______(initial here)

Page 2 of 4

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REVOCATION OF PREVIOUS DOCUMENTS: I revoke any previously-executed Power of Attorney for Health Care, Individual Health Care Instruction, or Natural Death Act Declaration. I have the right to revoke this directive at a future date by creating a new one.

PART 3: SIGNATURE OF PERSON WHO IS MAKING THIS DIRECTIVE

Sign the document in the presence of the witnesses or the Notary.

Date: __________________ Signature: ________________________________

If the person making this directive is unable to write, have the person make a mark
have a witness write the name of the person making this directive and sign next page.

PART 4: THIS DOCUMENT MUST EITHER BE NOTARIZED OR SIGNED BY TWO WITNESSES ON THE NEXT PAGE.

WITNESSES: Certain individuals cannot serve as witnesses. Those rules are set forth in the following witness statements:

I DECLARE UNDER PENALTY OF PERJURY UNDER THE LAWS OF CALIFORNIA
(1) That the individual who signed or acknowledged this Advance Health Care Directive is personally known to me, or that the individual’s identity was proven to me by convincing evidence.
(2) That the individual signed or acknowledged this Advance Directive in my presence,
(3) That the individual appears to be of sound mind and under no duress, fraud, or undue influence,
(4) That I am not a person appointed as agent by this Advance Directive, and
(5) That I am not the individual’s health care provider, an employee of the individual’s health care provider, the operator of a community care facility, an employee of an operator of a community care facility, the operator of a residential care facility for the elderly, nor an employee of an operator of a residential care facility for the elderly.

First Witness: ____________________________
Name (printed): ____________________________ Signature: ____________________________
Date: ____________________________ Address: ____________________________

Second Witness: ____________________________
Name (printed): ____________________________ Signature: ____________________________
Date: ____________________________ Address: ____________________________

ONE OF THE PRECEDING WITNESSES ALSO MUST SIGN THE FOLLOWING DECLARATION:
I further declare under penalty of perjury under the laws of California that I am not related to the individual executing this advance health care directive by blood, marriage, or adoption, and, to the best of my knowledge, I am not entitled to any part of the individual’s estate upon his or her death under a will now existing or by operations of law.

Date: ____________________________ Signature: ____________________________
Only if the person making this directive is unable to write, witnesses complete this section:

________________________________________, being unable to write, made his/her mark in
our presence and requested the first of the undersigned to write his/her name, which he/she did,
and we now subscribe our names as witnesses thereto.

________________________________________  Signature of Witness #1

________________________________________  Signature of Witness #2

If the principal (the person appointing the agent) currently resides in a nursing facility, this document also must be witnessed by a representative of California’s Long-Term Care Ombudsman Program. If the two-witness method is chosen, the Ombudsman Program representative may serve as one of the two witnesses, or may serve as a third witness. If the notarization method is chosen, the Ombudsman Program representative serves as a separate witness.

DECLARATION OF OMBUDSMAN PROGRAM REPRESENTATIVE
(Required ONLY if person appointing the agent currently resides in a nursing facility.)
I declare under penalty of perjury under the laws of California that I am an ombudsman
designated by the California Department of Aging and that I am serving as a witness as required
by Section 4675 of the California Probate Code.

________________________________________  Name (printed)

________________________________________  Signature  Date

CERTIFICATE OF ACKNOWLEDGEMENT OF NOTARY PUBLIC
(Not required if two-witness method is followed)
State of California, County of __________________________
On this ____ day of ______________________, ______, before me, the undersigned, a Notary Public in
and for said State, personally appeared ______________________________, personally
known to me or proved to me on the basis of satisfactory evidence to be the person whose name is
subscribed to the within instrument, and acknowledged to me that he/she executed it.

WITNESS my hand and official seal.

(seal)  Signature ______________________________
Only if the person making this directive is unable to write, witnesses complete this section:

_______________________________, being unable to write, made his/her mark in our presence and requested the first of the undersigned to write his/her name, which he/she did, and we now subscribe our names as witnesses thereto.

_______________________________  ______________________________
Signature of Witness #1  Signature of Witness #2

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_______________________________  ______________________________  ________________
Name (printed)  Signature  Date

CERTIFICATE OF ACKNOWLEDGEMENT OF NOTARY PUBLIC
(Not required if two-witness method is followed)

State of California, County of ________________________________

On this ____ day of _________________, ______, before me, the undersigned, a Notary Public in and for said State, personally appeared ________________________________, personally known to me or proved to me on the basis of satisfactory evidence to be the person whose name is subscribed to the within instrument, and acknowledged to me that he/she executed it.

WITNESS my hand and official seal.

(seal)  ________________________________
Signature
### Domain 3- Social Well Being: Family Caregivers

#### RESOURCE LIST

<table>
<thead>
<tr>
<th>Organization</th>
<th>Website/Contact Information</th>
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<tbody>
<tr>
<td>Family Caregiver Alliance</td>
<td><a href="http://www.caregiver.org">www.caregiver.org</a></td>
</tr>
<tr>
<td></td>
<td>(800) 445-8106</td>
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<tr>
<td>National Alliance for Caregiving</td>
<td><a href="http://www.caregiving.org/resources">www.caregiving.org/resources</a></td>
</tr>
<tr>
<td></td>
<td>(301) 718-8444</td>
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<tr>
<td>Caregiver Action Network</td>
<td><a href="http://caregiveraction.org">http://caregiveraction.org</a></td>
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<tr>
<td></td>
<td>(202) 454-3970</td>
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<tr>
<td>Cancer Legal Resource Center (CLRC)</td>
<td><a href="https://www.disabilityrightslegalcenter.org">https://www.disabilityrightslegalcenter.org</a></td>
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<td></td>
<td>(866) 999-3752</td>
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<tr>
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Domain 4- Spiritual Well Being: Family Caregivers
## Table of Contents for Domain 4- Spiritual Well Being

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>I. Introduction</td>
<td>D4CG-2</td>
</tr>
<tr>
<td>II. Distress Thermometer</td>
<td>D4CG-3</td>
</tr>
<tr>
<td>III. List of Symptoms</td>
<td>D4CG-3</td>
</tr>
<tr>
<td>IV. General Information on Caring for the Patient’s Spiritual Concerns</td>
<td>D4CG-4</td>
</tr>
<tr>
<td>V. Purpose and Meaning in Life</td>
<td>D4CG-6</td>
</tr>
<tr>
<td>VI. Hope</td>
<td>D4CG-6</td>
</tr>
<tr>
<td>VII. Redefining Self and Priorities in Life</td>
<td>D4CG-7</td>
</tr>
<tr>
<td>VIII. Inner Strength</td>
<td>D4CG-7</td>
</tr>
<tr>
<td>IX. Uncertainty</td>
<td>D4CG-8</td>
</tr>
<tr>
<td>X. Positive Changes</td>
<td>D4CG-8</td>
</tr>
<tr>
<td>XI. Spiritual Well Being Self-Care Plan</td>
<td>D4CG-9</td>
</tr>
<tr>
<td>XII. List of Spiritual Books and Websites</td>
<td>D4CG-13</td>
</tr>
</tbody>
</table>
Domain 4- Spiritual Well Being: Family Caregivers

**Domain 4 Introduction**

Spiritual well-being is focused on how living with a life-threatening disease such as lung cancer can impact a person’s spiritual or religious beliefs. Even people who don’t believe in a higher being have spiritual or existential questions when faced with a life-threatening illness such as lung cancer. An existential crisis happens when an individual questions the very foundations of his or her life: whether their life has any meaning, purpose or value. Spiritual values are important to patients and families coping with lung cancer. As a caregiver, your spiritual needs are very important to the well-being of the person who has cancer. It is important to make sure that your spiritual needs are met so that you are able to take part fully in your activities as a caregiver.

In this session, we will review some of the more common spiritual topics faced by your loved one with lung cancer. We will talk about how you can help your loved one manage his/her spiritual concerns. We will also talk about spiritual needs that you may experience as a cancer caregiver, and give you some self-care tips that can be used to manage your spiritual needs. We will continue working on developing your individualized self-care plan, which we started doing during our first session. Finally, at the end of the session, we will give you some resources that can help you be better prepared to meet you and your loved one’s spiritual needs.

At Kaiser, we have many services that are provided to help people cope with cancer. As we go through each of the sessions for this program, we will talk about how these services can help you as a family caregiver and refer you and your loved one to those services if needed.

In each of our sessions we will begin by asking you to give us some information about how you and your loved one are coping with lung cancer. Over the last two weeks ---

1. Have you noticed any changes in your loved one’s ability to function?
   - Bathing
   - Dressing
   - Walking
   - Mental status

2. Are you providing more or less personal care for your loved one?
   - More
   - Less
   - Same

3. What are the current goals of care or treatment plan for your loved one?
Domain 4- Spiritual Well Being: Family Caregivers

Next, we would like to rate your level of distress as a caregiver. This helps us to know overall how you are coping with your loved one’s lung cancer and your role as a caregiver. Using the thermometer below, please rate the number (0=no distress, 10=extreme distress) that best describes the overall distress you are feeling now.

My overall distress _______

It would be helpful if you would tell us what spiritual well-being topics you would like to learn about during today’s session. We find that asking you to identify which spiritual topics are most important makes the teaching more relevant to your personal needs as a cancer caregiver helping your loved one.

Below is a list of spiritual well-being topics that are common for patients who face lung cancer. Please pick three topics that you would like to learn about in today’s session. Your choices will help guide the content that we will cover for this session.

_____ Purpose and Meaning in Life (pg. 6)
_____ Hope (pg. 6)
_____ Redefining Self and Priorities in Life (pg. 7)
_____ Inner Strength (pg. 7)
_____ Uncertainty (pg. 8)
_____ Positive Changes (pg. 8)
Domain 4- Spiritual Well Being: Family Caregivers

GENERAL INFORMATION ON CARING FOR THE PATIENT’S SPIRITUAL CONCERNS

Key things to know:
- Spirituality is often defined as a search for meaning and purpose in life
- Beyond caring for the physical needs of your loved one, caregiving can also mean giving spiritual support
- You may be helping your loved one with lung cancer cope with his/her spiritual distress
- Keep in mind that taking care of your spiritual health makes you a more effective caregiver, which ultimately helps the person who is ill

Tips to help care for your loved one’s spiritual concerns:
- Ask to be referred to supportive services.
- If your loved one’s spiritual concerns are caused by uncontrolled symptoms such as pain or dyspnea, talk to your loved one’s doctor/nurse about better physical symptom management
- Call your loved one’s spiritual/religious counselor if you sense that your loved one:
  - Feels that he/she deserves this life-threatening illness
  - Feels that prayer or spiritual practices aren’t working
  - Used to believe in God, but now is not so sure
  - Has never believed in God, but now is beginning to wonder
  - Worries about how family/friends will get along without him/her
  - Is scared
- When your loved one is struggling with severe spiritual distress, do not leave him or her alone
- If available, encourage your loved one to accept outside help from your church/spiritual community (spiritual/religious leaders, church members)
- Encourage your loved one to use spiritual methods, such as prayer or reading spiritual writings, that may have helped him/her in the past
- Encourage your loved one to keep a journal or notebook to express their feelings and thoughts
- Provide a calm, safe, comforting environment and your calm presence
- Allow your loved one to express their feelings openly. Listen without judging or “cheerleading”
- Think about how you have helped each other feel better during a difficult time in the past. Do whatever works for you both and don’t be afraid to try something new
- Allow plenty of time for daily activities. Plan ahead. Do not rush yourself or your loved one
- Think about finding support as a caregiver, such as friends, other family members, or paying for outside help
- Help him/her live as normal a life as possible. To do this you might start by helping him decide what activities are most important. He may need to put aside those that are less important in order to do the things he enjoys most.
Domain 4- Spiritual Well Being: Family Caregivers

- Respect the need to be alone. Sometimes, we all need time alone -- even you
Domain 4- Spiritual Well Being: Family Caregivers

PURPOSE AND MEANING IN LIFE

Caregiver tips:

- Supportive care professionals that can help:
  - Spiritual counselor (chaplain)
  - Social worker
  - Psychologist
- What do you believe is your loved one’s purpose in life? Has this changed since his/her lung cancer diagnosis?
- Encourage your loved one to talk with a spiritual counselor or join a support group
- Encourage your loved one to use spiritual methods, such as prayer or reading spiritual writings, that may have helped him/her in the past
- Encourage your loved one to retreat to spiritual spaces and natural settings in the outdoors that may help with feeling a sense of peace
- Encourage your loved one to keep a journal or notebook to express his/her feelings and thoughts
- Consider joining a support group

HOPE

Caregiver tips:

- Supportive care professionals that can help:
  - Spiritual counselor (chaplain)
  - Social worker
  - Psychologist
- Help your loved one connect hope to things such as hoping that symptoms will get better or that he/she will be able to go home
- Encourage your loved one to talk with a spiritual counselor or join a support group
- Encourage your loved one to use spiritual methods, such as prayer or reading spiritual writings, that may have helped him/her in the past
- Encourage your loved one to retreat to spiritual spaces and natural settings in the outdoors that may help with feeling a spiritual sense of peace
- Encourage your loved one to keep a journal or notebook to express his/her feelings and thoughts
Domain 4- Spiritual Well Being: Family Caregivers

REDEFINING SELF AND PRIORITIES IN LIFE

Caregiver tips:
❖ Supportive care professionals that can help:
  • Spiritual counselor (chaplain)
  • Social worker
  • Psychologist
❖ What changes have occurred since your loved one’s cancer diagnosis? When he/she looks at life now, what is most important to him/her?
❖ Help your loved one redefine their goals and priorities
❖ Be flexible and patient with your loved one
❖ Encourage your loved one to talk with a spiritual counselor or join a support group
❖ Encourage your loved one to use spiritual methods, such as prayer or reading spiritual writings, that may have helped him/her in the past
❖ Encourage your loved one to keep a journal or notebook to express his/her feelings and thoughts
❖ Consider joining a support group

INNER STRENGTH

Caregiver tips:
❖ Supportive care professionals that can help:
  • Spiritual counselor (chaplain)
  • Social worker
  • Psychologist
❖ What are your loved one’s tasks for life and how have they changed since the lung cancer diagnosis? Do you know if your loved one has any unfinished business?
❖ Be flexible and patient with your loved one
❖ Encourage your loved one to use spiritual methods, such as prayer or reading spiritual writings, that may have helped him/her in the past
❖ Encourage your loved one to keep a journal or notebook to express his/her feelings and thoughts
❖ Consider joining a support group
Domain 4- Spiritual Well Being: Family Caregivers

UNCERTAINTY

Caregiver tips:
- Supportive care professionals that can help:
  - Spiritual counselor (chaplain)
  - Social worker
  - Psychologist
- Go to your loved one’s medical visits so you can help them hear what is being discussed and help with asking questions
- Help your loved one keep a journal or notebook to write down their questions and/or take notes during medical visits
- Help your loved one stay focused on what is happening right now
- Offer assurance regarding your commitment to be with him/her through this process

POSITIVE CHANGES

Caregiver tips:
- Supportive care professionals that can help:
  - Spiritual counselor (chaplain)
  - Social worker
  - Psychologist
- Since your loved one’s lung cancer diagnosis, has he/she experienced any positive changes? What types of positive changes happened?
- Encourage your loved one to keep a journal or notebook to identify and write down what positive changes happened since their diagnosis
- Encourage your loved one to use spiritual methods, such as prayer or reading spiritual writings, that may have helped him/her in the past
- Consider joining a support group
Domain 4- Spiritual Well Being: Family Caregivers

CARING FOR YOUR OWN SPIRITUAL NEEDS

Key things to know:
- Many caregivers find that cancer causes them to look at life in new ways
- They may reflect on spiritual concerns, the purpose of life, and what he/she values most
- It's normal to view the cancer experience both negatively and positively at the same time
- You and your loved one may be struggling to understand why cancer has entered your lives. You may wonder why you have to endure such a trial in your life
- You may have found that your faith, religion, or beliefs are a source of strength as you face life during cancer treatment
- Many say that through their faith, they have been able to find meaning in their lives and make sense of the cancer experience
- Spirituality can be a way for you and your loved one to connect with others in your community
- Hope may change as you go through lung cancer diagnosis and treatment with your loved one
- You may feel uncertain about not knowing what will happen next for your loved one
- Redefining yourself and your priorities means to identify what is important to you as a caregiver of someone who has a life-threatening illness such as lung cancer

How to talk about your spiritual needs:
- What does your loved one’s lung cancer and treatment mean to you?
- What are your hopes as a caregiver? Are you hoping that your loved one’s pain will get better? What are you hoping for today?
- When you look at your life now, what is important to you? What is important in relation to your family?
- I would like to ask you a few questions about your beliefs using a simple tool called FICA, to help me understand your spirituality
  - F = Faith and Belief
    - Do you consider yourself spiritual or religious? What gives your life meaning?
  - I = Importance
    - What importance do your beliefs or faith have in your life?
    - Have your beliefs influenced how you take care of yourself during your loved one’s life-threatening illness?
    - What role do your beliefs play in regaining your loved one’s health and your own well-being?
    - Do your beliefs influence your decisions about you and your loved one’s health care?
  - C = Community
    - Are you part of a spiritual or religious community?
    - Is this community of support to you and how?
Domain 4- Spiritual Well Being: Family Caregivers

- Is there a group of people you really love or who are important to you?
- A = Address in Care of Action
- How would you like your loved one’s healthcare team to address spiritual issues?
- What spiritual support do you need for you and your loved one while facing lung cancer?

Self-care tips:
- Call your spiritual/religious counselor if you sense that you:
  - Feel that prayer or spiritual practices aren’t working
  - Used to believe in God, but now are not so sure
  - Have never believed in God, but now am beginning to wonder
  - Are scared
- Write in a journal or notebook to express your thoughts and feelings
- If available, accept outside help from your church/spiritual community (spiritual/religious leaders, church members)
- Use spiritual methods, such as prayer or reading spiritual writings, that may have helped you in the past
- If needed, redefine your goals and priorities for your own life and as a caregiver
Domain 4- Spiritual Well Being: Family Caregivers

REFINING YOUR SELF-CARE PLAN

Key things to know:
- As a caregiver you need to balance caring for your loved one while keeping up with the needs of your family and your own needs.
- Your loved one’s needs are important; however it is also essential for you to stay in tune with the things you need to maintain your health and quality of life.
- One of the ways to take care of yourself is to use your self-care plan.
- Using your self-care plan will help improve your ability to cope as you deal with the many responsibilities in your caregiving role.

Refining your self-care plan:
- In today’s session, we will continue to develop your individualized self-care plan. Before we begin, have you been able to use the strategies that you chose during the last session to care for your social needs? Were there any activities that just didn’t fit or work for you? We can think about making revisions to your plan.
- For today, we will focus on your spiritual well-being. We will also have time today to revise and refine your self-care plan.

Assessment:
- To begin, let’s do some simple assessments.
- First, let’s review some of the common potential spiritual stressors for cancer caregivers.

Potential Caregiver Stressors:

<table>
<thead>
<tr>
<th>Spiritual</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Hopelessness</td>
</tr>
<tr>
<td>• Uncertainty</td>
</tr>
<tr>
<td>• Religious beliefs</td>
</tr>
<tr>
<td>• Meaning of illness</td>
</tr>
</tbody>
</table>

- Next, let’s discuss some of the strengths that you bring to your role as a caregiver. What are some of your personal strengths related to caring for your loved one’s spiritual concerns?
- Now, let’s consider your current coping strategies. What types of strategies have worked for you in the past to help address your own spiritual needs?
- Let’s also discuss your current self-care strategies for meeting your spiritual needs. What have you done in the past to take care of yourself spiritually?

Intention statement:
- Before beginning to write your self-care plan, let’s review the intention statement that you created. Has there been any change in how you want to define your goals for taking care of yourself?
Domain 4- Spiritual Well Being: Family Caregivers

Your spiritual well-being self-care plan:
- Using the information that we talked about today during this session, write at least one strategy you will use in the next week to help manage your spiritual needs.
- Include how often you will do it, and what support or resources you will need in order to do it.
- Make it a realistic strategy, and be as specific as you can.
- Spiritual well-being strategies: relaxation/inspirational music, prayer, going to religious services, speaking with spiritual counselors.
Domain 4- Spiritual Well Being: Family Caregivers

**Books/Websites**


Domain 4- Spiritual Well Being: Family Caregivers

Spiritual Well-Being Resources

Spiritual Directors International (to find a spiritual director)
http://www.sdiworld.org/find_a_spiritual_director

Retreat Centers
www.janjohnson.org/retreat_centers.html

List of local gardens for reflection, meditation

UC Riverside Botanical Gardens
http://gardens.ucr.edu/information.html

Fullerton Arboretum
http://fullertonarboretum.org/home.php

Moorten Botanical Garden and Cactarium
http://moortenbotanicalgarden.com/

Rancho Santa Ana Botanic Garden
http://www.rsabq.org/

UC Irvine Arboretum
http://arboretum.bio.uci.edu/

Classes/groups/directed retreats

Spiritual Growth Center (Catholic/Protestant) www.la-archdiocese.org/Pages/default.aspx

Center for Spiritual Development (Catholic/Protestant)
http://www.thecsd.com/

Holy Spirit Retreat Center (Catholic/Protestant)
http://www.hsrcenter.com/

Stillpoint (interfaith)
http://stillpointca.org/index.html

Labyrinth information
http://labyrinthsociety.org/resources
Introduction

Advances in cancer treatment and changing health care systems have led to shorter hospital stays and sicker people being cared for at home. Non-medical caregivers find themselves taking on roles that, just a short time ago, were carried out by trained health professionals. This guide gives you general information about caring for a person with cancer at home. It lists the more common problems people with cancer experience, signs of problems you can look for, and some ideas for things you can do if problems come up. It also lists some of the more common treatments and possible side effects that go with them. The information given here is not meant to replace talking with your doctor or nurse. The people who know your situation well can give you the information that you will need the most.

There are many other materials on cancer and cancer treatment that may be helpful to you. They are available from the local office of your American Cancer Society, on our Web site at cancer.org, or by calling 1-800-227-2345.

Trade names are used in this guide because they are well known. Their use does not represent any previous testing or backing by the American Cancer Society. Generic and other brands may be recommended by your doctor or cancer care team.

Anxiety and fear

Anxiety (a feeling of worry or unease) and fear are common feelings that patients and families sometimes have when coping with cancer. These feelings are normal responses to the stress of cancer, and may be more noticeable around the time the cancer is first diagnosed. Feelings of fear or anxiety may be due to changes in the ability to continue family duties, loss of control over events in life, changes in appearance or body image, or simply the shock of a cancer diagnosis. They may involve uncertainty about the future and concerns about suffering, pain, and the unknown. Fears around loss of independence, changes in relationships with loved ones, and becoming a burden to others may overwhelm the patient and complicate family life.

Family members may have these feelings because they, too, are uncertain about the future or angry that their loved one has cancer. They may feel guilt and frustration at not being able to "do enough." Or they may feel overwhelmed by everything they now have to do. Many caregivers feel stressed because of problems balancing work, child care, self care, and other tasks, along with more responsibility at home. All of this is on top of having to worry about and take care of the person with cancer.
Sometimes, a person with cancer may become overly anxious, fearful, or depressed and may no longer cope well with his day-to-day life. If this happens, it often helps the patient and family to get help from a professional therapist or counselor.

What to look for

- Feeling anxious
- Trouble thinking or solving problems
- Being nervous, agitated, irritable, or restless
- Feeling or looking tense
- Concern about "losing control"
- An uneasy sense that something bad is going to happen
- Trembling and shaking
- Headaches
- Being cranky or angry with others
- Tiredness or fatigue
- Trouble sleeping or restless sleep

What the patient can do

- Talk about feelings and fears that you or family members may have – it’s OK to feel sad and frustrated.
- Decide together with your family or caregiver what things you can do to support each other.
- Do not blame yourself and others when you feel anxious and afraid. Instead, look at your emotions, concerns, and beliefs about what has been going on in your life, and talk about those things.
- Get help through counseling and support groups.
- Use prayer, meditation, or other types of spiritual support.
- Try deep breathing and relaxation exercises several times a day. (For example, close your eyes, breathe deeply, focus on each body part, and relax it, starting with your toes and working up to your head. When you're relaxed, imagine yourself in a pleasant place, such as a breezy beach or a sunny meadow.)
• Cut down on caffeine. It can worsen anxiety symptoms.
• Think about asking your doctor or nurse for a referral to a counselor who can work with you and your family.
• Talk with your doctor about the possible use of medicine for anxiety.

What caregivers can do
• Gently invite the patient to talk about his fears and concerns.
• Do not try to force the patient to talk before he is ready.
• Listen carefully without judging the patient’s feelings, or your own.
• Decide together with the patient what you can do to support each other.
• For severe anxiety, it is usually not helpful to try to reason with the patient. Instead, talk with a doctor about the symptoms and problems you notice.
• To reduce your own stress, try suggestions from the above list or use any others that have worked for you in the past.
• Consider getting support for yourself through groups or individual counseling.

Call the doctor if the patient:
• Has trouble breathing
• Is sweating, with a fast or pounding heartbeat
• Is feeling very restless

Note that some medicines or supplements can cause or worsen anxiety symptoms. If anxiety gets worse after a new medicine is started, talk with your doctor about it.

For more in-depth information on anxiety and fear, call your American Cancer Society at 1-800-227-2345 and ask for a copy of the publication Anxiety, Fear, and Depression. You can also find information on the Web at cancer.org.
Appetite, poor

A person with a poor or no appetite may eat much less than he normally does or may not eat at all. A poor appetite can be caused by many things, such as trouble swallowing, depression, pain, nausea, or vomiting. (For more information on these causes, see the related sections in this booklet.) A poor appetite can also be due to a changed sense of taste or smell, feeling full, tumor growth, dehydration (see the section on fluids and dehydration in this booklet), or side effects of chemotherapy or radiation. A poor appetite is most often a short-term problem.

What to look for

- Lack of interest in food
- Refusing to eat favorite foods
- Weight loss

What the patient can do

- Talk with your doctor about what may be causing your poor appetite.
- Eat as much as you want to, but don’t force yourself to eat.
- Think of food as a necessary part of treatment.
- Start the day with breakfast.
- Eat small, frequent meals of favorite foods.
- Try foods high in calories that are easy to eat (such as pudding, gelatin, ice cream, sherbet, yogurt, or milk shakes).
- Add sauces and gravies to meats, and cut meats into small pieces to make them easy to swallow.
- Use butter, oils, syrups, and milk in foods to increase calories. Avoid low-fat foods unless fats cause heartburn or other problems.
- Try strong flavorings or spices.
- Create pleasant settings for meals. Soft music, conversation, and other distractions may help you eat better.
- Eat with other family members.
- Drink liquids between meals instead of with meals. (Liquids at mealtime can lead to early fullness.)
• Try light exercise an hour before meals.
• Hard candies, mint tea, or ginger ale may help get rid of strange tastes in the mouth.
• With your doctor’s OK, enjoy a glass of beer or wine before eating.
• Eat a snack at bedtime.
• When you don't feel like eating, try liquid meals, such as flavored supplements (such as Ensure, Sustacal, Boost, Carnation Instant Breakfast, and others). Using a straw may help.

What caregivers can do

• Try giving the patient 6 to 8 small meals and snacks each day.
• Offer starchy foods (such as bread, pasta, or potatoes) with high-protein foods, such as fish, chicken, meats, turkey, eggs, cheeses, milk, tofu, nuts, peanut butter, yogurt, peas, and beans.
• Keep cool drinks and juices within the patient’s reach.
• If the smell of food bothers the patient, offer bland foods served cold or at room temperature.
• Create pleasant settings for meals, and eat with the patient.
• Offer fruit smoothies, milkshakes, or liquid meals when the patient doesn't want to eat.
• Try plastic forks and knives instead of metal if the patient is bothered by bitter or metallic tastes.
• Don’t blame yourself when the patient refuses food or can’t eat.
• If the patient cannot eat, you may want to offer just your company. Or offer to read to them or give them a massage.

Call the doctor if the patient:

• Feels nauseated and cannot eat for a day or more
• Loses 5 pounds or more
• Feels pain when he eats
• Does not urinate for an entire day or does not move bowels for 2 days or more
• Does not urinate often, and when he does, the urine comes out in small amounts, smells strong, or is dark colored
• Vomits for more than 24 hours
• Is unable to drink or keep down liquids
• Has pain that is not controlled
Blood counts

Blood counts measure 3 important parts of blood:

The **hemoglobin** percentage measures the ability of the red blood cells to carry oxygen. A normal hemoglobin range is about 14.5 to 18 for men and 12 to 16 for women. Most people still feel well with a hemoglobin percentage as low as 10. A low hemoglobin level is called anemia.

The **white blood cell** count measures your body’s ability to fight infection. A normal white blood cell count is about 5,000 to 10,000. A low white blood cell count may put you at higher risk of infection. You will want to watch for signs of infection so that you can go to your doctor for treatment right away. A high white blood cell count may be a sign of an infection, or it may be due to certain types of disease.

The **platelet** count looks at the cells that help your blood to clot. A normal platelet count is about 150,000 to 450,000. Normal clotting is still possible with a platelet count of 100,000. Dangerous bleeding may occur when the platelet count goes below 20,000.

After cancer treatment, it may take a few weeks for your counts to get back to normal. If you see any other doctors or dentists during this time, be sure they know your counts are low. Some very common treatments may cause problems for you. Call the American Cancer Society at 1-800-227-2345 and ask for a copy of *Understanding Your Lab Results* if you would like to know more about what your lab values mean.

**Low hemoglobin**

What to look for

- New or worsening tiredness that makes it harder to do your regular activities
- Chest pain or shortness of breath
- Pale skin, nail beds, or gums
- Dizziness
- Weakness
- Blood in stool (bright red, dark red, or black stools)
- Vomiting dark brown or bright red material

(The last 2 are signs of bleeding, which can cause anemia.)

What the patient can do

- Balance rest and activities.
- Tell the doctor if you’re not able to get around as well as usual.
- Plan your important activities when you have the most energy.
- Eat a balanced diet that includes protein (meat, eggs, cheese, and legumes such as peas and beans) and drink 8-10 glasses of water a day, unless your care team gives you other instructions.

What caregivers can do

- Help schedule friends and family members to prepare meals, clean house, do yard work, or run errands for the patient.
• Watch for confusion, faintness, or dizziness, as noted below.

Call the doctor if the patient:
• Has chest pains
• Has shortness of breath when resting
• Feels dizzy or faint
• Becomes confused or cannot concentrate
• Has not been able to get out of bed for more than 24 hours
• Has blood in his stool
• Vomits dark brown or bright red material
Low white blood cell count

What to look for

• Temperature of more than 100.5° F when taken by mouth
• Any new area of redness or swelling
• Pus or yellowish discharge from an injury or other location
• New cough or shortness of breath
• New abdominal pain
• Shaking chills that may be followed by sweating
• Burning or pain when urinating
• Sore throat
• Sores or white patches in the mouth

What the patient can do

• Check your temperature by mouth or under your armpit if you can’t keep a thermometer in your mouth.
• Take acetaminophen (Tylenol) for a fever after calling your doctor.
• Keep warm.
• Take antibiotics or other medicine as prescribed.
• Drink fluids, but do not force more than you can tolerate.
• Avoid anything that can cause cuts in the skin.
• Wash cuts and scrapes with soap and water every day, apply antibiotic ointment, and keep them covered until healed.
• Keep your body clean by bathing daily and washing your hands after using the bathroom.
• Avoid crowds, and don't visit with people who have infections, coughs, or fevers.
• Talk with your doctor or nurse about eating raw fruits and vegetables. Some suggest eating only cooked fruits and vegetables until the white blood cell counts come up again. If you eat raw foods, wash them carefully and peel them to avoid germs.
• Keep your mouth clean by brushing your teeth twice a day and flossing once a day (unless you were told not to floss).
• Use a stool softener to avoid constipation and straining during a bowel movement. Do not use enemas or suppositories of any kind. (See the section on constipation in this booklet.)
• If constipated, see the section in this booklet on constipation. Check with your doctor before using laxatives.
• Drink 2 to 3 quarts of liquid each day, if your doctor approves.

What caregivers can do
• Watch for shaking chills, and check the patient’s temperature after the shaking stops.
• Check the patient's temperature by placing the thermometer in the patient’s mouth or under his armpit. (Do not take a rectal temperature.)
• Encourage visitors who have fevers or the flu to visit the patient only by phone until they are well.
• Offer extra fluids.
• Help the patient take medicines on schedule.

Call the doctor if the patient:
• Has a temperature of more than 100.5° F when taken by mouth
• Has shaking chills
• Feels or seems "different" to others
• Cannot take fluids
Low platelet count

What to look for

- Bleeding from anywhere (such as mouth, nose, or rectum)
  - New bruises on the skin
  - Red rash that looks like pinpoint dots, usually starting on feet and legs
  - Bad headaches, dizziness, or blurred vision
  - Weakness that gets worse
  - Pain in joints or muscles
  - Vomiting blood or dark material that looks like coffee grounds
  - Blood in stool (bright red, dark red, or black stools)
  - More than the usual amount of vaginal bleeding during monthly periods

What the patient can do

- Use only an electric razor (not blade) for shaving.
- Avoid contact sports (such as wrestling, boxing, or football) and any other activities that might result in injury.
- Protect your skin from cuts, scrapes, and sharp objects.
- Use a soft toothbrush.
- If your mouth is bleeding, rinse it out with cold water.
- Talk to your doctor or nurse about whether you should put off flossing your teeth until platelet counts improve.
- Do not blow your nose or cough with great force.
- Stay upright; keep your head level with or above your heart.
- Avoid placing anything in the rectum, including suppositories, enemas, thermometers, etc.
- Stay away from anti-inflammatory pain medicines, such as naproxen or ibuprofen, or medicines that contain aspirin unless your doctor tells you to use them.
- If bleeding starts, stay calm. Sit or lie down and get help.

What caregivers can do

- For nosebleeds, have the patient sit up with head tilted forward, to keep blood from dripping down the back of the throat. Put ice on the nose and pinch the nostrils shut for 5 minutes before releasing them. Ice on the back of the neck may also help.
- For bleeding from other areas, press on the bleeding area with a clean, dry washcloth until bleeding stops.

Call the doctor if the patient:

- Has bleeding or any of the symptoms listed in the "What to look for" section above
- Has trouble speaking or moving
Blood in stool

Blood in the stool may be caused by irritation of the bowel during a bowel movement. It can also be caused by straining very hard, by an ulcer or a tumor in the bowel, by hemorrhoids (enlarged blood vessels in or around the anus), by a pressure sore or ulcer in the anal area, or by a low platelet count. (See the section in this booklet on blood counts.)

What to look for

• Blood on toilet tissue
• Blood on underwear, sheets, or underpads
• Streaks of blood in stool
• Bright red blood from rectum
• Dark red or black bowel movements (But remember that eating beets can cause red stools, and iron tablets or bismuth medicines such as Pepto-Bismol and Kaopectate can cause black stools for a short time. This is normal.)

What the patient can do

• Check how much blood is being passed.
• Avoid placing anything in the rectum, including suppositories, enemas, thermometers, etc.
• Keep stool soft by taking in plenty of fluids and fiber.
• Use stool softeners, and avoid enemas or laxatives.
• Wash anal area very carefully with warm, soapy water, rinse well, and pat dry.
• Take a sitz bath (sitting in warm water), which may be helpful for hemorrhoids.

What caregivers can do

• Help the patient watch for bleeding.
• Offer extra fluids, fruits, and vegetables to keep the patient's stool soft.

Call the doctor if the patient:

• Has blood on toilet tissue 2 or more times
• Has blood streaks in stool
• Has bright red blood from rectum
• Has dark red or black stools
Blood in urine

Blood can be seen in the urine when a patient is bleeding in some part of his urinary system and the blood is being flushed out along with the urine. Common causes include urinary tract infections (UTIs), an injury to the urinary tract, kidney or bladder stones, a tumor growing in the urinary tract, or a low platelet count. (See the section in this booklet on blood counts.)

What to look for

• red, pink, or tea-colored urine
• blood or clots in urine
• pain with urination

What the patient can do

• Drink about 1 quart of water (or other fluids) during each 8-hour period (3 quarts each day), unless your doctor has limited the amount you can drink.
• Take medicines as prescribed.

What caregivers can do

• Offer extra fluids.
• Help the patient watch his urine, if needed.

Call the doctor if the patient:

• sees blood in the urine or discolored urine
• has pain in lower back or on lower sides of back when urinating
• has pink, cloudy, or foul-smelling urine
• has symptoms that do not improve after treatment
• has a sudden, urgent need to urinate
• urinates more often than usual
• is unable to urinate
• has a fever of more than 100.5° F when taken by mouth, or shaking chills
• is confused or feels or seems "different" to others
Bone marrow or stem cell transplants

Stem cells are cells in the bone marrow (the spongy, liquid center of certain bones) that constantly make blood cells for the body. Stem cell transplants are used to restock the bone marrow when it has been destroyed by chemotherapy, radiation, or disease. Stem cells can be taken from bone marrow or blood. Stem cells may be the patient’s own (autologous), or they may come from someone else (allogeneic).

Bone marrow transplants (BMTs) were the first method for replacing stem cells, but are used less often today. Now, peripheral blood stem cell transplant (SCT) is the most common method. In peripheral blood stem cell donation, stem cells are taken from circulating blood. Before collection, the donor must take special medicines to cause stem cells to grow and enter the bloodstream.

Your doctor or cancer care team will be able to tell you more about treatment or clinical trials using stem cell transplants.

If you have had a BMT/SCT

What to look for

- skin rashes, especially on palms of hands or soles of feet
- poor appetite, weight loss
- shortness of breath or cough
- tiredness or fatigue
- pain or aching
- stomach cramps
- nausea or vomiting
- mouth sores or dryness
- diarrhea
- skin or whites of eyes begin to look yellow
- dizziness, paleness, or other signs of low hemoglobin (See the section in this booklet on blood counts and low hemoglobin.)
- fever, shaking chills, or other signs of infection (See the section in this booklet on blood counts and low white blood cells.)
- blood in stool or urine, bleeding from anywhere (See the section in this booklet on blood counts and low platelets.)

What patients can do

- Go to every scheduled appointment.
- Ask questions. Your cancer care team will help you.
- Ask about side effects and what to do if you have them.
- Take medicines exactly as prescribed.
- Ask about when you should notify your doctor of any changes.
- If you are having other symptoms, such as nausea or vomiting, please see the related sections in this booklet and call your doctor.
What caregivers can do

• Go with the patient to appointments, and ask the cancer team about any concerns you have.
• Help watch for side effects and symptoms, and see the sections in this booklet related to those side effects.

Call the doctor if the patient:

• has any of the problems above or other symptoms that cause concern
• has a question or hears things about stem cell or bone marrow transplants that concern him

For more in-depth information on bone marrow or peripheral blood stem cell transplants, call your American Cancer Society at 1-800-227-2345 and ask for a copy of *Bone Marrow and Peripheral Blood Stem Cell Transplants*. You can also find information on the Web at cancer.org.
Chemotherapy

Chemotherapy is the use of drugs to kill cancer cells. It is often just called "chemo." The drugs are given in the form of injections or pills. They enter the bloodstream and reach all areas of the body. Chemo may be used along with surgery and other types of treatment in hopes of a cure, to get cancer into remission, or as a way to relieve symptoms in advanced cancer.

Another way to use these drugs is to inject them directly into the affected area of the body. This is called "regional chemo," and it is only used for certain types of cancer. It allows a higher dose of medicine to go right to the cancer site.

Side effects from chemo depend on the type of drug, how much is used, how often it is given, and for how long. Side effects can include short-term hair loss, fatigue, nausea, and vomiting, to name a few. There are drugs and other treatments to help with chemo side effects. It is important to know that many patients have few or no side effects. No one can predict who will and who will not. You may be among those who have few problems.

What the patient can do

- Find out what chemo drugs you will be taking, how they will be given, and how often and how long you will get them.
- Ask your doctor or nurse about side effects that might happen with the drugs you are taking and what you can do to prevent or reduce them.
- Ask about things you should or should not do during chemo.
- Talk with your doctor about how chemo will affect your plans to have children. (See the section on sexuality in this booklet.)
- Do not get pregnant while you are getting chemo. Ask your doctor how long you should wait after chemo to try to get pregnant.
- Learn how to contact your doctor or nurse during non-office hours.
- Find out whether you should take vitamins or supplements during your chemo.
- Before chemo starts, get all prescriptions filled and be sure you understand how to use each one.
- Go to every scheduled appointment.
- Report all side effects to your doctor.
- If you have nausea and vomiting, see the related sections in this booklet, and talk to your doctor.
- If you feel fatigued or tired, see the section on fatigue in this booklet.
- If you are suffering from diarrhea or constipation, see the related sections in this booklet.
- See the section in this booklet on blood counts if your hemoglobin, platelet, or white blood cell counts are low.
- For hair loss, you can wear hats, cotton scarves, or a wig. In cold weather, cover your head and ears. (See the section on hair loss in this booklet for more information.)
- Eat as much as you can. If you're not hungry, see the section in this booklet on appetite.
- If you have a fever, see the related section in this booklet.
What caregivers can do

• Go with the patient to appointments, especially on chemo days.
• If you are unable to drive or go for appointments, talk with the social worker or nurse at the doctor’s office to get help.
• Know how to get in touch with the patient's doctor, even when the office is closed.
• If the patient is unable to get to an appointment, talk with the doctor or nurse as soon as possible, and plan what to do next.
• Be sure that someone is with the patient during the first couple of days after each chemo treatment, since more help may be needed at those times.
• Help watch for side effects and symptoms, and see the sections related to those side effects in this booklet.

Call the doctor if the patient:

• has any side effect that lasts more than a day
• has a fever of more than 100.5°F when taken by mouth
• has any bleeding
• has pain or redness at the IV site where the chemo was given
• becomes unable to swallow or keep down chemo pills or liquids

For more in-depth information on chemo, call the American Cancer Society at 1-800-227-2345. You may want to ask for a copy of Understanding Chemotherapy: A Guide for Patients and Families and/or Oral Chemotherapy: What You Need to Know. You can also get information on each chemotherapy drug you will be taking and find out more about the type of cancer you have. This information is also available on cancer.org.
Clinical trials

Before a new treatment can be used on people, it is studied in the lab. If lab studies suggest the treatment will work, the next step is to test its value for patients. These studies in humans are called clinical trials. Clinical trials are needed to find new and better ways to treat people with cancer. You cannot be placed in a clinical trial without first volunteering for it, being informed about it, and signing a special consent form for it. Clinical trials are carried out in steps called phases. Each phase is designed to answer certain questions.

The main questions the researchers want to answer are:

- Is this treatment helpful?
- How does it work?
- Does it work better than the one we’re now using?
- What side effects does it cause?
- Do the benefits outweigh the risks, including the side effects?
- Which patients are most likely to find this treatment helpful?

During cancer treatment, your doctor may suggest taking part in a clinical trial. This does not mean that you are being asked to serve as a human "guinea pig." Nor does it mean that your case is hopeless and that your doctor is suggesting a last-ditch effort. A clinical trial is done only when there is some reason to believe that the treatment being studied may be more helpful than what is now in use.

Ask your doctor if there is a clinical trial that might be right for you. Then learn all you can about it. There may be risks as well as benefits. If you change your mind, you can leave the clinical trial at any time.

What the patient can do

- Ask about the purpose of the clinical trial.
- Ask about what the clinical trial involves, including what kinds of tests and treatments it might include.
- Ask about what other treatments might work for you if you do not take part in the clinical trial.
- Ask about how the study can affect your daily life.
- Ask about side effects that might result from the treatment and what can be done about these side effects.
- Ask how long the study will last.
- Ask about the need to be in the hospital, and find out how long and how often you may need to be in the hospital.
- Ask about the costs. Will any of the treatment be free? Will your insurance cover the costs?
- Ask about what treatment will be offered if you should be harmed as a result of the clinical trial.
- Ask about the type of long-term follow-up care that is offered as part of the clinical trial.
• Ask what will happen and how to go about it if you decide to drop out of the clinical trial.

What caregivers can do

• Encourage the patient to ask the doctor about clinical trials.
• Go with the patient to learn about any clinical trial he is considering.
• Be sure the patient’s questions have been answered to his satisfaction before enrolling in a clinical trial.

For more in-depth information on clinical trials, call your American Cancer Society at 1-800-227-2345. You may want to ask for a copy of Clinical Trials: What You Need to Know. You can also find more information on the Web at cancer.org.
Confusion

When the thought process is disturbed, or when a person has trouble thinking and acting like he normally does, he may be confused. There can be many causes of confusion, including:

- Low blood sugar
- Infection
- High fever
- Tumor spread into the brain
- Cancer in the fluid surrounding the brain
- Lack of oxygen to the brain
- Too much calcium in the blood
- Intense pain
- Too much pain medicine

Confusion can start or get worse when the patient goes to a new place and may worsen at night. Usually the cause of the confusion can and should be treated.

If a person becomes confused, call the doctor right away. The patient may need to see the doctor quickly so the cause of the problem can be found and treated. Sometimes, the patient may need to be in the hospital until the problem is treated. During this time, it is helpful for confused patients to have someone they know stay with them.

What to look for

- Sudden change in ability to speak, especially long pauses or slurred words
- Trouble staying alert or paying attention
- Patient needs help bathing and dressing when he was able to manage alone before
- Cloudy, disorganized thinking or a patient not knowing where he is
- Sudden changes in emotion; for instance, quick shifts from happy to irritated
- Forgetting what he is doing

What the patient can do

- Call the doctor right away if you realize you are having periods of confusion.
- Ask someone to stay with you to help keep you safe.

What caregivers can do

- Go to doctor's appointments with the patient so that you can describe the patient's problems and remember instructions for him.
- Focus attention by gently touching the patient and facing the patient when talking to him.
- Stay within a few feet of the patient when you are talking to him.
- Always tell the patient who you are.
- Turn off the radio or TV when you are talking.
- Talk slowly and use short sentences.
• Tell the patient the date, time, and where he is.
• Keep a calendar and clock where the patient can see them.
• Tell the patient just before you start doing something (such as changing the bed, dressing, or bathing them) and explain each step as you go along.
• Play soft, soothing music when the patient is in the room alone.
• Use a night-light so that the patient can see where he is.
• Label commonly used items with pictures. For example, put a picture of a toilet on the bathroom door and a picture of a flame over the stove.
• Protect the patient from injury.
• Help the patient with washing, going to the bathroom, and other daily activities that may be hard for him to do alone.
• Check to see what the patient eats. (He may forget to eat, or may not be able to eat.)
• Be sure that the patient takes the right medicines as prescribed.
• Keep medicines out of reach between doses.

Call the doctor if the patient:
• Becomes confused suddenly or if confusion worsens
• Has any sudden changes in his ability to do routine tasks or care for himself
• Becomes violent
• Hurts himself in some way
Constipation

Constipation is the infrequent or difficult passage of hard stool (feces), which often causes pain and discomfort. It is caused by too little fluid or not enough movement in the bowel. Lack of activity, weakness, ignoring the urge to have a bowel movement, pain medicine, or poor food and fluid intake can all add to this problem.

What to look for

- Small, hard bowel movements
- Leakage of soft, liquid stool that looks like diarrhea
- Stomach ache or cramps
- Passing a lot of gas or frequent belching
- Belly looks blown up or puffy
- No regular bowel movement within the past 3 days
- Vomiting or nausea
- Feeling of fullness or discomfort

What the patient can do

- Drink more fluids. Pasteurized fruit juices and warm or hot fluids in the morning are especially helpful.
- Increase the amount of fiber in the daily diet by eating foods such as:
  - Whole-grain breads and cereals
  - Fresh raw fruits with skins and seeds
  - Fresh raw vegetables
  - Fruit juices
  - Dates, apricots, raisins, prunes, prune juice, and nuts
- Avoid foods and drinks that cause gas, such as cabbage, broccoli, and fizzy drinks.
- Avoid or cut back on any foods that make you constipated, such as cheese or eggs.
- Get as much light exercise as you can.
- Do not use enemas or suppositories. Use stool softeners or laxatives only after talking with your doctor or nurse.
- Go to the bathroom as soon as you have the urge to have a bowel movement.
- Keep a record of bowel movements so that problems can be noticed quickly.

What caregivers can do

- Offer prune juice, hot lemon water, coffee, or tea to help stimulate bowel movements.
- Encourage extra fluids.
• Help keep a record of bowel movements.
• Offer high-fiber foods, such as whole grains, dried fruits, and bran.
• Talk with the doctor before using laxatives.

**Call the doctor if the patient:**

• Has not had a bowel movement in 48 hours
• Has blood in or around anal area or in the stool (See the section on blood in stool in this booklet.)
• Cannot move bowels within 1 or 2 days after taking laxative
• Has cramps or vomiting that doesn't stop
Depression

Some degree of depression is common when patients and family members are coping with cancer. Sadness and grief are normal, as are a range of other emotions. But when these feelings last a long time or get in the way of day-to-day activities, there is reason for concern. Clinical depression, a treatable illness, occurs in about 1 in 4 people with cancer. Depression causes greater distress, impaired functioning, and less ability to follow treatment plans. People who have had 1 or more bouts of serious depression are more likely to have depression after their cancer diagnosis.

The symptoms of clinical depression are listed below. Family and friends can look for these symptoms in a cancer patient and encourage him to get help for depression when symptoms are noticed. Patients do not usually have symptoms of anxiety and depression at the same time. (See the section on anxiety in this booklet.)

Treatments for depression in cancer patients include medicine, counseling, or a combination of both, and sometimes other specialized treatments. These treatments improve the depression, reduce the suffering, and help the person with cancer have a better quality of life.

What to look for

**Symptoms of clinical depression:**

- Sad or "empty" mood almost every day for most of the day
- Loss of interest or pleasure in activities that were once enjoyed
- Eating problems (loss of appetite or overeating), including weight loss or gain*
- Sleep changes (inability to sleep, early waking, or oversleeping)*
- Fatigue or decreased energy almost every day*
- Other people notice that you are restless or "slowed down" almost every day
- Feelings of guilt, worthlessness, and helplessness
- Trouble concentrating, remembering, or making decisions
- Thoughts of death or suicide, or attempts at suicide
- Wide mood swings from depression to periods of agitation and high energy

If 5 or more of the above symptoms last for 2 weeks or longer or are severe enough to hinder normal functioning, an evaluation for clinical depression by a qualified health professional or mental health specialist is recommended.

*Physical problems such as fatigue, poor appetite, and sleep changes can also be side effects of cancer treatment, and may linger after cancer treatment is over. Talk to your doctor about the possible causes of these symptoms and whether depression might be a factor.

What the patient can do

- Talk about feelings and fears that you or family members may have. It’s OK to feel sad and frustrated.
  - Listen carefully to each other.
  - Decide together what you can do to support each other.
  - Encourage, but do not force, one another to talk.
- Seek help through counseling and support groups.
• Use prayer or other types of spiritual support.
• Try deep breathing and relaxation exercises several times a day. (For example, close your eyes, breathe deeply, focus on each body part, and relax it, starting with your toes and working up to your head. When you're relaxed, imagine yourself in a pleasant place, such as a breezy beach or a sunny meadow.)
• Talk with your doctor about the possible treatments for anxiety or depression.
• Consider working with a professional counselor to deal with the changes in your life.
• Be sure the doctor has a list of all drugs you are taking before antidepressants are started.
• Take all medicines as prescribed.
• Expect antidepressants to take at least 2 to 4 weeks to improve your depression symptoms. Sometimes, stimulant drugs are used during this time to relieve symptoms.
• Let your doctor know if you are having side effects after starting an antidepressant.
• Avoid alcohol while on an antidepressant unless you check with your doctor or pharmacist.
• Find out if the antidepressant causes drowsiness before you try to drive.
• Do not suddenly stop taking the antidepressant medicine.

What caregivers can do
• Gently invite the patient to talk about his fears and concerns.
• Do not force the patient to talk before he is ready.
• Listen carefully without judging the patient’s feelings or your own. It is OK to point out and disagree with negative or self-defeating thoughts.
• Decide together what you can do to support each other.
• Avoid telling the person to "cheer up" if he is depressed.
• Do not try to reason with the person if fear, anxiety, or depression is severe. Talk with the doctor about medicines and other kinds of help.
• If necessary, help make the appointment for evaluation or treatment and take the patient to the doctor.
• Engage the person in activities he enjoys.
• If the patient starts antidepressants, encourage him to continue treatment until symptoms improve (which may take 2 to 4 weeks) or to seek different treatment if symptoms don't improve.
• Reassure the depressed person that with time and treatment, he will begin to feel better.
• Keep in mind that caregivers can also become depressed. All these suggestions may be used for caregivers, too.
• Take time to care for yourself. Spend time with friends or doing activities you enjoy.
• Consider getting support for yourself through groups or individual counseling.

Call the doctor if the patient:
• Has thoughts of suicide, or cannot stop thinking about death
• Behaves in such a way that you are concerned for his safety
• Cannot eat or sleep and is not interested in the activities of daily living for several days
• Has trouble breathing, is sweating, or feels restless

For more in-depth information on depression, call your American Cancer Society at 1-800-227-2345 and ask for a copy of *Anxiety, Fear, and Depression*. You can also find more information on the Web at cancer.org.
Diarrhea

Diarrhea is the passage of loose or watery stools 3 or more times a day with or without discomfort. It happens when the water in the intestine is not being absorbed back into the body for some reason. Sometimes, diarrhea can be caused by an overflow of intestinal liquids around stool that is lodged in the intestine (impaction). Other causes can include chemotherapy; radiation therapy to the abdomen; medicines; infections; surgery; anxiety; supplemental feedings that contain large amounts of vitamins, minerals, sugar, and electrolytes; and tumor growth. Diarrhea caused by chemotherapy or radiation therapy may last for up to 3 weeks after treatment ends.

What the patient can do

• Try a clear liquid diet (one that includes water, weak tea, apple juice, peach nectar, clear broth, popsicles, and gelatin with no solids added) as soon as diarrhea starts or when you feel that it’s going to start. Avoid acidic drinks, such as tomato juice, citrus juices, and fizzy soft drinks.
• Eat frequent small meals. Do not eat foods that are very hot or spicy.
• Avoid greasy foods, bran, raw fruits and vegetables, and caffeine.
• Avoid pastries, candies, rich desserts, jellies, preserves, and nuts.
• Do not drink alcohol or use tobacco.
• Avoid milk or milk products if they seem to make diarrhea worse.
• Be sure your diet includes foods that are high in potassium (such as bananas, potatoes, apricots, and sports drinks such as Gatorade or Powerade). Potassium is an important mineral that you may lose if you have diarrhea.
• Monitor the amount and frequency of bowel movements.
• Clean your anal area with a mild soap after each bowel movement, rinse well with warm water, and pat dry. Or use baby wipes to clean yourself after each bowel movement.
• Apply a water-repellent ointment, such as A&D Ointment or petroleum jelly, to the anal area.
• Sitting in a tub of warm water or a sitz bath may help reduce discomfort.
• Take medicine for diarrhea as prescribed by your doctor.
• When the diarrhea starts to improve, try eating small amounts of foods that are easy to digest such as rice, bananas, applesauce, yogurt, mashed potatoes, low-fat cottage cheese, and dry toast. If the diarrhea keeps getting better after a day or 2, start small regular meals.

What caregivers can do

• See that the patient drinks about 3 quarts of fluids each day.
• Keep a record of bowel movements to help decide when the doctor should be called.
• Check with the doctor before using any over-the-counter diarrhea medicine. Many of these contain compounds that are like aspirin, which can worsen bleeding problems. Talk to the doctor about using a prescription medicine.
• Check the anal area for red, scaly, broken skin. If present, see the section in this booklet on skin sores.
• Protect the bed and chairs from being soiled by putting pads with plastic backing under the buttocks where the patient will lie down or sit.

Call the doctor if the patient:

• Has 6 or more loose bowel movements a day with no improvement in 2 days
• Has blood in or around anal area or in stool (See the section in this booklet on blood in stool.)
• Loses 5 pounds or more after the diarrhea starts
• Has new abdominal pain or cramps for 2 days or more
• Does not urinate for 12 hours or more
• Does not drink liquids for 48 hours or more
• Has a fever of 100.5° F or higher when taken by mouth
• Gets a puffy or swollen belly
• Has been constipated for several days and then begins to have small amounts of diarrhea or oozing of liquid stool, which could suggest an impaction (severe constipation)
Exercise

It is important to exercise as much as you can to keep muscles working as well as possible. Exercise helps prevent problems that are caused by long-term bed rest, such as stiff joints, weak muscles, breathing problems, constipation, skin sores, poor appetite, and mental changes. It also helps reduce stress and relieve fatigue. Talk with your doctor about exercises that you can safely do, and then set goals for slowly increasing your physical activity level. If you have trouble moving around, please see the section in this booklet on weakness.

What the patient can do

• Do as much daily self-care as possible.
• Take a walk every day.
• Do range-of-motion exercises as instructed by your nurse, doctor, or physical therapist. Active range of motion is when you move a joint without any help from others. Passive range of motion is when someone else moves it for you. You can do either type of range-of-motion exercises without getting out of bed. Avoid moving any joint that is painful.

What caregivers can do

• Go with the patient on walks or other exercise outings.
• Encourage the patient to do as much as possible for himself.
• Talk with the doctor or nurse about range-of-motion exercises if the patient has trouble getting out of bed. You may remind the patient to do active range-of-motion exercises several times a day, if he is able. If not, you may learn to help the patient with passive range of motion.

Call the doctor if the patient:

• Gets weaker, starts losing his balance, or starts falling
• Has new pain or pain that gets worse
• Has headaches or gets dizzy
• Has blurred vision, new numbness, or tingling in arms or legs
Falls

A person who is unsteady on his feet, a little confused, or just weak is at high risk for falling. A person who has these problems is likely to fall while trying to get out of bed. Or the patient can fall off the toilet or commode, slip in the bathtub or shower, or tire out and fall as he is walking.

What the patient can do

- If you notice problems with weakness or poor balance, ask for help getting up or walking.
- If you fall, let your doctor and your caregivers know. They will want to help prevent future falls, and may need to check you for injuries.
- If you have trouble walking, ask your doctor about a home health nursing visit. Home care nurses may be able to make your home safer for you. They also have ways to help you walk more safely.

What caregivers can do

- When the patient needs to get out of bed, first sit him on the side of the bed for a minute or so. This will help if the change in position causes the patient to be dizzy or unsteady.
- If the patient is unsteady, help him when walking.
- If the patient feels light-headed, stay with the patient when he goes to the bathroom.
- Remind the patient to call for help before trying to get up.
- To help in the tub or shower, use bath mats or non-slip stickers. You can also use a shower stool or chair so the patient can sit while bathing.
- Keep electric cords off the floor. Walking paths need to be clear of clothing, throw rugs, and other items that may cause tripping or slipping.
- Tape the edges of rugs to the floor.
- Have a bedpan or urinal within easy reach.
- If possible, place a commode near the bed, or place the bed near a bathroom.
- The patient should wear shoes or non-skid slippers when walking or standing. Avoid using slippery shoes or open-heel bedroom slippers.
- Ask the doctor about a home health care visit to check your home for ways to prevent falls. Handrails, bedside commodes, grab bars, shower chairs, and other tools can help keep some patients from falling.

If the patient falls:

- Leave the patient where he has fallen until you can find out if there are serious injuries.
- If the patient is unconscious, bleeding, or has fluid draining from the mouth, ears, or nose, call the doctor or emergency services (911) right away.
- If the patient is not breathing, call 911 unless the patient is in hospice or has a Durable Power of Attorney for Health Care that states his wish not to be revived.
- If the patient can respond to you, ask if he feels any pain.
- Check the patient’s head, arms, legs, and buttocks for cuts and bruises, and look to see if the area looks strange or out of shape (possibly due to a broken bone).
• Apply ice packs and pressure to any bleeding area. (Put ice in a plastic bag and wrap bag in a towel.)

• If you cannot move the patient, make him as comfortable as possible until help comes. • If the patient is not in pain and is not bleeding, help him back to a bed or chair. (If possible, have 2 people move the patient.)

Call the doctor if the patient:

• Notices new weakness, numbness, or change in mental status (such as if the patient is confused, doesn’t know where he is, becomes forgetful, or isn’t making sense)

• Gets weak or unsteady enough that a fall is likely

• Is not breathing

• Has bleeding, has fluid draining from the mouth, ears, or nose, or is unconscious

• Is concerned about possible injury from a fall
**Fatigue**

Fatigue is when a person has less energy to do the things he normally does or wants to do. It is the most common side effect of cancer treatment. Cancer treatment fatigue is different from that of everyday life. Fatigue related to cancer treatment can appear suddenly and can be overwhelming. It is not relieved by rest. It can last for months after treatment ends. This type of fatigue can affect many aspects of a person’s life, including the ability to do his usual activities.

Cancer fatigue is real and should not be ignored. It can be worse when a person is dehydrated, anemic, in pain, not sleeping well, or has an infection. (See the sections in this booklet on fluids and dehydration, blood counts, pain, sleep problems, and fever.) Recent studies have shown that exercise programs during treatment can help reduce fatigue.

**What to look for**

- Feeling like you have no energy
- Sleeping more than normal
- Not wanting to or not being able to do normal activities
- Paying less attention to personal appearance
- Feeling tired even after sleeping
- Trouble thinking or concentrating
- Trouble finding words and speaking

**What the patient can do**

- Balance rest and activities.
- Tell the doctor if you’re not able to get around as well as usual.
- Plan your important activities for when you have the most energy.
- Schedule important activities throughout the day rather than all at once.
- Get enough rest and sleep. Short naps and rest breaks may be needed.
- Remember that fatigue caused by treatment is short term and that your energy will slowly get better after treatment has ended.
- Ask others to help you by cooking meals and doing housework, yard work, and errands.
- Eat a balanced diet that includes protein (meat, eggs, cheese, and legumes such as peas and beans) and drink about 8 to 10 glasses of water a day, unless your care team gives you other instructions.
- See the section in this booklet on exercise.

**What caregivers can do**

- Help schedule friends and family members to prepare meals, clean house, do yard work, or run errands for the patient.
- Try not to push the patient to do more than he is able.
- Help the patient set up a routine for activities during the day.

**Call the doctor if the patient:**

- Is too tired to get out of bed for more than a 24-hour period
• Becomes confused (see the section in this booklet on confusion) or cannot think clearly
• Has trouble sleeping at night
• Has fatigue that keeps getting worse
• Feels out of breath or has a racing heart after only a small activity
Fever

Fever is a body temperature of more than 100.5°F (when taken by mouth) that lasts for a day or more. Fever is usually caused by an infection. Infections can be viral (in which case the symptoms can be treated even though there may be no treatment for the cause), or they can be bacterial or fungal (in which case medicines may be prescribed after the infection is diagnosed). Other causes of fever include inflammatory illness, drug reactions, or tumor growth. Sometimes, the cause may not be known. In an infection, the fever is a result of the body "heating up" to try to kill any invading germs. A fever is an important natural defense against germs.

People getting chemo are more likely to have infections because they have lower numbers of the white blood cells needed to fight them (see the section in this booklet on blood counts). It is good to have an easy-to-read, easy-to-use, oral thermometer (one made to take your temperature by mouth) so you can check your temperature to see if you have a fever.

What to look for

- Increased skin temperature
- Feeling warm
- Feeling tired
- Headache
- Feeling cold
- Shaking chills
- Body aches
- Skin rashes
- Any new area of redness or swelling
- Pus or yellowish discharge from an injury or other location
- New cough or shortness of breath
- New abdominal pain
- Burning or pain when urinating
- Sore throat
- The patient is confused, doesn’t know where he is, becomes forgetful, or isn’t making sense. (See the section in this booklet on confusion.)

What the patient can do

- If you start feeling warm or cold, check your temperature by mouth every 2 to 3 hours. If you are unable to hold the thermometer in your mouth, put it under your armpit.
- Keep a record of temperature readings.
- Drink a lot of liquids (such as water, fruit juices, cola, Popsicles, and soups).
- Get enough rest.
- Cover yourself with a blanket if you get chilly.
- Cover yourself only with a sheet if you feel hot.
- Use a cold compress on your forehead if you feel hot.
- Take acetaminophen (Tylenol) or other medicines for fever only if your doctor tells you to do so.

**What caregivers can do**

- Watch for shaking chills, and check the patient's temperature after the shaking stops.
- Check the patient's temperature by placing the thermometer in mouth or under his armpit. (Do not take the temperature rectally unless the doctor tells you it's OK.)
- Encourage visitors who have fevers or the flu to visit the patient by phone until they are well again.
- Offer extra fluids and snacks.
- Help the patient take medicines on schedule.
- Call the doctor if the patient is confused, doesn’t know where he is, becomes forgetful, or isn’t making sense. (See the section in this booklet on confusion.)

**Call the doctor if the patient:**

- Has a temperature of 100.5°F or higher when taken by mouth
- Has 2 or more of the symptoms listed under the "What to look for" section above
- Has a fever lasting for more than 24 hours
- Has shaking chills
- Cannot take fluids
Fluids and dehydration

Everything in the body contains fluid (water). The human body must have a certain amount of liquid, and reduced amounts of fluid in the body can cause changes in how a person feels. Fluid balance means that the body’s fluids are properly regulated and in the right places. Swelling is too much water in the body. (If you have this symptom, see the section in this booklet on swelling.) Dehydration is not having enough water in the body or not having enough fluid where it is needed in the body.

What to look for

- Dry mouth, thirst
- Dizziness, weakness, constipation (See the section in this booklet on constipation.)
- Having trouble swallowing dry food
- Dry or sticky tissues in the mouth that make it hard to talk
- Dry skin, skin that "tents" (stays up) when lightly pinched
- A swollen, cracked, or dry tongue
- Fever (See the section in this booklet on fever.)
- Weight loss (See the section in this booklet on weight changes.)
- Little or no urine
- Fatigue (See the section of this booklet on fatigue.)
- Sunken eyeballs

What the patient can do

- Drink fluids. Sometimes iced fluids are easier.
- Remember that food contains fluid. Try to eat fruits, vegetables, soups, gelatins, Popsicles, and other moist foods.
- Apply lotion often to soften dry skin.
- Try to get rid of the cause of dehydration, such as vomiting, diarrhea, or fever. (See the related sections in this booklet for information on these causes.)
- Apply lubricant to lips to avoid painful cracking.
- If it is tiring to get up, fill a small cooler with ice and small cans of juice or bottled water and keep it next to you.
- Use ice chips to relieve dry mouth if you can't drink enough liquid.

What caregivers can do

- Offer cold or cool liquids every hour or so.
- Encourage the patient to eat small meals if he is able.
- Include moist foods, soups, and fruit smoothies (made with ice in a blender) as snacks.
- Watch the patient's urine output to see if it gets dark or the patient stops urinating.
- Check with the patient often to be sure that he hasn’t become confused.
- Stand nearby when he or she gets up, in case of dizziness or fainting.
Call the doctor if the patient:

• Has vomiting, diarrhea, or fever that lasts for more than 24 hours
• Has urine that is either very dark or only comes in a small amount, or if there is no urine for 12 hours or more
• Becomes dizzy or feels faint when standing up
• Becomes disoriented or confused
Gene therapy

Gene therapy is the use of genes in the treatment of diseases in the body. Genes are made from DNA and are the basic unit of heredity. Any type of treatment that can change a gene’s structure or function is considered gene therapy. Since cancer is a disease of genetic changes, gene therapy has great promise in prevention and treatment. It is being studied for use in a number of ways.

One approach to gene therapy is to supply healthy copies of missing or flawed genes. Instead of giving a patient a drug to treat or control the symptoms of the disease, researchers try to correct the basic problem by changing the genetic makeup of some of the patient’s cells. Another kind of gene therapy uses genes to keep cancer cells from making new blood vessels, which helps stop cancer growth. Other gene therapies include adding genes to cancer cells to make them easier for cancer treatments or the patient’s immune system to kill. Some cause the patient's white blood cells to make a special protein that helps them find and attack tumor cells. Newer gene treatments give the patient a "pro-drug" that inserts suicide genes into cancer cells. This causes the cancer cells to die.

As of early 2009, gene therapy is still experimental. You can only be treated with gene therapy in clinical trials or research studies. Gene therapy for cancer is a challenge because cancer is not caused by one single genetic flaw, but a combination of gene flaws. Many gene treatments are being studied today to find out how safe they are and how useful they might be. Your doctor or cancer care team will be able to tell you more about clinical trials using gene therapy.

If you are getting gene therapy:

What the patient can do

- Go to every scheduled appointment.
- Ask questions. Be sure you understand your treatment. Your cancer care team will help you.
- Ask about expected side effects and what to do if you have any.
- Ask when you should call your doctor.
- If you are having symptoms such as nausea or vomiting, see the related sections in this booklet, and let your doctor know.

What caregivers can do

- Go with the patient to appointments to learn about the gene therapy he is getting and any expected effects.
- Find out how to reach the doctor when the office is closed.
- Help the patient watch for and manage side effects.

Call the doctor if the patient:

- Has a fever (See the section in this booklet on fever.)
- Has any bleeding
- Has any other side effect you've been told you should report
- Has any change in how he is feeling
- Has questions or hears things about gene therapy that cause concern
Genetic testing and counseling

Certain inherited gene flaws have been linked to higher risk of some cancers. Tests (called predictive gene tests) have been developed that will find some of these cancer-related genes in the human body. Gene testing can show if someone is at a higher risk of getting a disease before any symptoms appear. An accurate gene test can tell if a person has or does not have a disease-related gene flaw (mutation). It cannot predict whether a person will actually develop cancer.

If the flawed gene is present, many other factors can influence the chances that the person will actually develop cancer. This means that many people with the gene flaw may not get cancer at all. Even those who do not have the flawed gene may still be at risk for certain types of cancer.

Many questions are yet to be answered about gene testing. Scientists want to be sure that the tests are reliable. Patients and health professionals must also know the limits and possible dangers of testing. For instance, telling others about gene test results can sometimes cause emotional harm to the patient and family.

It is important for people who are thinking about being tested to talk with professional genetic counselors. These counselors are often nurses who are trained to help people as they consider testing. Once testing is done, these counselors can help the patient and family understand the results and help them decide about prevention or treatment options.

You may have questions about whether genetic testing is a good idea for you or your family members. Please discuss your questions with your doctor and health care team.

What the patient can do

• Ask to talk with a genetic counselor before you decide to have genetic testing.
• Ask how the test can help you and your family. Find out what problems it may cause.
• Ask how the test results might affect your ability to keep and get life, disability, and health insurance.
• Ask how the test results might affect your current or future job prospects.
• Ask about the privacy of your genetic testing results.
• Learn what you can do to lower your cancer risk, or your children’s cancer risk, if testing shows that you have a flawed gene.
• Give yourself time to talk the testing over with your family before you make a decision, and come back if you have more questions.

For more in-depth information on genetic testing, call your American Cancer Society at 1-800-227-2345. You may want to ask for a copy of *Genetic Testing: What You Need to Know*. You may also find information on the Web at cancer.org.
Grooming and appearance

Caring for your appearance can help you feel better about yourself. It is especially important when you are ill, because it can be harder to feel good about yourself when you are sick.

In addition to routine hygiene, you may want to put extra time and energy into the way you look. Looking your best can help you feel more confident and in control.

What the patient can do

• Keep up with your regular grooming habits, such as shaving, putting on make-up, and fixing your hair, even if you are confined to bed.
• If you will need a wig or toupee, see the section in this booklet on hair loss.
• Have your clothes altered if you lose or gain weight.
• Pamper yourself. Have a manicure or pedicure, a facial, a massage, or something else that makes you feel good. (Check with your doctor or nurse first.)
• Use an electric razor for routine shaving to prevent nicks and cuts.
• Exercise each day, but only as much as you can manage comfortably. Ask your doctor or nurse about an exercise plan, or just take slow, easy walks. (See the section in this booklet on exercise).
• Get enough rest.
• Keep up with regular dental care.

What caregivers can do

• When the patient is strong enough, encourage short outings that he can enjoy.
• Help the patient keep a supply of his preferred toiletries, lotions, and grooming supplies on hand.
Hair loss

The normal scalp contains about 100,000 hairs. They are constantly growing, with old hairs falling out and being replaced by new ones. Some cancer treatments will cause people to lose some or all of their hair, most often in clumps during shampooing or brushing. Sometimes, clumps of hair are found on the pillow in the morning.

It is normal for men and women to feel upset about hair loss. It helps to understand why it happens, to know that hair will grow back, and to take steps to make it less of a problem for you.

Hair loss can happen when chemotherapy drugs travel throughout the body to kill cancer cells. Some of these drugs damage hair follicles, causing the hair to fall out. Hair loss can be hard to predict. Some patients have it, and others do not, even when they take the same drugs. Some drugs can cause hair loss on the scalp and the loss of pubic hair, arm and leg hair, eyebrows, and eyelashes. Some drugs can cause only the loss of head hair. Radiation therapy to the head often causes scalp hair loss. Sometimes, depending on the dose of radiation to the head, the hair does not grow back the same as it was before.

If hair loss does occur, it most often begins within 2 weeks of the start of treatment and gets worse 1 to 2 months after starting therapy. Your scalp may feel very sensitive to washing, combing, or brushing during the short time when your hair is actually falling out. Hair often starts to grow back even before therapy is completed.

What the patient can do

• If you think you might want a wig, buy it before treatment begins or at the very start of treatment. Ask if the wig can be adjusted – your wig size can shrink as you lose hair.

• If you buy a wig before hair loss begins, the wig shop can better match your hair color and texture. Or you can cut a swatch of hair from the top front of your head, where hair is lightest, to use for matching.

• Be sure to get a prescription from your doctor for the wig because it is often covered by insurance.

• Get a list of wig shops in your area from your doctor or nurse, other patients, or from the phone book. You can also order a "tlc"™ catalog (for women with hair loss due to cancer treatment) by calling 1-800-850-9445 or by visiting www.tlcdirect.org.

• If you are going to buy a wig, try on different styles until you find one that you really like. Consider buying 2 wigs, one for everyday use and one for special occasions.

• Synthetic wigs need less styling than human hair wigs. They may be easier to care for if you have low energy during cancer treatment.

• Some people find wigs to be hot or itchy. In that case, turbans or scarves can be used instead of wigs. Cotton items tend to stay on your smooth scalp better than nylon or polyester.

• Be gentle when brushing and washing your hair.

• Wear a hat or scarf outdoors in cold weather to reduce the loss of body heat.

• Use sunscreen, sunblock, or a hat to protect your scalp from the sun.

• Hair loss can be somewhat reduced by avoiding too much brushing or pulling of hair and by avoiding heat (such as electric rollers, hair dryers, and curling irons).
• Wear a hair net at night, or sleep on a satin pillowcase to keep hair from coming out in clumps.
• Avoid styles that pull on the hair, such as braids or ponytails.
• Use a wide-toothed comb.
• Be gentle with eyelashes and eyebrows, which are sometimes affected, too.
• If you are bothered by hair falling out, you may choose to cut your hair very short or even shave your head.
• When new hair starts to grow, it may break easily at first. Avoid perms for the first few months. Keep hair short and easy to style.
Health insurance

Health insurance helps cover the cost of the diagnosis and treatment of cancer. In the past, most people in the United States had private, fee-for-service (indemnity) insurance. This meant that a person could go to any doctor or hospital. The insurance company and the patient would each pay part of the bill. Today, more than half of Americans who have health insurance are enrolled in some type of managed care plan, another way of providing and paying for health care services.

For those who are 65 or older, health coverage is offered through Medicare, a federal insurance program. People with Medicare now are offered either managed care or indemnity plans. Medicaid, a joint federal and state health insurance program that is run by the states, covers some low-income people (especially women and children) and disabled people. Each state chooses the type of health plan to offer these people. Veterans may receive benefits through a Veterans Administration (VA) program.

Whatever the type of insurance you have, you will want to get the most that you can from your plan. You will get the best care if you stay informed and know about the benefits, coverage, and limits of your plan. Take charge of your care by asking questions. Be involved in making decisions about your care, and keep track of the care you receive.

What the patient can do

• Get a copy of your health insurance policy and find out what it covers, especially related to your cancer and cancer treatment.
• If you are able to work and have a job with health insurance benefits, consider keeping it until you have a new job with the coverage you need.
• Keep your insurance needs in mind when you look at getting a new job.
• Do not let your health insurance expire.
• If you are unable to work for a time, talk with your employer about ways to keep your health insurance. For instance, the Family and Medical Leave Act (FMLA), paid or unpaid time off, or short-term disability benefits may be helpful.
• Keep careful records of all your health care expenses and claims. If your health insurance requires claims, send them in for all covered costs.
• Get help in filing a claim if you need it.
• Work with your doctor’s office staff or billing department to get the most coverage you can.
• Follow up with your insurance company and ask questions about filed claims.
• If a claim is denied, submit it again.
• Keep complete records of all claims submitted, pending, and paid.
• Find out if a case manager has been assigned to you by your insurance company. Get to know this person and keep him informed of what’s happening with your treatment. This person can help you through many of the health insurance issues that may come up.
• Consider filing an insurance complaint if you feel you have been treated unfairly.
• Look at all the options for getting health insurance if you do not have it. Options may include joining your state’s "high risk" health insurance pool for people who cannot get regular health coverage; using Medicare or Medicaid; getting dependent coverage under your
spouse's insurance plan; joining your current company plan; getting coverage through an independent broker; or getting group insurance through an organization you’ve joined.

• If your cancer care team has a social worker, talk with them about your insurance and job situation.

What caregivers can do

• Help the patient track insurance claims for treatments, drugs, and hospitals. You may need to handle the paperwork during times that the patient is very weak or sick.

• Keep the phone numbers of employer’s benefits departments, insurance companies, and claim agents in a handy place. You may want to keep all the insurance information in a notebook or binder.

For more in-depth information on health insurance, call your American Cancer Society at 1-800-227-2345. You may want to ask for a copy of Medical Insurance and Financial Assistance for the Cancer Patient. You can also find more information on the Web at cancer.org.
Hiccups

Hiccups happen when the diaphragm (the main muscle used in breathing) suddenly contracts between normal breaths. Hiccups can be caused by irritation of the nerve that controls the diaphragm, certain drugs, problems in the brain, problems in the esophagus (the swallowing tube that goes from the throat to the stomach), pressure on the stomach, and other conditions. Hiccups that last a long time can be serious. They can interfere with eating, sleeping, and breathing, and lead to exhaustion.

What the patient can do

- Breathe slowly and deeply into a paper bag for 10 breaths at a time.
- Drink water slowly.
- Hold a teaspoon of sugar in the mouth and then swallow.
- Avoid forcing yourself to eat.

What caregivers can do

- Watch the patient to be sure that he is able to drink enough liquids.
- If medicine is given for hiccups, watch for dizziness. The patient may need help getting up or walking.

Call the doctor if the patient:

- Has trouble breathing
- Develops a puffy or bloated stomach
- Has hiccups that last for more than a day
Hospice care

Hospice programs provide supportive care for the patient and the family in the final stages of disease, that is, the last days, weeks, or months of life. Hospice care can be provided in the home, in hospitals that have hospice units, or in free-standing hospice programs. Hospice care seeks to make the patient as comfortable as possible, to relieve symptoms, and help the patient and family have the best possible quality of life.

Some people prefer to die at home, and others feel better in a hospital setting. There are no right or wrong choices, only the personal choices that are best for you and your family. A hospice works with the family to provide care and to meet the physical, functional, emotional, and spiritual needs of the patient. Accepting death is central to the hospice approach, although the focus is on caring for and supporting the patient so he may live as fully as possible until death.

Whatever the setting, hospice care is offered widely. It is covered by Medicare, Medicaid, and most insurance plans.

What the patient can do

• Ask if your insurance plan covers hospice care.
• Talk through your feelings and your family’s feelings about dying at home.
• Ask to speak to someone from some local hospice programs and have them discuss the type of care they can offer.

What caregivers can do

• If at-home hospice care is planned, find out how the program would care for the patient and what would be expected of you and your family. Talk honestly with the hospice staff about any concerns you have.
• Remember that illnesses that are not related to cancer can still be treated if it will make the patient more comfortable.
• After being enrolled in a hospice program, keep the phone numbers for the nurse, social worker, chaplain, and others handy. Tell the nurse about any changes in the patient's physical condition, any unrelieved pain, or any problems the patient has.

For more in-depth information on hospice care, contact the American Cancer Society at 1-800-227-2345, or visit cancer.org. You may also call the National Hospice and Palliative Care Organization's Hospice Helpline at 1-800-658-8898, or visit their Web site at www.nhpco.org.
Immunotherapy

Immunotherapy is a promising type of treatment for certain cancers. It is sometimes called biologic therapy, biotherapy, or biological response modifier therapy. These therapies use different parts of the body’s immune system to fight cancer or to lessen the side effects of some cancer treatments.

Immunotherapies can work in several ways in cancer treatment. For instance, they may slow or stop the growth of cancer cells. Or they may help healthy cells, especially immune cells that control cancer. They may also help to repair or replace normal cells damaged by other cancer treatments.

There are different kinds of immunotherapy now in use. You may hear terms such as interferons, interleukins, cytokines, monoclonal antibodies, or tumor necrosis factor. If you are having immunotherapy, ask your doctor to explain what kind it is and how the medicine works. More than one kind may be used at different times or together. They may also be used with chemotherapy or radiation treatment. Some types of immunotherapy have been in use for years, but others are fairly new.

If you are not getting immunotherapy, you may want to ask your doctor or cancer care team if it is an option for your type of cancer. Many of these treatments are being studied today to learn how well they work and how safe they are. Your doctor or cancer care team will be able to tell you more about clinical trials using immunotherapy.

What the patient can do

• Go to every scheduled appointment.
• Ask questions. Your cancer care team will help you.
• Consider getting a second opinion before starting a new immunotherapy.
• Ask about expected side effects and what to do if you have any.
• Ask about when you should call your doctor.
• If you are having symptoms such as fatigue, see the related sections in this booklet and tell your doctor or nurse.

What caregivers can do

• Find out how to reach the doctor when his or her office is closed.
• Watch for confusion or dizziness that may not be noticed right away by the patient.
• Keep a list of questions to ask to the doctor or cancer care team. It may help to make notes of problems that the patient may forget.
• If the patient is fatigued, nauseated, or vomiting, see the related section in this booklet.

Call the doctor if the patient:

• Develops a fever (a temperature of 100.5° F or higher when taken by mouth)
• Has severe nausea and vomiting
• Gets dizzy or has trouble breathing
• Becomes confused or disoriented
Infection

Please see the section in this booklet on fever.

Itching

Itching can cause restlessness, anxiety, skin sores, and infection. Common causes of itching in people with cancer include dry skin, changes in the blood, allergies, side effects of medicines, and chemo or radiation therapy. Other illnesses and certain kinds of cancer can also cause itching.

What to look for

- Dry, red, rough, flaky skin
- A yellow color of the skin or of the whites of eyes
- Rash or bumps
- Scratch marks
- Skin sores
- Scratching without thinking about it

What the patient can do

To soothe the skin:

- Apply skin creams with a water-soluble base, such as aloe vera or menthol-based lotion, 2 to 3 times a day, especially after a bath when the skin is damp. Or use calamine lotion (Caladryl) or witch hazel if they soothe the itching, but note that they can cause dryness.
- Use warm water for bathing instead of hot water.
- Add baking soda, oatmeal (in a cloth or mesh bag), or bath oil to bath water.
- Wash your skin gently using a mild, unscented soap.
- Use baking soda instead of deodorant.
- Avoid using scented or alcohol-based products on the skin (such as powders, after shaves, perfumes). Cornstarch-based powders may clump in moist areas and cause irritation.
- Use an electric razor rather than a blade to avoid cuts and irritation.
- Change your bed sheets daily.
- Keep your room cool (60° to 70° F) and well ventilated to avoid sweating.
- Drink plenty of water and other fluids.
- Get enough rest.

To reduce the desire to scratch:

- Apply cool, wet packs (crushed ice in a plastic bag that is then wrapped in a towel) to the skin. Remove the pack when it becomes warm, and let your skin dry. Use again as needed.
- Keep nails clean and short. Wear clean fabric gloves if you scratch without thinking about it.
• Try rubbing, pressure, cool cloths, or vibration instead of scratching. Avoid breaking the skin. Get gentle massages at night.
• Wear loose clothing made of a soft fabric.
• Distract yourself with music, reading, and the company of others.
• Take medicines for itching as prescribed by your doctor.

What caregivers can do

• Try using mild, unscented detergents to wash the patient's clothes and bedding.
• If the patient scratches in his sleep, ask him to wear clean cotton gloves which may reduce skin damage.

Call the doctor if the patient:

• Has itching that does not go away after 2 or more days
• Develops a yellowish color of the skin or has urine the color of tea
• Scratches skin until it is open or bleeding
• Has a rash that gets worse after creams or ointments have been applied
• Has foul-smelling drainage or has pus coming from the skin
• Becomes very anxious and restless (cannot sleep through the night due to itching)
• Develops hives (itchy white or red welts on the skin), shortness of breath, swelling of the throat or face, or other symptoms of a severe allergic reaction
Leg cramps

Leg cramps or spasms are a painful tightening of the muscles in the leg. Staying in bed for long periods of time sometimes can cause muscles in the leg or foot to cramp. Dehydration, certain drugs, and brain or nerve diseases can also cause cramps. Other causes of cramping are pressure on the calf muscles or on the back of the knee, too much phosphorus, too little calcium, low blood sugar, or too little potassium in the body. All of these are chemistry imbalances in the blood.

What to look for

• Sudden pain or discomfort in a leg or foot and a tight or stiff feeling

• Trouble moving the foot or pain when moving the foot or leg

What the patient can do

• Change position often.

• If you are bed-bound, use a bed cradle to protect the legs and feet from the weight of the bed clothes. A bed cradle is a support at the end of the bed that holds the sheets and blanket up off the legs and feet.

• Exercise your legs in bed by bending and straightening them 10 times twice a day or as many times as you can. A family member can move your legs for you if you can't.

• Tell your doctor or nurse about the cramps. They may be able to help prevent them. For example, they may prescribe a muscle relaxant.

• Apply heat to legs when they cramp if it's allowed by your doctor. Talk to your doctor or nurse about what kind of heat to use and how long you should use it.

• Massage the leg if allowed by your doctor.

• Keep warm.

• Contract the opposite muscle group to stretch the tight muscle as much as you can without hurting it. For example, for a calf muscle cramp, try pointing the toes upward toward the knees, or walk around.

• Follow your doctor’s instructions for correcting imbalances in calcium, potassium, or phosphorus.

What caregivers can do

• Help the patient stretch the tight muscle if he can't.

• Use ice or a cold washcloth to gently rub the cramped muscle.

• If muscle relaxers are prescribed, watch for dizziness or stumbling.

Call the doctor if the patient:

• Has cramping that is not relieved by heat, massage, or by stretching the cramped muscle (as described above)

• Has cramping that lasts for more than 6 to 8 hours

• Has a cramped leg that becomes red, swollen, or hot
Mouth, bleeding in

Bleeding in the mouth is generally caused by mouth sores, gum (periodontal) disease, or by a low platelet count (cells that help the blood to clot). Low platelet counts can be a side effect of chemo or radiation treatment. This is usually a short-term problem. Cancers that affect the blood-forming system, such as leukemia, can also cause a drop in platelets. A person with low platelets may bleed easily. Everyday actions such as brushing or flossing teeth can cause bleeding (if platelet count is low, see the section in this booklet on blood counts). Side effects of chemo or radiation can include dryness in the mouth or small mouth ulcers, which can bleed.

What to look for

- Blood or bruises in mouth (from or on the gums, tongue, etc.)
- Rash or bright red pinpoint-sized dots on tongue, under tongue, on roof of mouth, and/or on inside of cheeks
- Oozing of blood from mouth

What the patient can do

- Rinse your mouth gently with ice water every 2 hours.
- Have ice chips on hand to suck on. (Avoid hard candies if your mouth is bleeding.)
- Rinse your mouth or brush your teeth with a soft toothbrush after eating. Rinse the toothbrush in warm water to soften the bristles even more.
- Use soft foam mouth swabs or gauze wrapped around a Popsicle stick or tongue depressor to brush teeth if a soft toothbrush causes bleeding.
- Avoid store-bought mouthwash. See the section on mouth dryness in this booklet to learn how to make a gentle mouth rinse.
- Eat foods that are soft and smooth in consistency and high in calories and protein. Refrigerated soft foods, such as ice cream, applesauce, puddings, and yogurt, are helpful because cold helps to control bleeding.
- Put hard foods, such as apples, pears, etc., in the blender.
- Avoid hot drinks, such as coffee and tea. Heat enlarges blood vessels and can worsen bleeding.
- Apply cream or salve to lips to prevent dryness.
- If you wear dentures, keep them out of your mouth, especially if they do not fit well.
- Avoid aspirin products. Check labels of over-the-counter drugs to be sure they don’t contain aspirin, or check with your pharmacist.

What caregivers can do

- Offer the patient cold water mouth rinses before each meal. Keep ice water nearby.
- If the mouth is oozing blood, keep a bowl nearby for spitting out mouth rinses.
- Make milk shakes or smoothies in the blender, and offer other soft frozen treats. Avoid nuts, caramel, and hard coatings.
- Freeze a few wet tea bags, and have the patient press one on any area of bleeding.
**Call the doctor if the patient:**

- Is bleeding from the mouth for the first time
- Has bleeding that lasts for more than a half hour
- Vomits blood or material that looks like coffee grounds
- Feels light-headed or dizzy
Mouth dryness

Dry mouth happens when there is not enough saliva in the mouth. It can be caused by breathing through the mouth, or it may be a side effect of medicine, radiation treatment to the head and neck, or dehydration. (See the section on fluids and dehydration in this booklet.)

What to look for

- Dried, flaky, whitish saliva in and around the mouth
- Thick saliva that’s more like mucus and that sticks to lips when you open your mouth
- Trouble swallowing foods or thick liquids
- Mouth always open to breathe
- Burning tongue
- Debris stuck to teeth, tongue, and gums
- Tongue surface looks ridged or cracked

What the patient can do

- Rinse your mouth every 2 hours with a salt and soda solution. You can make this solution by adding 1 teaspoon of salt and 1 teaspoon of baking soda to 1 quart of warm water. Shake the solution before each use, then swish it in the mouth and spit. Do not swallow it.
- Drink liquids with meals to moisten foods and help with swallowing.
- Try ice chips, sugarless hard candies, and sugarless chewing gum.
- Add liquids (such as gravy, sauce, milk, and yogurt) to solid foods.
- Use petroleum jelly, cocoa butter, or a mild lip balm to keep lips moist.
- Use artificial saliva, which is sold at drugstores.
- Avoid hot, spicy, or acidic foods.
- Avoid chewy candies, tough meats, and hard raw fruits or vegetables.
- Avoid alcohol, including that in store-bought mouthwashes.
- Avoid tobacco.

What caregivers can do

- Offer small soft meals with extra sauce or dressings for dipping.
- Offer ice cream, gelatin desserts, ice chips, and frozen drinks.
- Help the patient keep track of his fluid intake, and encourage the patient to take in 2 or 3 quarts of liquid each day, if the doctor approves. Ice, ice cream, sherbet, Popsicles, and gelatin count as liquids.

Call the doctor if the patient:

- Has a dry mouth for more than 3 days
- Is unable to take medicines or swallow pills
- Is unable to drink or eat
- Has dry, cracked lips or mouth sores (See the section on mouth sores in this booklet.)
- Has trouble breathing
Mouth sores

Mouth sores are like little cuts or ulcers in the mouth. The sores may be very red, or may have small white patches in the middle. They may bleed or become infected. They can appear 1 to 2 weeks after some kinds of chemo. They can also be caused by radiation treatments to the head and neck area, infection, dehydration, poor mouth care, oxygen therapy, alcohol or tobacco, not getting enough vitamins, or lack of protein. Healing may take 2 to 4 weeks. Mouth sores can be very painful and lead to dehydration, poor eating, and weight loss. (See the section on fluids and dehydration in this booklet.)

What to look for

• Inside of mouth and gums look red, shiny, or swollen
• Blood in mouth
• Small ulcers or sores in mouth, on gums, or on or under tongue
• A white or yellow film in the mouth or on the tongue
• Soreness or pain in mouth or throat
• Feeling of dryness, mild burning, or pain when eating hot and cold foods
• Soft whitish patches or pus in the mouth
• Increased mucus in the mouth

What the patient can do

• Check mouth twice a day using a small flashlight and a padded Popsicle stick. If you wear dentures, take them out before you inspect your mouth. Tell your doctor or nurse if your mouth looks or feels different or if you notice changes in how things taste.
• Follow the plan below for mouth care 30 minutes after eating and every 4 hours while awake, or at least twice a day unless your doctor or nurse gives you other instructions:
  ➢ Brush your teeth using a soft nylon bristle toothbrush. To soften the bristles even more, soak the brush in hot water before brushing and rinse brush with hot water during brushing. If the toothbrush hurts, use a Popsicle stick with gauze wrapped around it or a cotton swab instead. Or you can get soft foam mouth swabs from the drugstore. Rinse toothbrush well in hot water after use and store in a cool, dry place.
  ➢ Use a non-abrasive toothpaste that contains fluoride. Note that whitening toothpastes may contain hydrogen peroxide, which can irritate sore mouths.
  ➢ Remove and clean your dentures between meals on a regular time schedule. If you have sores under your dentures, leave your dentures out between meals and at night.
  ➢ Clean dentures well between uses, and store them in an anti-bacterial soak. If your dentures fit poorly, do not use them during treatment.
• Gently rinse your mouth before and after meals and at bedtime with one of the following solutions (Stir or shake the solution well, then swish it around and gently gargle, then spit it out.):
  ➢ 1 teaspoon baking soda
  ➢ 2 cups water
Or

- 1 teaspoon salt
- 1 teaspoon baking soda
- 1 quart water

- If you normally floss, keep flossing at least once a day unless you are told not to do so. Tell your doctor if this causes bleeding or other problems. If you do not usually floss, talk with your doctor before you start.

- Avoid store-bought mouthwashes, which often contain alcohol or other irritants.
- Keep lips moist with petroleum jelly, a mild lip balm, or cocoa butter.
- Drink at least 2 to 3 quarts of fluids each day, if your doctor approves.

- If mouth pain is severe or makes it hard to eat, ask your doctor about medicine that can be swished 15-20 minutes before meals or painted on a painful sore with a cotton swab before meals. If this does not work, you may need stronger pain medicines.

- To promote healing, ask your doctor about using Maalox or Milk of Magnesia. You can use these products to help sores by allowing them to settle and separate, pouring the liquid off the top of the solution, and then swabbing the pasty part onto the sore area with a cotton swab. Rinse your mouth with water after 15-20 minutes.

- Sip warm tea slowly.

- Eat chilled foods and fluids (for instance, Popsicles, ice cubes, frozen yogurt, sherbet, or ice cream).

- Eat soft foods that are moist and easy to swallow.

- Eat small, frequent meals of bland, moist, non-spicy foods. Avoid raw vegetable and fruits, and other hard, dry, or crusty foods, such as chips or pretzels.

- Avoid very salty or high-sugar foods.

- Avoid acidic fruits and juices, such as tomato, orange, grapefruit, lime, or lemon.

- Avoid fizzy drinks, alcohol, and tobacco.

- Create a pleasant mealtime atmosphere.

What caregivers can do

- Use a flashlight to check the patient’s mouth for red areas or white patches, which often become sores. If patient wears dentures, remove them before looking.

- Offer liquids with a straw, which may help bypass the sore area in the mouth.

- Mash or puree hard foods in a blender to make them easier to eat.

- Try coating mouth sores with Anbesol before meals to numb the sores during eating.

- Offer pain medicines a half hour before mealtime.

**Call the doctor if the patient:**

- Has redness or shininess in mouth that lasts for more than 48 hours

- Has bleeding gums

- Notices any type of "cut" or sore in the mouth
• Has a temperature of 100.5° F or higher when taken by mouth
• Has white patches on the tongue or inside the mouth
• Has taken in little food or fluid for 2 days
• Cannot take medicines due to sores in mouth
Nausea and vomiting

Nausea is having a sick or queasy feeling in the stomach, and vomiting is throwing up food or liquids from the stomach. Nausea can occur even when a person is not thinking about food. A person can vomit even if he has not eaten anything and hasn’t had any nausea. Nausea or vomiting can be caused by eating something that disagrees with you, bacteria in food, infections, or by radiation or chemo treatments for cancer. Many people have little or no nausea and vomiting with these treatments. For others, just thinking about going for one of the treatments can cause nausea or vomiting. Cancer by itself may cause nausea and vomiting.

Frequent vomiting can be dangerous because it can lead to dehydration. (See the section in this booklet on fluids and dehydration.) It can also cause choking or inhaling food or liquids. Talk with your doctor about what is causing your nausea and vomiting and what you can do about it.

What to look for

- Changes in eating habits
- Foul mouth odor
- Yellow or green foul-smelling fluids on bedclothes
- Feeling queasy or having an upset stomach
- Increased saliva, clamminess, and sweating that may come before vomiting

What the patient can do

For nausea:

- Eat bland foods, such as dry toast and crackers.
- If the nausea only happens between meals, eat frequent, small meals and have a snack at bedtime.
- Drink clear liquids served cold and sipped slowly. (Clear liquids are those that you can see through, such as ginger ale, apple juice, broth, tea, etc.) Also try Popsicles or gelatin.
- Seek out the foods you like. Many people develop a dislike for red meat and meat broths during treatment. Try other protein sources, such as fish, chicken, beans, and nuts.
- Suck on hard candy with pleasant smells, such as lemon drops or mints, to help get rid of bad tastes.
- Eat food cold or at room temperature to decrease its smell and taste. Avoid fatty, fried, spicy, or very sweet foods.
- Try small amounts of foods high in calories that are easy to eat (such as pudding, ice cream, sherbets, yogurt, and milkshakes) several times a day. Use butter, oils, syrups, sauces, and milk in foods to raise calories. Avoid low-fat foods unless fats upset your stomach or cause other problems.
- Tart or sour foods may be easier to keep down (unless you have mouth sores).
- Try to rest quietly while sitting upright for at least an hour after each meal.
- Distract yourself with soft music, a favorite television program, or the company of others.
- If you have nausea, relax and take slow, deep breaths.
- Tell your doctor about the nausea because there are several drugs that can help it.
• Take your anti-nausea medicine at the first signs of nausea to help prevent vomiting.
• If nausea occurs just before chemo or doctor visits, ask about medicines, hypnosis, relaxation, or behavioral treatment to lessen this problem.

For vomiting:
• If you are in bed, lie on your side so that you will not inhale the vomit.
• Request that medicines be prescribed in suppository form, if possible. Take medicine at the first hint of nausea to prevent vomiting.
• Try liquids in the form of ice chips or frozen juice chips, which can be taken slowly.
• After vomiting stops, begin by taking in 1 teaspoon of cool liquid every 10 minutes. Gradually increase to 1 tablespoon every half hour. If you are able to keep that down after an hour or so, try larger amounts.

What caregivers can do
• When the patient feels nauseated, offer to make meals or ask others to make meals to reduce bothersome food odors. Use kitchen vent fans to reduce smells.
• Cover or remove foods with strong or unpleasant smells.
• Try plastic forks and spoons rather than metal ones, which may cause a bitter taste.
• If the patient starts vomiting, weigh him at the same time each day to help decide whether dehydration is getting severe.
• Talk to the doctor about medicines to help prevent vomiting.
• Watch the patient for dizziness, weakness, or confusion.
• Try to help the patient avoid constipation and dehydration. Either of these can make nausea worse.

Call the doctor if the patient:
• May have inhaled some of the vomited material
• Vomits more than 3 times an hour for 3 or more hours
• Vomits blood or material that looks like coffee grounds
• Cannot take in more than 4 cups of liquid or ice chips in a day or cannot eat substantial foods for more than 2 days
• Cannot take his medicines
• Becomes weak, dizzy, or confused
• Loses 2 or more pounds in 1 to 2 days (This means he or she is losing too much water.)
• Develops dark yellow urine and doesn’t have to urinate as often as usual
Pain
Pain

When people say they are having pain, it usually means they are hurting somewhere in their body. But it can also mean that they just can’t get comfortable. They may be feeling bad in general, not in any one place. The feeling of pain can be worse if a person is anxious, sad, or depressed. Some people may have a hard time talking about their pain. This may be because of the way they were brought up, the way people in the family usually express themselves, or just because that’s the way they are. In general, the way they talked about pain in the past, before the illness, will be the way they talk about it now.

Even severe pain can be very well-controlled by combinations of medicines that can be taken by mouth. These combinations usually include opioids (OH-pee-oyds), such as morphine or codeine. Some people may not want to use these pain medicines because they fear they will become addicted. But people with cancer who have never abused drugs do not become addicted or use the opioid pain-relieving drugs for pleasure. Their bodies can become tolerant of the pain medicine after a time, so the dose may need to be increased to get the same pain relief. This is a common sign of opioid tolerance. But when the person has cancer pain, it is not a sign of addiction.

Pain medicines work best if they are used around the clock before the pain becomes severe. It takes more medicine to control severe pain than milder pain, so it’s best to treat it when it first starts and regularly after that. If the cause of the pain is treated, the need for medicine will slowly decrease or disappear. Drug dosage and schedule should be adjusted by the doctor as the patient's needs change.

If you have pain from cancer that has spread, or some other long-term cancer pain, it can exhaust you. This type of chronic or long-term pain can interfere with your life and keep you from doing things that you want and need to do. Even with around-the-clock pain medicines, pain often "breaks through" between doses. Breakthrough pain usually calls for a second pain medicine that you can safely take in addition to your regular pain medicine. Don’t be surprised if it takes more than 2 medicines to control your pain. Help your doctor keep your pain under control by taking pain medicines as prescribed, and keeping your doctor informed about your level of pain.

What to look for

- Pain that doesn't seem to go away or that seems to go away, then comes back before your next dose of medicine is due (This may indicate that your medicine plan needs to be changed.)
- Trouble sleeping
- Lack of interest in things you used to enjoy
- Worry about things that had not caused concern in the past
- New areas of pain or a change in your pain
- Reduced ability to move around or less physical activity

What the patient can do

- Talk with your doctor or nurse about your pain -- where the pain is, when it began, how long it lasts, what it feels like, what makes it better, what makes it worse, and how it affects your life.
- If the prescribed pain medicines don’t work as expected, let your doctor or nurse know.
- Rate your pain using a pain rating scale, such as 0 = no pain to 10 = the worst pain you can imagine. You can use this scale to explain your pain to others.
• Take your pain medicine exactly as prescribed. (For chronic pain, medicine should be given around the clock on a schedule rather than only when pain is severe.) Check with your doctor if this schedule needs to be adjusted.

• As the pain is relieved with medicines, increase your activity level.

• Do not wait until the pain is severe before taking pain medicine.

• Avoid suddenly stopping any of your pain medicines. Instead, reduce the dosage slowly as the pain decreases. Talk with your doctor, nurse, or pharmacist before you do this, or if you have questions.

• Some people feel nauseated even when they are taking the right dose of pain medicine. If your pain medicine makes you feel sick, ask your doctor to change it or to give you something to control the nausea.

• Some pain medicines make you drowsy or dizzy. This often lessens after a few days, but you may need help getting up or walking. Don’t try to drive or do anything dangerous until you are sure of the effects.

• People receiving opioid pain medicines are normally given laxatives and stool softeners to prevent constipation, which is a common side effect of opioids.

• Keep track of any other side effects you notice. Discuss them with your doctor or nurse.

• Avoid crushing or breaking your pain pills unless you check with your doctor, nurse, or pharmacist. If medicines are in time-release form, taking broken pills can be dangerous.

• If pain medicines are not keeping your pain under control, talk with the doctor about other measures. If you keep having trouble, ask to see a pain specialist.

• Keep at least a one-week supply of pain medicines on hand. Most pain medicines cannot be refilled by telephone, so you will need a written prescription.

What caregivers can do

• Watch the patient for signs of unrelieved pain. Ask the patient about pain if you notice grimacing, moaning, tension, or reluctance to move around in bed.

• Try warm baths or warm washcloths on painful areas. (Avoid areas where radiation was given.) If this doesn’t help, you can try ice or cool packs. Gentle massage or pressure may help some types of pain.

• Watch for confusion and dizziness, especially after new medicines are started or when doses are changed. Help the patient with walking until you know he can do it safely.

• Encourage pleasant distractions that the patient enjoys.

• Plan activities for when the patient is most comfortable and awake.

• Offer plenty of fluids and food with fiber.

• If the patient seems forgetful, help him track when pain medicines are due to avoid over- or under-dosing.

• Help the patient remember to take stool softeners and laxatives the doctor suggests to prevent constipation. (See the section in this booklet on constipation.)

• If the patient is having frequent, severe pain, talk with the doctor about medicine to take around the clock. If pain "breaks through," find out if there is another medicine to use between doses of the main pain medicine.
• If the patient is having trouble taking pills, talk with the doctor about medicines that come in liquids, suppositories, skin patches, or other forms.

• Check with the doctor, nurse, or pharmacist before you crush or dissolve pain pills to make them easier to swallow. Some pills can cause a dangerous overdose if broken.

• Remind the patient that pain medicine, when used as directed, does not cause addiction.

• Talk with the doctor or nurse so that you understand which medicines are for pain and how each is to be used.

• Be sure that the patient has a list of all the medicines he is on, including pain medicines. This is even more important if unexpected medical problems come up.

• Know how to reach the doctor when his office is closed.

• Plan time for activities you enjoy and take care of yourself. A support group for family members may be helpful.

• If you help the patient with pain patches, be sure you know how to avoid touching the part with the pain medicine on it, and how to dispose of used patches safely.

• Keep opioid pain medicines away from others, especially children and pets.

**Call the doctor if the patient:**

• Has any new or more severe pain

• Cannot take anything by mouth, including the pain medicine

• Does not get pain relief, or if the relief doesn’t last long enough with the medicines that have been prescribed

• Has trouble waking up, or if you have trouble keeping him awake

• Becomes constipated, nauseated, or confused

• Has any questions about how to take the medicines

• Develops a new symptom (for instance, is unable to walk, eat, or urinate)

For more in-depth information on pain management, call the American Cancer Society at 1-800-227-2345. You may want to ask for a copy of *Pain Control: A Guide for Those with Cancer and their Loved Ones*. You may also find information on the American Cancer Society Web site at cancer.org.
Prostheses

Prostheses (pross-THEE-sees) are man-made substitutes for missing body parts. Sometimes, parts of the body must be removed if they contain cancer that could grow and spread. Prostheses are used to help a person look as though the body part had never been removed, and to help the person function as normally as possible.

There are many different types of prostheses. Some are external (worn on the outside) and can be put on and taken off, and others are implanted during surgery. Those most commonly needed by people with cancer are prostheses for the breast, leg, or testicles and penile implants. Wigs used to cover the short-term hair loss that may happen with some kinds of chemo can also be considered prostheses. (See the section in this booklet on hair loss.)

What the patient can do

• Before surgery, ask your doctor about prostheses.
• Find out if you might need a prosthesis. If so, ask if the prosthesis can be placed or implanted during surgery. (Prostheses for testicles, breasts, and some limbs may be implanted during the first surgery.)
• Make sure that you get a prescription for the prosthesis from your doctor, because it may be covered by medical insurance (this includes wigs).

Breast prostheses:

• Contact your local chapter of the American Cancer Society Reach to Recovery®, a support group for women with breast cancer, for information and ideas.
• Wear a breast form (external prosthesis) while waiting for reconstructive surgery.
• Small prostheses ("equalizers") are available for women who have had part of a breast removed (through lumpectomy or a segmental mastectomy).
• Nipple prostheses are available for breast reconstruction when the nipple cannot be saved. External nipple prostheses are also sold to cover flat or missing nipples.
• External prostheses are sold in surgical supply stores, lingerie shops, and in the lingerie departments of many department stores. Call before you go to make sure that a professional fitter will be there.
• Wear a form-fitting top when you shop for a prosthesis, so that you can better see how it looks when you move.
• Have your partner or a good friend go with you.
• Try many different types. Prostheses vary in shape, weight, and consistency. Custom-made forms are also available.
• Shop around; find the best fit and the right price.
• Prostheses may feel heavy, but they should feel comfortable, show natural contour and consistency, and stay in place when you move.
• Ask if the prosthesis absorbs perspiration and about how to care for it.
• Talk with your partner about your feelings about reconstructive surgery and changes in your body.
• See the section in this booklet on sexuality for more information.

**Leg or limb prostheses:**
• Before surgery, ask about your options, including when and how your prosthesis will be fitted.
• Often, a temporary leg prosthesis is fitted during the first surgery. Put your weight on it as advised by your doctor or physical therapist. The permanent prosthesis can be fitted after you are stronger.
• Cosmetic, non-functional (non-working) limbs are available for people who cannot use a permanent prosthesis.
• Ask questions about how to care for the surgical site and the prosthesis. If you have discomfort, redness, or blisters, talk with your doctor. If the prosthesis needs to be adjusted, take it back to a professional rather than trying to do it yourself.

**Testicular prostheses:**
• A gel-filled plastic sac can be placed during surgery or at a later date.
• Not all men want or feel that they need a testicular prosthesis. Discuss the possibility of a prosthesis with your partner.
• Before surgery, talk with your doctor about whether you want testicular prostheses.
• See the section in this booklet on sexuality for more information.

**Penile implants:**
• Penile implants or prostheses are placed 6 to 12 months after surgery.
• Two different types are available: inflatable and semi-rigid rod. Discuss the type that is best for you with your partner and your doctor. See the section in this booklet on sexuality for more information.

**Call the doctor if the patient:**
• Develops redness, swelling, pain, pus, or drainage at the prosthesis site
Radiation therapy

Radiation therapy (or radiotherapy) uses an invisible ray or beam of high-energy particles to kill cancer cells. It is aimed at the cancer area using marks on the skin so that the beam can be directed only to the cancer site. Sometimes, small radioactive pellets, ribbons, or wires may be put into a tumor. Radiation can shrink tumors and relieve symptoms. Some cancers can be cured with radiation treatment (Hodgkin disease, for instance). Other cancers (such as breast cancers) can now be treated with radiation to allow for less surgery.

Doctors do not expose people who are not ill to radiation treatment because it could cause problems for some. But the benefit to people with cancer far outweighs the small risk of causing new problems. In order not to expose the people you care about to radiation, friends and relatives cannot be with you during the treatment itself. During external beam radiation treatments, you will be in a radiation therapy room by yourself. Technologists will watch you on a TV monitor in a room close by. They can talk to you and hear you if you need anything during the actual treatment.

The side effects of radiation depend on the area of the body that needs to be treated. Because it treats only a certain area of the body, side effects from radiation tend to involve only that area. It is common for the skin that the radiation goes through to get red during treatment. It usually stays that way for 3 or 4 weeks after radiation treatments are finished. The skin may dry and flake, or peel and ooze like a burn. Afterward, the skin may look darker or more tan for a few months or even for years.

With today's modern equipment and skilled ability to aim the beams or carefully place the pellets or wires, the radiation dose is focused on the tumor. That way, other areas of the body do not suffer so many ill effects. For instance, if the chest is treated, there is no loss of scalp hair and usually no nausea or vomiting. On the other hand, if the brain requires treatment, hair loss is expected. The patient may also have nausea and vomiting because there is a “nausea center” in the brain. Talk with your radiation oncologist (doctor trained to give radiation therapy) or oncology nurse about what side effects to expect.

What the patient can do

• Tell your doctor about all the medicines you are taking, including all over-the-counter medicines or supplements, such as vitamins and herbs.
• Go to every scheduled therapy appointment.
• Ask questions. Your radiation treatment team is there to help you.
• If you have nausea, vomiting, loss of appetite, diarrhea, or fatigue, see the related sections in this booklet and tell your doctor or nurse.
• Sometimes, small tattoos are made on your skin to help aim the radiation. But if the area to be treated is only marked in ink, take sponge baths instead of regular baths or showers to keep the markings in place. Ask your radiation team if and when you can wash off the ink.
• Protect the treated area from direct sunlight during treatment and for at least 1 year after.
• Wear loose, comfortable clothing over the radiated area. Soft cotton clothing is preferred.
• Talk with the nurse or doctor about using skin creams, powder, deodorant, or make-up on the radiated skin. Avoid adhesive tape, hot or cold packs, and anything that dries or irritates skin.
• Bathe in lukewarm water, using mild soap.
• Avoid crowds, and don't visit with people who have colds, infections, coughs, or fevers while you are in treatment.

• See the section on blood counts if your hemoglobin, platelet, or white blood cell counts are low.

• Use birth control during radiation treatment and for 3 months afterward. (See the section in this booklet on sexuality).

• If the area that is being treated is in the pelvis (such as bladder, prostate, vagina, cervix, or uterus), talk with your doctor or nurse about sexual side effects and what you can do. (See the section in this booklet on sexuality.)

• If you notice skin blisters or oozing, you may need special dressings to protect the area of skin where you received radiation. Talk to your doctor or nurse about this.

What caregivers can do

• Watch for fatigue, which may increase as radiation treatment continues.

• Encourage the patient to eat nutritious foods and drink enough liquids. The patient may need help preparing meals, especially later in treatment.

• Help the patient keep all appointments. Radiation treatment is often given every day for many weeks. You may need to get friends to drive the patient.

• Encourage friends with infections to visit only by phone until they are completely well.

• If the patient develops side effects or other symptoms, see the related sections in this booklet.

Call the doctor if the patient:

• Develops bloody, weeping (wet), or discolored skin

• Has a fever of 100.5° F or more when taken by mouth

• Has pain

• Has questions or hears things about radiation therapy that cause concern

For more in-depth information, contact the American Cancer Society at 1-800-227-2345 and ask for Understanding Radiation Therapy: A Guide for Patients and Families. You can also find information on the Web at cancer.org.
Scars and wounds

A wound is a physical injury to the body that causes disruption in body structure. The wound may be present only under the skin, may affect only the skin surface, or may involve both. An incision from surgery is a wound. A wound also can be caused by a fall or accident, tumor growth, pressure on bony areas, or the side effects of radiation therapy. Proper care for a wound is important to protect the wound from infection and help it heal. Scars are healed wounds.

What to look for

- Redness or purple bruising of skin
- Scaly, broken skin (See the section in this booklet on skin sores.)
- Crusts, scabs, or cuts in the skin
- Drainage or pus
- Bleeding
- Swelling
- Warmth or heat at the affected area
- Pain

What the patient can do

- Wash your hands well before and after changing wound dressing. Never re-use dressings.
- Always keep the wound clean. Unless you were given different instructions, clean the wound every day with soap and water, rinse well, and pat it dry with a clean towel.
- Dress wounds as instructed by the doctor or nurse, or use sterile, non-stick gauze. If possible, use paper tape.
- Keep your dressing clean and dry. If it gets wet or dirty, change it right away.
- If the wound is bleeding, clean it well and apply moderate pressure with a cool cloth or ice pack until the bleeding stops. Then continue with dressing change.
- If possible, do not place tape directly on skin. (Use a "skin prep" solution, or wrap gauze over the bandage and then tape the gauze. Check with your nurse or pharmacist about supplies.)
- Avoid scratching or rubbing the wound or removing scabs.
- Eat citrus fruits, green leafy vegetables, whole grains, meat, fish, and eggs. They contain vitamins and minerals that help promote wound healing.

What caregivers can do

- Help clean wounds or change dressings if the patient is unable to do it for himself. If you can, wear a fresh pair of disposable plastic gloves each time you clean the area and put on a new dressing. Wash your hands before and after changing a dressing, even if you wear gloves.
- Be sure the patient has enough supplies to change the dressing as often as you were instructed.
- Check for signs of infection.
Call the doctor if the patient:

- Has a wound that bleeds for 15 minutes or more
- Has a wound that looks very red around the edges and is hot or swollen
- Has more pain than usual at the wound site
- Develops a bad smell from the wound
- Has yellow pus or greenish liquid that oozes from the wound
- Has a fever of 100.5° F or higher when taken by mouth
Seizures

A seizure is the uncontrolled movement of muscles. It happens when nerve cells in the brain become overexcited and do not work properly. Seizures usually last less than 5 minutes. They are followed by a period of sleepiness and confusion, which can last for several hours. Seizures in cancer patients can be caused by high fevers, head injury, serious infections of the fluid around the spine and brain, an imbalance in body chemistry, and tumor growth in the spine or brain.

What to look for

- Eyes stare blankly or roll back
- Patient suddenly loses control of urine and bowels
- Jerking movements of the body, especially the arms and legs

What the patient can do

- Talk to the doctor about your seizures. Bring the person who saw your seizure to the doctor with you to answer the doctor’s questions about it.
- Take anti-seizure medicines as prescribed.

What caregivers can do

- Keep the patient safe. If a seizure starts while the patient is in bed or on a chair, cradle the patient in your arms to keep him from falling to the floor.
- Stay with the patient.
- Stay calm.
- Loosen any clothing around the patient’s neck.
- If the patient falls to the floor, place padding (such as rolled-up clothes or towels) underneath the head and roll the patient onto his left side.
- If the patient is lying on his back, gently turn the head to the side if possible. Do not move any part of the body forcefully.
- Try to notice what type of movements the patient makes, how long the seizure lasts, and which parts of the body move with the seizure.
- Do not try to open the mouth during a seizure, even if the patient is biting his tongue. Keep your fingers and hands away from the patient’s mouth.
- Do not move the patient unless he is in a dangerous location (for instance, near a hot radiator, glass door, or stairs).
- Once the seizure is over, cover the patient with a blanket and allow him to rest.
- Do not give medicines, food, or liquids until you call the doctor and the patient is fully awake.
- If the patient is prone to seizures, use side rails and bumper pads on his bed. Be sure someone is with the patient when he is walking or sitting in a chair.
- Give anti-seizure medicine as prescribed by the doctor.

Call the doctor if the patient:

- Has a seizure, once it is over and the patient is comfortable (If someone else is with you, stay with the patient and have the other person call the doctor.)
Sexuality

Sexuality includes all the feelings and actions associated with loving someone. It includes holding hands, special looks, hugging, kissing, etc. It is not just the act of sex. This section addresses side effects of different treatments that affect your sex life and ways to relieve some common problems. It is important that you talk about any questions or concerns with your doctor or nurse, and most importantly, with your partner. Remember that warmth, caring, physical closeness, and emotional intimacy are as necessary and rewarding as any other kind of human interaction.

Cancer treatment often affects the ability of men or women to have children. Chemo, radiation, and some surgery can affect the reproductive system and cause infertility. In women, treatment may cause early menopause. It is hard to predict the outcome for any one person. Some people are still fertile after treatment; others are not.

Chemo and radiation can also cause birth defects if a child is conceived during the course of treatment or within several weeks of ending treatment. Avoid pregnancy during chemo or radiation. Find out if there is a period of time you should wait after your specific type of treatment before trying to conceive. Talk with your doctor about what to expect, and about any plans to have children. Do this before treatment begins.

What the patient can do

• Realize that your sexual desire may decrease due to the fear of having cancer and treatment, as well as because of treatment itself. Chemo can make you very tired or sick. (See the section in this booklet on chemotherapy.) Radiation therapy to the pelvis or genital area can sometimes cause pain during sex. (See the section in this booklet on radiation therapy.) Hormone treatment and the removal of the ovaries or testicles will change your body’s hormone levels. This can affect sexual desire.
• Talk with your partner about your feelings and concerns.
• Wait until you feel ready for sexual activity. Do not push yourself.
• Express desire for sexual contact when you feel able; do not wait for your partner to ask.
• Avoid intercourse if your white blood counts are dangerously low to reduce your chance of infection. (See the section in this booklet on blood counts for more information.) Check with your doctor to see if this is an issue for you.
• Enjoy other forms of closeness, such as touching, caressing, and holding each other.
• If you’ve had major surgery, ask your doctor if implants or reconstructive surgery is possible.
• Understand that you are not contaminated:
  - You cannot give your partner cancer.
  - You cannot pass chemo or radiation on to your partner.
• Try other things if your usual sexual activities are uncomfortable, such as:
  --Manual stimulation (using hands)
  --Oral-genital stimulation
  --Caressing, fondling, kissing
--Different positions (for instance, lying on your sides either facing or spooning, switch who is on top). New positions can allow you to control thrusting, avoid pressure on tender areas, or avoid tiring.

**Men:**

- Before you have chemo or radiation to the genital area, ask your doctor about saving sperm in a sperm bank.
- In about 40% to 60% of men, some degree of impotence (inability to get an erection) may slowly develop over 1 or more years after radiation to the genital area. Impotence usually does not happen right after radiation treatment. This is different from the effects of prostate surgery, which are seen right away and may improve over time.
- Men who have been treated for testicular, prostate, bladder, colorectal, and even head and neck cancers often report having trouble getting erections after treatment.
- Ask your doctor about getting serum testosterone levels checked to see if hormone replacement therapy would help you. Ask about other medicines or treatments that may help you, too.
- Radiation treatment to the genital area can cause pain during ejaculation for a short time. It can also reduce the amount of semen and cause skin irritation.
- Men who have testicular cancer and have lymph nodes removed often have little or no semen at orgasm. (This is called "dry ejaculation.") The return of your semen may take months or years, or may not happen at all. Semen is not needed for your or your partner’s satisfaction.
- For men who have prostate cancer, blood in the semen is not unusual during diagnosis or treatment, especially after a needle biopsy. This is not harmful or worrisome, but should be reported to your doctor.
- Sometimes, urination may occur accidentally during sexual activity. There is no need for concern about this. Urine is normally sterile and will not harm your partner.
- Use erotic stimulation, such as romantic dinners and prolonged foreplay.
- Shower together and use sexual play.
- Men with prostate cancer who have had radiation seeds implanted may need to use condoms for a few weeks as the seeds may become dislodged during sexual activity. Ask your doctor how long you will need to use condoms.

**Women:**

- Pain during intercourse is very common after surgery for many gynecologic cancers because the treatment may shorten or narrow the vagina. Ask your surgeon about the exact extent of your surgery. To help with this:
  --Use positions that give you control of depth and force of thrusting (e.g., woman on top, or both partners lying on their side).
  --Use your thumb and index finger at the vaginal entrance to circle around the penis. This can provide extra length and keep your partner from thrusting too deeply.
  --Keep the vagina from shrinking and tightening during radiation therapy to the pelvis or vagina. You will need to insert fingers, your partner’s penis, or special vaginal dilators (enlargers) 3 to 4 times a week while you get radiation treatment and afterward.
--If surgery that involves the vagina is planned, talk with your doctor or nurse about vaginal dilators to use after surgery. Be sure to find out when to start using them and how.

--Use an unscented, uncolored lubricant such as K-Y Jelly or Astroglide if lubrication becomes a problem. Surgery, radiation, or hormone treatment can cause dryness.

--Show your partner ways of touching or positioning that are comfortable to you, such as between the thighs or buttocks or between breasts

--Before you try sex with your partner, check to see if there is any soreness in your genital area.

• Chemo can cause thinning of the vaginal wall. Slight bleeding after sex is not a major concern, but it may help to use extra water-based lubricant. Avoid contraceptive gels, films, or foams, which contain chemicals that can irritate the vagina.

• Chemo can also reduce sexual desire and make it harder to reach orgasm. This usually gets better after treatment is over.

• Burning during sex may suggest a yeast infection. Talk to your doctor if this happens.

• Chemo may cause you to stop menstruating for some time, but may not entirely stop the ovaries from working. It may still be possible to get pregnant even if you haven’t menstruated for several months. Talk with your doctor about birth control, since chemo drugs can hurt a growing fetus.

• Chemo, radiation, or surgery that removes the ovaries may cause early menopause. Ask your doctor about your chances of this happening in your situation.

• If infertility is likely, talk with your doctor about the possibility of freezing ovarian tissue or eggs. This does require special surgery and is very expensive, but it may be an option for some women.

If you have an ostomy:

• Empty the pouch before sexual activity.

• Ask your enterostomal therapist about a pouch cover that doesn’t look "medical."

• If a leak occurs, shower together and continue sexual play.

• Tuck pouch into a supportive belt or cummerbund.

• Turn appliance to the side.

• Try different positions if there is friction.

• For women, try crotchless, lacy underwear or lingerie that covers the appliance, but leaves the genital area open.

• Some people are more comfortable wearing a T-shirt to cover the stoma at first.

What partners can do

• Find out how cancer and the cancer treatment are likely to affect your sexual relationship. Chemo can cause side effects such as fatigue. (See the section in this booklet on chemotherapy.) Surgery and radiation in the genital area may permanently change the structure and function of the genitals.

• Learn what changes to expect if the person is taking hormones, which may affect sexual function or desire.
• Be patient during chemo or radiation. Wait for times when your partner feels ready for sexual activity.

• Offer physical closeness and touching when the patient’s energy is low. Intimacy can be achieved without intercourse, erections, or orgasms. Kindness, affection, and respect go a long way toward reaching this goal.

• Find out how the patient feels about his body and about sexual activity. Sometimes, people feel unattractive after cancer treatment.

• It is normal to grieve about losses and changes in body image, which affect both of you. Consider talking with a mental health professional if you have had difficult changes in your relationship.

• When your partner is ready, be willing to try more gentle activities and new positions that feel good to both of you. Plan for private time when you will not be interrupted.

• Use unscented, uncolored water-based lubricant (such as K-Y Jelly or Astroglide) if dryness causes discomfort for either of you.

• If you are afraid of hurting your partner, talk about it with your partner and with the doctor or nurse.

**Call the doctor if the patient:**

• Notices new or more pain

• Notices bleeding

• Has a change in erectile function or in the amount of semen

• Has any sexual problems or questions concerning sexual activity

For more in-depth information, contact the American Cancer Society at 1-800-227-2345 and ask for *Sexuality for the Woman With Cancer*, or *Sexuality for the Man With Cancer*. You can also find information on the Web at cancer.org. For questions about fertility options, such as freezing eggs or sperm before chemo, visit www.fertilehope.org or call 1-888-994-HOPE.
Shortness of breath

If the patient has trouble breathing, the body may not get enough oxygen. Either the lungs cannot take in enough air, or the body cannot get enough oxygen through the bloodstream. A number of different problems can cause this, including chronic lung disorders, blocked airways, pneumonia, weak breathing muscles, or obesity. It can also be caused by pain, immobility, poor nutrition, stress or anxiety, allergic reactions, surgery, anemia, side effects of chemo or radiation treatment, tumor, fluid in the lungs, heart failure, and other problems.

What to look for

- Shortness of breath or trouble breathing at rest, when eating or talking, or with exercise
- Chest pain
- Faster breathing
- Faster heartbeat
- Pale or bluish-looking skin
- Blue fingernail beds
- Cold and clammy feeling skin
- Nostrils flaring when inhaling
- Wheezing

What the patient can do

- Stay calm.
- Sit up or raise the upper body to a 45° angle by raising the bed or using pillows.
- Take medicine or treatments prescribed for breathing (for example, oxygen, medicine for relief of wheezing, inhalers, or nebulizers).
- If you are not in a lot of distress, check your temperature and pulse.
- Inhale deeply through your nose and exhale through pursed lips for twice as long as it took to inhale. (This is called pursed-lip breathing.)
- If there is still no relief after 5 minutes, sit up on the side of the bed, with feet resting on a stool, arms resting on an overbed table or side table with pillows on it, and head tilted slightly forward.
- If you are coughing and spitting, note the amount of sputum and what it looks and smells like.
- Talk with your doctor about how your breathing problem affects you, especially if you avoid some of your usual activities to keep from getting out of breath.
- Try muscle relaxation to reduce anxiety. Anxiety makes breathing problems worse.
- If you keep having trouble breathing, ask your doctor about medicines you can use to help.
• If new shortness of breath starts suddenly and does not improve; your skin looks pale or blue; or if you have chest discomfort, trouble speaking, dizziness, or weakness, call 911.

What caregivers can do

• Use a watch with a second hand to check the patient’s pulse, counting the number of beats per minute. (If you count the number of beats per minute, do it without telling the patient. If the patient knows when you are counting, he may slow down or speed up the breathing rate without realizing it.)
• Check the patient’s temperature to see if he has a fever.
• If the patient is short of breath, remove or loosen tight clothing.
• Have the patient sit up in a resting position that feels comfortable to him.
• Remind him or her to take slow, deep breaths, and exhale slowly.
• Remove the patient from extreme temperatures, especially heat, which may make it harder to breathe.
• Note whether the patient gets out of breath when doing strenuous activity, normal activity, or when he is at rest, and whether it happens when the patient is standing, sitting, or lying down.
• Putting the patient in front of an open window or placing a fan that blows gently on the face may help some people.
• Offer any medicines or inhalers prescribed for shortness of breath.
• If home oxygen is prescribed, be sure that you know how to set it up and what flow rate to use. (Do not change the flow rate without first talking to the doctor.) Don’t allow smoking or fire when oxygen is in use.

Call the doctor if the patient:

• Has trouble breathing or chest pain
• Has thick, yellow, green, and/or bloody sputum
• Develops pale or bluish skin or if the skin feels cold and clammy
• Has a fever of 100.5° F when taken by mouth
• Has flared nostrils during breathing
• Becomes confused or restless
• Has trouble speaking
• Has dizziness or weakness
• Has swelling of the face, neck, or arms
• Develops wheezing
Skin color changes

Skin color changes usually happen because there is some type of change in the body. For example, a person may look yellow because of liver problems, blue because of breathing problems, bruised because of blood disorders, or red because of skin problems. Changes in the skin can be due to tumor growth, sun exposure, or the side effects of chemo or radiation therapy. Some color changes may improve over time, while others may be permanent.

What to look for

- Yellowish color to skin and/or whites of eyes
- Deep orange to brown urine
- White or clay-colored (light brown or gray-looking) stools
- Bruises or areas of blue or purple skin that have no known cause
- Trouble breathing (If present, see section on shortness of breath.)
- Redness or rash on skin
- Swelling in an area that is discolored
- Itching (See the section in this booklet on itching.)

What the patient can do

- Clean the area gently with warm water, gentle soap, and a soft cloth.
- Rinse the area carefully and pat dry.
- Apply water-repellent salve, such as petroleum jelly or A & D ointment.
- Wear loose-fitting clothing made of soft fabrics, such as cotton.
- Expose the affected skin to air whenever possible.
- Protect the affected area from heat and cold.
- Keep your skin protected from the sun. (For instance, wear a wide-brimmed hat and long-sleeved shirts when outside.)
- Apply sunscreen with an SPF of 15 or higher to any skin exposed to the sun.
- Apply medicine prescribed for skin reactions.

What caregivers can do

- Keep track of any new medicines, soaps, detergents, or new foods that may have caused a rash.
- If a patient’s hands are affected, do not let the patient do tasks involving hot water.
- Offer gentle massages with moisturizing lotions or creams.

Call the doctor if the patient:

- Has urine that remains dark or orange for a day or more
- Has stool that looks white or clay-colored for 2 or more bowel movements
- Develops a yellowish color on the skin or in the whites of the eyes
- Has severe itching (See the section in this booklet on itching.)
• Has bruises that do not go away within a week, or new bruises that continue to appear for 3 days
• Has red or rash-like areas on the skin

**Skin dryness**

Dry skin can be rough, flaky, red, and sometimes painful. It is caused by not enough oil and water in the layers of the skin. Common causes of dry skin include dehydration, heat, cold, poor nutrition, and side effects of radiation treatment or chemo.

**What to look for**
• Red, rough, flaky skin (although dry skin can look normal)
  • Cracks in the skin
  • Slight bleeding between the lines of skin covering body areas, such as knuckles or elbows

**What the patient can do**
• Add mineral or baby oil to warm bath water, or apply after showering while skin is still damp. (This can make you slippery, so be careful to keep from falling.)
• Wash with cool or warm water – not hot water.
• Avoid scrubbing during showers or baths. Gently pat skin dry after bathing.
• Avoid water-based creams twice a day, especially after baths.
• Avoid colognes, after-shaves, and after-bath splashes that contain alcohol.
• Use an electric razor.
• Drink 2 to 3 quarts of liquid a day if it's OK with your doctor.
• Protect your skin from cold and wind. Avoid hot water and heat, especially dry heat.

**What caregivers can do**
• Apply lotions or oils on hard-to-reach places.
• Offer extra fluids.

**Call the doctor if the patient:**
• Develops very rough, red, or painful skin
• Has signs of infection, such as pus or tenderness near broken skin
Skin (pressure) sores

A skin or pressure sore develops when the blood supply to an area of the body is stopped and the skin in that area dies. A person who is bedridden or always in a wheelchair puts pressure on the same places much of the time. This reduces the blood flow to these places, making them more likely to develop open sores. These areas are made worse when the patient rubs against his sheets or is roughly pulled up in the bed or chair.

What to look for

• Red areas on the skin that do not go away even after the pressure is removed
• Cracked, blistered, scaly, or broken skin
• An open sore involving skin surface or tissue under the skin
• Yellowish stains on clothing, sheets, or chairs (may be tinged with blood)
• Painful or tender "pressure points" (such as on the back of the head, ears, back of shoulders, elbows, buttocks, hips, heels, or any place a bony part rests on the bed surface)

What the patient can do

• Change position at least every 2 hours from your left side, to your back, to your right side.
• In a wheelchair, shift your weight every 15 minutes. Use special seat cushion to reduce pressure.
• Protect other "pressure points" with pillows to help prevent new sores. If possible, use pressure-reducing mattress or 3- to 4-inch foam layer over your mattress.
• Exercise as much as possible For example, take a short walk 2 or 3 times a day. If you are not able to walk, pull up, and move your arms and legs up and down and back and forth.
• Eat foods high in protein (such as tuna or other fish, eggs, meats, milk, or peanut butter).
• Increase fluids. (If you are not eating well, try high-calorie liquids such as milkshakes.)
• Bathe each day, and look at the pressure point areas.
• Always protect the sore and the area around it with a foam wedge or pillow.
• Rinse any open sore with water very carefully and cover with a bandage. Do this every time the bandage gets soiled, or at least twice a day as instructed by your doctor or nurse. If your doctor gives you ointments or creams, use them as prescribed. Report any itching or blistering in the area.

What caregivers can do

• Remind the patient to change position often, or help the patient turn every 2 hours.
• If the patient cannot control his bowel and bladder, change his underwear as soon as you notice soiling, and then apply an ointment (such as A & D ointment®) to keep the area dry. Sprinkle cornstarch over the ointment. Avoid using plastic underwear unless the patient is out of bed. Use underpads to prevent the patient from soiling the bed while lying down.
• If the skin is open, talk with the doctor about special dressings to help protect it.
• If the patient is bedridden:
  ➢ Keep the bottom sheets pulled tight to prevent wrinkles.
Keep the head of bed flat or at a 30° angle.
Sprinkle sheets with cornstarch to reduce friction from rubbing against them.
Inspect the patient's back and sides each day to be sure that the skin looks normal. If a reddened "pressure area" (an area that stays red after pressure is taken off it) is noticed, keep the pressure off it as much as possible to try to prevent further breakdown. Use pillows and have the patient change position frequently.
• If the patient has trouble staying on her side, find out about foam wedges to help hold positions.
• Foam pads for the bed and chairs may help some patients.
• If the problem continues, talk to the doctor or nurse about home care options. Find out about special beds that reduce pressure areas.

Call the doctor if the patient:
• Has cracked, blistered, scaly, or broken skin
• Has a sore that is getting larger
• Has a thick or bad-smelling liquid draining from the sore
• Needs a referral to a home care agency for help with pressure sore care and supplies
Sleep problems

Sleep problems can be defined as a change in usual sleeping habits. People who are getting treatment for cancer may get tired more easily and may need to sleep more than usual. Sometimes, the opposite problem occurs and people may have trouble sleeping. Reasons for changes in usual sleeping habits include pain, anxiety, worry, depression (see the related sections in this booklet), night sweats, or side effects of treatment or prescription drugs.

What the patient can do

- Sleep as much as your body tells you to, but when you are awake, try to exercise at least once a day. Do this at least 2 to 3 hours before bedtime. (See the section on exercise in this booklet.)
- Avoid drinks with caffeine for 6 to 8 hours before bedtime.
- Avoid alcoholic drinks in the late evening. They can keep you awake as they "wear off."
- Drink warm, caffeine-free drinks, such as warm milk with honey or decaf tea, before sleep.
- Use a quiet setting for rest during the same period of time each day.
- Take sleeping medicine or pain relievers prescribed by the doctor at the same time each night. If pain keeps you awake, see the section in this booklet on pain.
- Have someone give you backrubs or massage your feet before bedtime.
- Keep sheets clean, neatly tucked in, and as free from wrinkles as possible.
- Talk with your doctor about relaxation therapy or a referral to a hypnotherapist.

What caregivers can do

- Help keep the room as quiet and comfortable as possible during sleep times.
- Offer gentle backrubs or foot massages near bedtime.
- Offer a light bedtime snack.
- Let the doctor know if the patient appears to be confused during the night.

Call the doctor if the patient:

- Is confused at night
- Is unable to sleep at all during the night
Steroids and hormones

Hormones are natural substances in the body. Corticosteroids (or steroids), such as cortisol, are produced by a small gland (the adrenal gland) on top of each kidney. Estrogens are female hormones produced by the ovaries. Androgens, such as testosterone, are produced by the testicles.

Testosterone can promote growth of prostate cancer. That is why men with prostate cancer may take anti-androgen drugs to slow the cancer growth. Estrogens are rarely used to treat prostate cancer.

Some breast cancers depend on estrogen to grow. Drugs that block estrogen or reduce its production (such as tamoxifen or aromatase inhibitors) are used to slow the growth of these breast cancers or keep them from coming back.

Corticosteroids are used to treat many different kinds of cancer. They also help reduce nausea, improve appetite, and reduce swelling caused by cancer in the brain.

What to look for

Corticosteroids can cause short-term side effects such as:

- Mood changes
- Trouble sleeping
- Fluid retention
- More facial hair
- Increased urination
- Increased thirst and appetite
- Muscle weakness
- Fat build-up in the cheeks, abdomen, and the back of the neck

Prolonged high doses can cause osteoporosis (bone thinning), which raises the risk of broken bones (fractures).

Estrogens can cause short-term side effects. In women, estrogens can cause fluid retention and vaginal discharge or bleeding. In men, they can cause tender and swollen breasts and less interest in sex.

Estrogen-blocking drugs such as tamoxifen can cause hot flashes and vaginal dryness and discharge in women.

Androgen-blocking drugs may cause hot flashes in men, as well as less interest in sex, decreased sexual performance, tiredness, and mood changes.

What the patient can do

- Talk with your doctor about what to expect from the hormones you will be taking.
- Cut back on your salt intake.
- Watch your calorie intake to avoid too much weight gain.
- Take your medicines as directed.
- Remember that these side effects are short-lived and will get better after the steroid or hormone treatment is done.
- Do not suddenly stop taking your medicines. Talk with your doctor if there are problems.
What caregivers can do

• Find out what medicines the patient is on. Talk with the doctor so that you will have some idea what to expect while the patient is on hormone therapy.
• Watch for mood swings.

**Call the doctor if the patient:**

• Is vomiting or having pain in the abdomen
• Has mood swings that are disturbing you and others
• Is having trouble sleeping
• Becomes short of breath (See the section in this booklet on shortness of breath.)
• Becomes dehydrated (See the section in this booklet on fluids and dehydration.)
• Has a fever of 100.5° F or higher when taken by mouth
• Has stools that look black like tar or contain blood
• Has pain

For more in-depth information on the specific hormones you are taking, contact your American Cancer Society at 1-800-227-2345, or visit cancer.org.
Stomas (or ostomies)

A stoma is a surgically created opening in the body that replaces a normal opening. It is needed when the normal opening is blocked by a tumor or has been altered as part of cancer treatment. Stomas serve as new sites for basic bodily functions.

There are different types of stomas. Three are commonly seen in people with cancer:

- Tracheostomy (pronounced tray-key-OSS-tuh-mee, or trake for short) in the trachea, or windpipe
- Urostomy in the bladder or urinary system
- Colostomy in the colon

What the patient can do

**Tracheostomy:**

- Use pad and paper for "speaking" with others.
- Do not remove the outer tube of the tracheostomy unless your doctor or nurse tells you to.
- Clean your tracheostomy tube at least once a day as instructed by your nurse or doctor.
- Suction the tube as needed or as directed by your nurse or doctor.
- Wash your hands carefully before and after handling your tracheostomy to help prevent infections.
- Be careful to keep water out of the tracheostomy while bathing. A child's bib with the plastic side facing outward can be used to keep water out and allow breathing while you shower.
- Do not swim. Being around water that may get close to your neck will be risky for you because water can get into your lungs.
- Wear a scarf or shirt that covers the opening but is made of thin fabric (such as cotton) that allows air to get through. This helps protect the stoma from dust and loose fibers.
- Ask to meet with a respiratory therapist or ostomy nurse if you need more information.
- You may want to visit www.larynxlink.com or call 1-866-425-3678 to learn about the International Association of Laryngectomees.

**Urostomy and colostomy:**

- Every day, gently clean the skin around your stoma with warm water only. (You may see a small amount of blood while cleaning. This is OK.)
- Gently pat dry or allow to air dry.
- Showers or baths can be taken with pouch on or off.
- Apply barriers, borders, or pastes to the skin around the stoma before putting on the pouch.
- Empty the pouch when it is one-third full.
- Change the colostomy pouch before there is a leak; if possible, not more than once a day and not less than once every 3 or 4 days.
- Change the urostomy pouch every 3 to 5 days.
- Irrigate the stoma as instructed by a nurse or doctor.
• Ask your enterostomal therapy nurse or therapist any questions you may have.
• If you live in a large community, consider joining a support group. Visit www.uoaa.org or call 1-800-826-0826 for information from United Ostomy Associations of America, Inc.
• See the section on sexuality in this booklet for tips on managing the stoma during sex.

What caregivers can do

**Tracheostomy:**

• Learn how to care for the tracheostomy.
• Learn to suction out mucus from the upper airway.
• Moist air helps keep mucus from being too thick and sticky. A humidifier, especially in the bedroom, may be helpful. Check with the doctor or nurse on how to clean the humidifier.

**Urostomy and colostomy:**

• Learn how to care for the stoma, including the skin around the opening.
• Offer help if the patient is having trouble. Often, the patient feels embarrassed and will not ask for help.
• Encourage the patient to join an ostomy club for support and practical tips.
Swallowing problems

Swallowing problems occur when a person has trouble getting food or liquid down his throat. A person may gag, cough, spit, or feel pain when trying to swallow. There can be a number of causes. It may be a short-term side effect of chemo or radiation treatment to the throat or chest. It may also be caused by an infection of the mouth or esophagus (the swallowing tube that goes from the throat to the stomach), as well as other problems.

What to look for

• Gagging, coughing, or vomiting of food
• Weight loss
• Food building up in mouth
• Drooling out of the side of mouth; too much saliva
• Little or no saliva
• Inside of mouth is red, shiny, glossy, or swollen
• Open sores in mouth
• Pain in throat or mid-chest when you swallow
• Feeling like the food is "sticking" on its way down
• White patches or a coating on the inside of the mouth

What the patient can do

• Eat bland foods that are soft and smooth but high in calories and protein (such as pudding, gelatin, ice cream, yogurt, and milk shakes).
• Take small bites, and swallow each bite completely before taking another.
• Use a straw for liquids and soft foods.
• Try thicker liquids (such as fruit that has been pureed in the blender), because they are easier to swallow than thin liquids.
• Mash or puree foods (such as meats, cereals, and fresh fruits) so that they are as soft as baby food. You may need to add liquids to dry foods before blending.
• Dunk breads in milk to soften.
• Refrigerate food (the cold helps numb pain) or serve cool or lukewarm. (Pain in the esophagus may feel worse with cold liquids. If so, serve food at room temperature.)
• Try crushed ice and liquids at meals.
• Frequent small meals and snacks may be easier to manage.
• Crush medicines in pill or tablet form; mix in juice, applesauce, jelly, or pudding. (Check with your nurse or pharmacist first, because some medicines can be dangerous if crushed or broken. Others react badly with certain foods or must be taken on an empty stomach.)
• Avoid alcohol and hot, spicy foods or liquids.
• Avoid acidic foods, such as citrus fruits and drinks, or fizzy drinks (like cola or ginger ale).
• Avoid hard, dry foods such as crackers, nuts, and chips.
• Sit upright to eat and drink and for a few minutes after meals.
• If pain is a problem, use a numbing gel or pain reliever, such as viscous lidocaine (by doctor’s prescription) or liquid Tylenol. (See the section in this booklet on mouth sores.)
• Ask your doctor about seeing a speech therapist or swallowing therapist.

What caregivers can do

• Offer soft, moist foods. Baked egg dishes, tuna salads, and thick liquids such as yogurt may be easier to swallow.
• Avoid chewy foods or raw crunchy vegetables.
• Sauces and gravies make meats easier to swallow.

Call the doctor if the patient:

• Gags, coughs, or chokes more than usual, especially while eating or drinking
• Has a severe sore throat
• Has a red, shiny mouth or ulcers in the mouth or on tongue
• Has a fever greater than 100.5° F when taken by mouth
• Has trouble breathing
• Has chest congestion
• Has problems with food "sticking" as it goes down
• Cannot swallow medicines or eat
Sweating

Sweating is heavy perspiration that can happen at night or even when the room is cool. It can be heavy enough to soak a person’s clothes. Such sweating is common when a fever breaks. You may notice sweating happens a short time after the person has shaking chills. (See the section in this booklet on fever.)

You can have a fever with or without a known infection. Sometimes, no fever is detected, only the sweating that goes along with a drop or break in fever.

What to look for

• Feeling wet or damp during the night or waking up to find sheets damp
• Fever followed by heavy sweating as the body temperature goes back down
• Shaking chills
• Drenching sweats even when there is no fever

What the patient can do

• Take medicine to reduce fever, such as Tylenol, but only if instructed by the doctor or nurse.
• Dress in 2 layers of clothing. The layer on the outside will act as a wick to pull moisture up and away from the skin.
• Change wet clothes as quickly as possible.
• Keep your bed linens dry.
• Bathe at least once a day to soothe skin and to maintain good hygiene.

What caregivers can do

• Help the patient keep clothes and bed linens dry.
• Check the patient’s temperature several times a day to find out if there is fever. Wait 10-15 minutes after the patient eats or drinks to check temperature.
• Offer extra liquids to replace the fluid that is lost through sweat.
• For comfort, offer to help the patient with a tub bath or shower if needed.

Call the doctor if the patient:

• Becomes dehydrated from frequent soaking sweats (See the section in this booklet on fluids and dehydration.)
• Has fever of 100.5° F or higher (when taken by mouth) for more than 24 hours
• Has tremors or shaking chills
Swelling

Swelling (edema) is a build-up of water in the tissues. Common causes include salt and water retention (due to medicines or heart, liver, or kidney failure), poor nutrition, pelvic tumors, or blockage in the veins or lymph system. Fluid can also build up in the abdomen. This is known as ascites (as-SIHGH-tees). It makes the belly look swollen.

What to look for

• Feet and lower legs get larger when you sit in a chair, stand, or walk
• Rings feel too tight for fingers
• Hands feel tight when making a fist
• Large, puffy, or blown-up abdomen (belly)
• Trouble breathing, especially when lying down (See the section in this booklet on shortness of breath.)
• Heart racing or palpitations (or an awareness that the heart beat is fast or irregular)

What the patient can do

• Limit your use of salt on food. Avoid use of table salt and salt in cooking, and don’t eat foods that are very high in salt.
• Talk with the doctor about how to reduce your salt intake.
• Eat as well as you can. (See the section in this booklet on poor appetite.)
• Take medicines as prescribed by the doctor.
• Rest in bed with your feet up on 2 pillows.
• When sitting up in a chair, keep your feet level with your chest by placing them on a stool with pillows.

What caregivers can do

• Watch for any new symptoms, especially shortness of breath or swelling in the face.
• Encourage the patient to keep the swollen body part propped up as high as is comfortable when sitting or lying down.
• Don’t add salt, soy sauce, or monosodium glutamate during cooking.
• Weigh the patient every day or 2 on the same scale, at the same time of day. Keep a list of weights and dates.

Call the doctor if the patient:

• Can’t eat for a day or more
• Hasn’t urinated, or has urinated very little, for a day or more
• Can press a finger into a swollen area and the fingertip mark remains
• Has swelling that spreads up legs or arms
• Develops a puffy or blown-up belly
• Feels that the swollen area is getting red or hot
• Has shortness of breath or a racing heart
• Has a swollen face and neck, especially in the mornings
• Gains 5 or more pounds in a week or less
Treatment at home

Treatment for cancer sometimes can be given at home rather than in the hospital or clinic. Pills, intravenous (or IV) chemo, IV antibiotics, subcutaneous injections (shots given under the skin, also known as "sub-Q" injections), intramuscular injections (shots given into a muscle, also called "IM" injections), and other treatments may be given at home. Talk with your doctor about it. It is important to take medicines as prescribed and to look for side effects that sometimes happen. Usually, a home care nurse or IV therapy (infusion) nurse will come to your home often to give, teach you about, or check on home treatments.

Home treatments sometimes cannot be done due to problems with health insurance. You may want to contact your insurance company to find out more. Patients who cannot make frequent visits to the doctor’s office or clinic may qualify for some kinds of home care. To be eligible for this, you must be homebound, only going out for doctor’s visits or church.

What the patient can do

Pills:

- Take your pills exactly as you were told to.
- You may have to set an alarm for the middle of the night so you can take your pills at the right time. Put the pill dose and a glass of water on your bedside table so you don't have to get up.
- If taking pills only once a day, you may want to try taking them just before bedtime to avoid side effects, such as nausea. Check with your doctor or nurse about the best time and way to take each medicine.
- Ask your doctor or nurse about any side effects you may have and about ways to control these side effects. (For instance, if your pills could cause nausea, should you take them before meals? Is there something else you can take that would help?)
- Keep all medicines out of the reach of children and pets.
- Check with your doctor, nurse, or pharmacist before you cut or crush your pills. Some time-released drugs can be dangerous if the pills are broken.

Intravenous (IV) medicine:

- A home health or infusion nurse will come to your home to give drugs intravenously (into a vein) or to teach you and your family how to do so.
- See the section in this booklet on tubes and IV lines for further information on care of the IV site.

Injections (under the skin or into a muscle):

- Wash your hands well with soap and water before starting.
- Take medicines as instructed by your doctor or nurse.
- Check to be sure that the dosage in the syringe is your prescribed dosage.
- Wipe your skin with alcohol and let it dry for 30 seconds before injecting.
- If the needle touches anything that isn’t sterile before you use it to inject, throw the needle away, put a new one on the syringe, and start over.
- Use a different place on the body for each shot.
• For shots under the skin, use a site at least 1 inch away from the place you used before.

• For intramuscular injections (shots into a muscle), ask for a picture or chart of places on the body that are safe to use.

• Check old injection sites for signs of infection, including redness, warmth, swelling, pain, or oozing. A temperature over 100.5° F or higher when taken by mouth may be a sign of infection.

• Throw away used needles and syringes in an empty coffee can with a lid or an empty plastic bleach bottle. Take the full container to the clinic for proper disposal. Or ask the home health nurse if you can get a needle disposal box. Keep the needle container away from children, pets, and visitors.

What caregivers can do

• Learn how to give the medicines in case the patient can’t do it.

• If you help with shots, be careful to not stick yourself with the needles. Put the used needle container near the patient before you start. Drop the needle and syringe in as soon as you’re finished. Don’t put the cap back on the needle before throwing it away.

• Keep the doctor’s office number (including emergency numbers) handy.

• If you have a home health nurse who helps with injections, keep his phone number nearby in case you have questions.

Call the doctor if the patient:

• Is about to need a prescription refill

• Spills or loses medicine, or if a dose is vomited or thrown up

• Learns that any person, other than himself, has taken his medicine

• Misses a dose

• Has redness, warmth, swelling, drainage, or pain at any injection site

• Has a fever greater than 100.5° F when taken by mouth

• Has uncomfortable side effects, such as nausea, vomiting, diarrhea, or pain

• Cannot give himself the shots or take the pills for any reason

• Notices itching, dizziness, shortness of breath, hives (raised itchy skin welts), or other signs of an allergic reaction after a shot (If this is the case, call emergency medical services (911) before calling the doctor.)
Tubes and IV lines

Tubes and intravenous, or IV, lines allow liquid medicines, fluids, and even nourishment to flow into the body. See the section in this booklet on treatment at home for more information on tubes and IV lines.

**Intravenous** (IV) lines are thin, flexible, plastic hoses that run from a bottle or bag of medicine into a tiny needle or intravenous catheter (a small flexible tube) placed in a vein in your body. Some patients may have a port (like a small drum) permanently placed in the chest or arm. Special needles are then put into the port. Some patients may have long-term tubes (catheters) that require no needles.

Some medicines are injected into the catheter. Other medicines and fluids are given slowly (infused). The speed (rate) of the infusion is set by a roller clamp on the tube, by a balloon that squeezes out the medicine, or by an electronic pump.

**Tube feedings** are liquid food that is given through a tube placed in the stomach or the small intestine. The tube may go in through the nose or the wall of the stomach.

**Oxygen** may be given through masks or little tubes placed just inside the nostrils called nasal cannula. Tubing connects the mask or cannula to the oxygen tank or oxygen concentrator.

An important difference between these types of tubes is that anything that goes in the IV line must be sterile (completely germ free) in order to avoid putting germs into the bloodstream and causing infections. IV equipment is used only once. It must be handled carefully to keep germs out of the body. After use, it is thrown out and replaced with new, sterile equipment fresh out of the package.

Tube feedings and oxygen tubes are kept clean, but do not have to be sterile. Tube feeding or oxygen equipment can be re-used as long as it is used by the same person. When tube feeding bags need cleaning, liquid soap and water are fine.

People getting chemo, antibiotics, hyperalimentation (hi-per-al-uh-men-TAY-shun, also called total parenteral nutrition, or TPN), tube feedings, and/or oxygen at home may be faced with many tubes and IV lines that they must learn to keep track of and use safely. At first it may seem confusing, but you can master taking care of many tubes or lines. A home health nurse will help you learn. Usually, chemo and blood products are given by a nurse who comes to your home. You and your family will be able to manage most other IV medicines. If you cannot, other plans will be made for you to get your treatment.

What the patient can do

**IVs:**

- Focus on only 1 set of lines at a time. If you get frustrated, just take a deep breath and start again.
- Color code each set of lines with colored tape. For example, red for chemo, green for antibiotics, etc. Keep a record of what you have marked. You may want to use blue tape on oxygen tubes to keep them clearly separate from the IV lines.
• For permanent IV sites (such as Hickman, Port-a-Cath, PasPort, or Infusaport):
  
  Keep extra clamps handy at all times.
  
  If a tube breaks and you notice blood leaking out, clamp the tube between your body and the leak and call your doctor right away.
  
  Shower facing away from the showerhead. If you have an electric pump, unplug it before showering or bathing to avoid an electrical hazard. Try to keep the dressing dry, but change it if it gets wet.
  
  Watch for redness, swelling, pain, and tenderness at the site.
  
  Use a calendar to record when you change injection caps and dressings and to note delivery dates, daily weights, and urine testing results. It is also helpful to record your daily fluid intake and output (how much liquid you drink and infuse, and how much urine you put out.) Your doctor or nurse will tell you what things you need to keep track of.

• Keep the IV site clean and dry.
• Avoid the temptation to speed up your IV medicines or fluids. Many IV medicines and fluids can harm you if they go in too fast.
• Wash your hands well with soap and water before touching the IV site.
• Check the IV site daily:
  
  Look for any tenderness, pain, redness, burning, swelling, or warmth; any slowing of the flow rate of the IV; or drainage (bloody, yellowish, or clear). Any of these might mean the site is getting infected or clogged.
  
  Be sure the tape is holding the IV in place and the dressing is clean and dry.
  
  Take your temperature each day to see if you have a fever. (See the section on fever in this booklet.)
  
  If you notice any of the above symptoms, take off the dressing, look at the IV site and tell your doctor or home health nurse what you found.

• If the IV comes out or the site begins to bleed, call your doctor or nurse right away.
• Avoid activities that may pull out the IV or rub on the dressing.
• Keep a daily log of procedures performed.

Hyperalimentation (TPN or total parenteral nutrition):

• Your home care nurse will teach you exactly how to begin and end each infusion.
• Infuse the TPN slowly overnight so that you have more free time during the day.
• If you find that you are having trouble sleeping because you need to go to the bathroom often, TPN may be infused during the day or early evening. It must still go in slowly.
• Intravenous fat emulsions are usually given along with TPN 2 to 7 times a week. They provide essential fatty acids and to increase calorie intake. Fat emulsions can be added to the TPN solution through a port on the TPN tubing. These can be infused by gravity (without a pump) in adults. Your home health nurse will show you how to set the speed by using the

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City of Hope
May 9, 2016

Resource
A Guide for Patients and Families

Page R-91
roller clamp and timing it to give you the right number of drops per minute. A pump is needed for children.

- Infuse your TPN in a room near a bathroom so that you do not have to carry the pump too far. Use a night light so that if you need to get up at night, you don’t trip over or pull the tubing.
- Most pumps are battery-powered. Check with the home health nurse about how long the pump can run before new batteries are needed. Be sure that you have enough batteries for your type of pump, and know how to put them in.
- Keep a clean work area for supplies.
- If possible, use a separate place in the refrigerator (or a separate refrigerator if you have an extra one) for IV solutions.
- Throw away needles and syringes in a metal coffee can with a lid, in a bleach bottle, or in a used needle container provided by the home health team. Keep the container out of the reach of children, pets, and others.
- Always check the expiration date on all your supplies.
- Home health care nurses will draw blood samples to check fluids and blood chemistry.

**Tube feedings:**

- The tubes used for tube feedings may be short or long term. The nasogastric (NG) tube, which runs from nose to stomach, is short term. Jejunostomy tubes (J-tubes) or gastrostomy tubes (G-tubes), which are surgically placed in the upper intestine or stomach and come out through the belly, are for long-term use.
- Tube feedings are best given at night.
- Feedings usually consist of products like Ensure or Sustacal.
- Give tube feedings at room temperature. Most do not need to be refrigerated.
- Check the placement of NG tubes as instructed by your doctor or nurse.
- Pour the feeding liquid into the special feeding bag.
- Allow the liquid to run through the entire tubing. Tap the tube to make air bubbles rise. (It takes about 3 to 4 feet of air in the tube before it causes problems.)
- Attach the tube containing the liquid food to NG, G-tube, or J-tube. Tape the connection.
- Set the pump to the required rate.
- Add more feeding liquid to bag as needed.
- Rinse tubes and bag with water after the infusion is completed.
- Cap off the tube as instructed.
- Feedings can also be given with large syringes instead of bags and tubing. Be sure you are comfortable using whichever method you are taught.
- Check the skin around the tubes each day for redness, drainage, or skin problems.
- Apply petroleum jelly (such as Vaseline) to the nostrils if an NG tube is in place.
- Change the tape at the NG tube every other day. Be sure the skin around the nose and nostril is not sore, red, or painful.
• Always keep the feeding tubes securely taped in place. If the tube seems to be coming out, tape it in place, and do not use it. Call your doctor or home health nurse to find out what needs to be done.

• Weigh yourself each day and write down dates and weights.

Oxygen:

• Be sure you know how to turn the oxygen on and off and set the flow rate. Never increase the oxygen flow above the prescribed level.

• The nurse will show you how to use the oxygen mask or cannula.

• Use a water-based lubricant, rather than petroleum jelly, on the lips and cheeks.

• If the nasal cannula rubs your upper lip, you can put a small piece of gauze or fabric under it for padding.

• Keep a new tank of oxygen available at all times. Even if you use an oxygen machine, you will need a small tank for when you leave the house and during power failures.

• If you use a tank, be sure it is attached to a stable cart so it won’t fall or roll.

• Do not smoke or go near sparks or flames while using oxygen. Keep sparks and flames away from tanks, oxygen machines, and tubing.

What caregivers can do

• Learn as much as you can about how to use the tubes and equipment, and practice while the home health nurse is there to watch you. You may need to do these tasks when the patient cannot.

• Help the patient. In the beginning, you will probably both feel more comfortable if you do these treatments together.

• Keep home health nurses’ phone numbers handy, and call when you have questions or problems.

• Be sure that the patient keeps all appointments.

• Watch for confusion, especially at night.

Call the doctor if the patient:

• Has redness, swelling, drainage, pain, tenderness, or warmth at an IV site or at the site of a permanent IV access device

• Has a temperature of 100.5° F or higher when taken by mouth

• Has bleeding from the IV or access site

• Cannot flush or use his catheter or tube

• Becomes confused, disoriented, or unusually drowsy

• Becomes more short of breath

• Develops a cough

• Has diarrhea for more than 1 day
Weakness

A person who has trouble moving may have general weakness and problems walking, and he may find it hard to get from one place to another. When a person spends a lot of time in bed, muscles get weaker. Other things that can make it hard to move include pain in the joints or legs, as well as some of the side effects of chemotherapy and radiation. It is important to move and exercise as much as possible to prevent new problems. Problems caused by being less active may include poor or no appetite, constipation, skin sores, problems with breathing, stiff joints, and mental changes.

What the patient can do

- Do active or passive range-of-motion exercises as instructed by the nurse, doctor, or physical therapist. (See the section in this booklet on exercise.)
- Take pain medicines as prescribed.
- Drink as much liquid as your doctor will allow.
- Keep a record of bowel movements. (See the section on constipation in this booklet for information about foods that help prevent this problem.)
- Change positions at least every 2 hours while at rest.
- Wear shoes (not slippers that slide off easily) when walking or standing.
- Use any brace, cane, walker, or other support prescribed by your doctor or nurse.
- Take short walks if you can. Even if you are bedridden, try to sit up in a chair for meals and walk to the bathroom or bedside commode.
- If you need help walking, have a family member support you on your weakest side. (For instance, if your right side is weak, have someone stand on your right side before you get up. Have your helper put his left arm around you, and put his right forearm and hand in front of your right shoulder.)

What caregivers can do

- When lifting the patient, keep your back straight and bend and lift from your knees and hips. Stand as close to the patient as possible, and keep your feet spread for a firm base and good balance.
- Always lock the wheels on the bed or wheelchair.
- Always pull the patient toward you when rolling him in bed.
- Clear the floor so that you can help the person to the chair or bathroom without tripping over rugs, cords, fallen objects, clothing, and without slipping on liquids.
- If the patient is unsteady but still able to get up, see the section in this booklet on falls.
- If the patient is to be alone for a while, be sure that the phone and emergency phone numbers are within easy reach.

Call the doctor if the patient:

- Is getting weaker
- Falls
- Has a headache, blurred vision, numbness, or tingling
- Has a change in mental status, such as getting confused, disoriented, or very sleepy
- Has pain that gets worse
Weight changes

Weight changes during treatment for cancer are common. There are a number of causes for weight loss including:

- Eating less due to nausea or poor appetite
- Diarrhea
- Vomiting
- Dehydration

(You can learn more about each of these causes in the related sections in this booklet.)

Causes for gaining weight include:

- Less activity
- Eating more
- Retaining water (See the section in this booklet on swelling.)
- Certain medicines

Weight changes of more than 5 pounds in a week should be reported to your doctor. A decrease in weight over time may affect the person's ability to function, leaving people feeling weak and unable to perform daily activities. Quick weight loss is often a sign of dehydration. An increase in weight over time may suggest a serious health condition, such as diabetes or high blood pressure. You may be able to tell if you gain or lose 5 pounds in a week by the way you feel or the way your clothes fit, or you can weigh yourself on a scale once a week or so.

What to look for

- Weight loss of 5 pounds or more in a week or less
- Dry skin
- Fatigue, weakness
- Feeling very thirsty
- Dizziness
- Clothes or rings are too big

**OR**

- Weight gain of 5 pounds or more in a week or less
- Swollen ankles
- Shortness of breath
- Feeling puffy or bloated
- Tight shoes, clothes, or rings

What the patient can do

**If you have lost weight:**

- Drink extra high-protein and high-calorie fluids between meals.
- Be sure to drink enough water or other liquids that have no caffeine.
• Eat high-protein foods. You may also try liquid food supplements.
• Ask your doctor or nurse to arrange a meeting with a dietitian.

If you have gained weight:
• Talk with your doctor or nurse about limiting fluid if your ankles are swollen.
• Limit your salt intake.
• Limit high-calorie foods.
• Ask your doctor or nurse to arrange a meeting with a dietitian.

What caregivers can do
• Weigh the patient at the same time every day and write it down along with the date. In the morning, before breakfast, is a good time.
• Talk to the doctor if the patient’s weight loss or weight gain concerns you.
• Watch the patient for other symptoms.

Call the doctor if the patient:
• Loses or gains more than 5 pounds in a week
• Has shortness of breath
• Feels dizzy or becomes confused
When death is approaching

When you are caring for a loved one who has advanced cancer, you may be there at the time of death. The following covers common events that often happen near the end of life. Knowing more about what to expect may help ease some of the anxiety around events that might otherwise be alarming. This section lists some signs that death may be close.

People often use this time to gather the family to say goodbye to their loved one. They may take turns with the patient, holding hands, talking to the patient, or just sitting quietly. It can also be a time to perform any religious rituals and other activities the patient wants before death. It is a chance for many families and friends to express their love and appreciation for the patient and for each other.

It is important to have a plan for what to do after death, so that people will know what to do during this very emotional time. If the patient is in hospice, the hospice nurse and social worker will help you. If the patient is not in hospice, talk with your doctor about it so that you will know what to do at the time of death. (See the section in this booklet on hospice care.) Not all of the following symptoms will happen, but it may be comforting to know about them.

For more information on what to expect when death is approaching, contact the American Cancer Society at 1-800-227-2345 and ask for Nearing the End of Life. You can also find more information on the Web at cancer.org.

What to look for

- Profound weakness – usually the patient cannot get out of bed and has trouble moving around in bed
- Patient needing help with nearly everything he does
- Less and less interest in food, often with very little food and fluid intake for days
- More drowsiness – the patient may doze or sleep much of the time if the pain is relieved or may be hard to rouse or wake
- Restless and picking or pulling at bed linens
- Anxiety, fear, restlessness, and loneliness that may be worse at night
- A short attention span from the patient, who may not be able to focus on what is happening
- Confusion about time, place, or people
- Trouble swallowing pills and medicines
- Limited ability to cooperate with caregiver

Possible changes in body function

- Weakness – has trouble moving around in bed and most likely is not able to get out of bed
- Cannot change positions without help
- Trouble swallowing food, medicines, or even liquids
- Sudden movement of any muscle, jerking of hands, arms, legs, or face

What caregivers can do

- Help patient turn and change positions every hour or 2.
- Avoid sudden noises or movements to lessen the startle reflex.
• Speak in a calm, quiet voice to reduce your chances of startling the patient.
• If the patient has trouble swallowing pain medicines, ask the doctor or hospice nurse about getting liquid pain medicines or a pain patch.
• If the patient is having trouble swallowing, avoid solid foods. Give ice chips or sips of liquid through a straw.
• Do not push the patient to drink fluids. Near the end of life, some dehydration is normal and is more comfortable for the patient.
• Apply cool, moist cloths to the patient's head, face, and body for comfort.

Possible changes in consciousness
• More sleeping during the day
• Hard to wake or rouse from sleep
• Confusion about time, place, or people
• Restless – may pick or pull at bed linens
• May talk about things unrelated to the events or people present
• May be more anxious, restless, fearful, and lonely at night
• After a period of sleepiness and confusion, may have a short time when he is mentally clear before going back into semi-consciousness

What caregivers can do
• Plan your times with the patient when he is most alert or during the night when your presence may be comforting.
• When talking with the patient, remind him who you are and what day and time it is.
• Continue pain medicines up to the end of life.
• If the patient is very restless, try to find out if he is having pain. If it appears so, give breakthrough pain medicines as prescribed, or check with the doctor or hospice nurse if needed. (See the section in this booklet on pain.)
• When talking with a confused person, use calm, confident, gentle tones to reduce the chances of startling or frightening the patient.
• Touching, caressing, holding, and rocking are usually helpful and comforting.

Possible changes in metabolism
• The patient may have less interest in food. (The patient has less need for food and drink.)
• Mouth may dry out. (See "Possible changes in secretions" in this section.)
• The patient may no longer need some of his medicines, such as vitamins, chemo, replacement hormones, blood pressure medicines, and diuretics, unless they help make the patient more comfortable.
• Check with the doctor to see which medicines may be stopped. Medicines for pain, nausea, fever, seizures, or anxiety should be continued to keep the patient comfortable.

Possible changes in secretions
• Mucus in the mouth may collect in the back of the throat. (This can be a very distressing sound to hear, but it usually isn't uncomfortable to the patient.)
• Secretions may thicken due to a lower fluid intake and build up because the patient cannot cough.

What caregivers can do
• If mouth secretions increase, keep them loose by adding humidity to the room with a cool mist humidifier.
• If the patient can swallow, ice chips or sips of liquid through a straw may thin the secretions.
• Change the patient’s position. Turning the patient to the side may help secretions drain from the mouth. Continue to clean the patient’s teeth with a soft toothbrush or soft foam mouth swabs.
• Certain medicines may help – ask your hospice or home care nurse.

Possible changes in circulation and temperature
• Arms and legs may feel cool to the touch as circulation slows down.
• Skin of arms, legs, hands, and feet may darken in color and look blue or mottled (blotchy).
• Other areas of the body may become either darker or paler.
• Skin may feel cold and either dry or damp.
• Heart rate may become fast, faint, or irregular.
• Blood pressure may get lower and hard to hear.

What caregivers can do
• Keep patient warm with blankets or light bed coverings.
• Avoid use of electric blankets, heating pads, etc.

Possible changes in senses and perception
• Vision may become blurry or dim.
• Hearing may decrease, but most patients are able to hear you even after they can no longer speak.

What caregivers can do
• Leave indirect lights on as vision decreases.
• Never assume the patient cannot hear you.
• Continue to speak with and touch the patient to reassure him of your presence. Your words of affection and support are likely to be understood and appreciated.
Possible changes in breathing
- Breathing may speed up and slow down due to less blood circulation and build-up of waste products in the body.
- Mucus in the back of the throat may cause rattling or gurgling with each breath.
- The patient may not breathe for periods of 10 to 30 seconds.

What caregivers can do
- Put the patient on his back, or slightly to one side.
- Raise the patient’s head, which may give some relief.
- Use pillows to prop up the patient's head and chest at an angle, or raise the head of a hospital bed.
- Any position that seems to make breathing easier is OK, including sitting up with good support. A small person may be more comfortable in your arms.

Possible changes in elimination
- Smaller amounts of urine, which may be darker in color
- When death is near, loss of control of urine and stool

What caregivers can do
- Pad the bed beneath the patient with layers of disposable waterproof pads.
- If patient has a catheter, the home health nurse will teach you to care for it.

Signs that death has occurred
- Breathing stops
- Blood pressure cannot be heard
- Pulse stops
- Eyes stop moving and may stay open
- Pupils of the eyes stay large, even in bright light
- Control of bowels or bladder is lost as the muscles relax

What caregivers can do
- After death occurs, it is OK to sit with your loved one for a while. There is no rush to get anything done right away. Many families find this is an important time to pray or talk together and reconfirm your love for each other as well as for the person who has passed away.
- If the patient dies in the home, caregivers are responsible for calling the proper people. Regulations or laws about who must be notified and how the body should be moved differ from one community to another. Your doctor or nurse can get this information for you. If you have a hospice or home care agency involved, call them. If you have completed funeral arrangements, calling the funeral director and doctor are usually all you have to do.

An important note: If you call 911 or emergency medical services (EMS), even after an expected death at home, the law often requires that EMS try to revive the patient or take him to a hospital. This
can complicate the situation and delay funeral plans. Be sure that family and friends are ready and know exactly whom to call, so that they don't dial 911 in confusion or panic.

Through the information presented here, we have tried to prepare you for some of the problems and concerns you may face. We’ve also tried to make a few suggestions for coping with some of the stresses that may come with caring for a person with cancer at home. If you or your family needs more information, please call us anytime, day or night, at 1-800-227-2345. We have Cancer Information Specialists who can help you with your questions and help you find the resources you need.
Additional resources

More information from your American Cancer Society

The following information may also be helpful to you. These free materials may be ordered from our toll-free number, 1-800-227-2345, or by visiting our Web site, cancer.org.

A Message of Hope: Coping with Cancer in Everyday Life (also available in Spanish)

Advance Directives

American Cancer Society Cancer Survivors’ Network (CSN)

Anemia in People with Cancer

Anxiety, Fear and Depression

Bone Marrow and Peripheral Blood Stem Cell Transplants

Bone Metastasis

Clinical Trials: What You Need to Know

Coping with the Loss of a Loved One (also available in Spanish)

Genetic Testing: What You Need to Know

Family Medical Leave Act

Fatigue in People With Cancer

Fertility and Cancer: What Are My Options?

Financial Guidance for Cancer Survivors and Their Families: Advanced Illness

Helping Children When A Family Member Has Cancer: Dealing With A Parent's Terminal Illness

Helping Children When A Family Member Has Cancer: Understanding Psychosocial Support Services

Home Care Agencies (also available in Spanish)

Hospice Care (also available in Spanish)

Listen With Your Heart (also available in Spanish)

Health Insurance and Financial Assistance for the Cancer Patient (also available in Spanish)

Nausea and Vomiting

Nutrition for the Person With Cancer: A Guide for Patient and Families (also available in Spanish)

Oral Chemotherapy: What You Need to Know

Pain Control: A Guide for Those With Cancer and Their Loved Ones (also available in Spanish)

Sexuality for the Man With Cancer (also available in Spanish)

Sexuality for the Woman With Cancer (also available in Spanish)

Talking With Friends and Relatives About Your Cancer (also available in Spanish)

Talking With Your Doctor (also available in Spanish)

Understanding Chemotherapy: A Guide for Patients and Families
Understanding Your Lab Values

The following books are available from the American Cancer Society. Call us at 1-800-227-2345 to ask about costs or to place your order.

*Cancer in the Family: Helping Children Cope With a Parent’s Illness*

*Caregiving: A Step-By-Step Resource for Caring for the Person With Cancer at Home, Revised Edition*

*When the Focus Is On Care: Palliative Care and Cancer*
References


Cope DG, Reb AM. An Evidence-Based Approach to the Treatment and Care of the Older Adult with Cancer. Pittsburgh: Oncology Nursing Society, 2006.


