

# Charting Your Course

**An Intervention for People and  
Families Living with Cancer**



**A Research Project Funded by  
the National Cancer Institute**

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Supported by a grant from the National Cancer Institute CA 1 R01 CA101704-01  
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Graphic Design: **Sideline Graphics**

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# Introduction



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## INTRODUCTION

**Living with cancer can be both difficult and stressful. Few of us are ready for the hard choices that will have to be made when this disease is identified.**

It can be difficult for everyone involved—the ill person and their family and loved ones. But there are ways to ease the pain and make life better for people living with a cancer.

To assist you and your family during these difficult times we are testing a new program called Project ENABLE II. We designed the program to improve the health care and quality of life of people with cancer and their families. The program uses principles of palliative care. Palliative care (sometimes referred to as supportive care) is a medical specialty that improves quality of life for patients by helping them manage their symptoms and deal with emotional, physical, spiritual, and financial issues. Our new program also emphasizes problem-solving skills and ongoing support in concert with the services that currently exist at Dartmouth-Hitchcock Medical Center (DHMC).

### **The program involves:**

- 1)** Coordination of your care by a nurse educator to help match resources to your needs.
- 2)** Training in problem-solving skills to reduce distress and help you with decision making around a number of issues such as symptom management, life planning, and quality of life.
- 3)** Education about many of the problems and concerns you may be coping with when you have cancer.
- 4)** And finally, your participation in the Shared Medical Appointments (SMAs) that will address a broad array of physical and emotional symptoms. These appointments will be held once a week for 1 ½ hours. They will include 10-12 people and will be led by a physician and nurse practitioner from the Pain and Palliative Medicine Department at DHMC.

The goal of this research study is to determine if these additional supportive services improve patient care and quality of life.





## How to Use This Notebook

This notebook contains 4 chapters focused on issues that many people face when newly diagnosed with cancer. Each week of this program, you and the nurse educator will select a chapter to work on. We ask that you read the chapter selected and complete the “activity” associated with that chapter, in preparation for your next session with the nurse educator. After the first 4 weeks of the program, the nurse educator will call you at least once per month to assist you in finding resources and to help you problem-solve around any new or ongoing concerns. The notebook also contains general resource information in the appendix that may be helpful to you in problem solving around current life concerns related to cancer and its treatment.

Please feel free to contact us at the numbers below if you have any questions or concerns in relation to the project and non-urgent symptom management.

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## What is Palliative Care?

Palliative care means taking care of the whole person — body, mind and spirit. The goal of palliative care is to help you have the best quality of life you can have when living with a serious illness.

The following Five Principles of Palliative Care describe what care can and should be like for everyone facing a serious illness. Some of these ideas may seem simple or just common sense. But all together they give a new and more complete way to look at your care during a serious illness.

### The Five Principles of Palliative Care<sup>1</sup>

**1)** Palliative care respects the goals, likes, and choices of the ill person and family. It...

- Respects your needs and wants as well as those of your family and other loved ones.
- Finds out from you who you want to help plan and give you care.
- Helps you understand your illness and what you can expect in the future.
- Assists you in finding out what is important to you and your family.
- Tries to meet your likes and dislikes: where you get health care, the kinds of services you want, and where you want to live.
- Helps you work together with your health care provider and plan to solve problems.

**2)** Palliative care looks after the medical, emotional, social, and spiritual needs of the person with a serious illness and their family. It...

- Recognizes that a life threatening illness is an important time for you and your family.
- Offers ways for you to be comfortable and ease pain and other physical discomfort.
- Gives you the chance to say and do what matters most to you.
- Helps you and your family make necessary changes if the illness gets worse.
- Makes sure you are not alone.
- Understands there may be difficulties, fears, and painful feelings.
- Helps you look back on your life and make peace, even giving you a chance to grow.



- 3)** Palliative care supports the needs of the family members. It...
- Understands that families and loved ones need help, too.
  - Offers support services to family caregivers, such as time off for rest, and advice and support by telephone.
  - Knows that care giving may put some family members at risk of getting sick themselves. It plans for their special needs.
  - Finds ways for family members to cope with the costs of caregiving, like loss of income, and other expenses.
  - Helps family and loved ones as they grieve.
- 4)** Palliative care helps gain access to needed health care providers and appropriate care settings. It...
- Uses many kinds of trained care providers—doctors, nurses, pharmacists, clergy, social workers, and personal caregivers.
  - Helps you use hospitals, home care hospice, and other services, if needed. Tailors options to meet the needs of you and your family.
- 5)** Palliative care builds ways to provide excellent care during your illness. It...
- Helps care providers learn about the best ways to care for you during your illness. It gives them the education and support they need.
  - Works to make sure there are good policies and laws in place.
  - Seeks funding from private health insurers, health plans, and government agencies.

<sup>1</sup>Adapted from A Vision for Better Care at the End of Life: Five Principles of Palliative Care. Last Acts. [www.lastacts.org](http://www.lastacts.org).

# Problem Solving Module

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## PROBLEM SOLVING MODULE

### Introduction to Problem Solving Therapy

When experiencing a serious illness one can be faced with difficult decisions about health care, as well as trying to solve new life problems that may have never been encountered before. It can be very useful to have an organized method to think through ones' options and to ultimately make more informed decisions. This problem-solving process can help move a person through the many difficult decisions that must be made toward the end of life.

Unresolved problems can also cause emotional distress, and cause or worsen depression. In turn, this distress or depressed mood leads to physical changes in the body that can increase physical symptoms such as pain and fatigue. By learning ways to "cope" with stress, one can gain more control over mood and physical symptoms.

Problem solving is a structured method to help you cope with the stress from everyday problems, symptom-related problems, or other problems that may arise from changes in your health. By changing the way you handle problems you can reduce your distress and ultimately gain more control over your physical and mental health and symptoms. Problem solving skills will not only be useful for current life problems but also in the future as problems arise.

Understanding the relationship between stressors and physical response is central to improving symptom management. Stress leads to physical changes in the body that can increase your symptoms and impact your ability to successfully control your disease and symptom management. By learning ways to "cope" with stress you can gain more improved symptom management related to disease and treatment.



## Stages of Problem Solving

There are six important stages in problem solving:

### Stage 1.

Write down a clear description of the **main problem**. Try to break up complicated problems into several smaller problems and consider each separately.

- What is the nature of the problem?
- When does it occur?
- Where does the problem occur?
- Who is involved?
- What leads up to it?
- What happens afterward?
- Be sure to consider what **your role** is in the development or continuation of the problem.

### Stage 2.

Choose your **goal**. Be sure that your goals are definite and reasonable. For example, if your problem is fatigue you may set a goal to conserve energy.

### Stage 3.

List as many **alternative solutions** as you can, even if they seem far out, before considering the pros and cons for each one. Be as creative as possible and list as many as possible.

### Stage 4.

Consider the **pros and cons** of each solution:

- What are the likely positive and negative factors related to each solution?
- How will you feel if you choose a particular solution?
- How much time and effort will it take?
- How likely are you to follow through with doing it?
- What problems do you anticipate in carrying it out?
- What are the possible financial costs?
- Who else might be involved?
- Will the solution resolve the problem?

**Stage 5.**

Choose your **best solution** after considering all your options. You may want to look over the list and combine some of your ideas to come up with the best plan. Try to pick something that you will feel good about and that you are likely to be able to accomplish. It's important to keep an optimistic "can do" attitude, but be realistic.

**Stage 6.**

Set out clear **steps to achieve the solution then do it!** Specify exactly what you are going to do and when. Once you have your plan, the final step is to make your solution work. If your plan works the first time—great! If it doesn't then you may have to go back to the solution list and try a new plan.

### Activity - Identifying Problem Areas

To start the problem-solving process, first fill out the following table as it applies to you. Write in the spaces below the possible problems you are currently facing or expect you may be facing in the near future.

Problems with relationships: Spouse or partner - Family members - Friends - Other -	Problems with loss of function:
Problems with work or volunteer activities:	Problems with finding meaning in life or hope:
Problems with money or finances:	Problems preparing for end of life:
Problems with living arrangements:	Problems with unfinished business:
Problems with health or physical symptom management:	Problems with family's acceptance of illness or physical limitations:
Problems doing pleasant activities:	Problems with medications:

## Example of Problem Solving

<p><b>1) Problem:</b> Fatigue-especially in the afternoon.</p>		
<p><b>2) Achievable Goal:</b> Use at least one energy conservation strategy per day to decrease fatigue.</p>		
<p><b>3) Solutions:</b> a) Pace morning routine, that is, take rest breaks between morning chores even if not tired yet.</p>	<p><b>4) *Pros (+)</b> • Will probably conserve energy.</p>	<p><b>4) *Cons (-)</b> • Takes too much time.</p>
<p>b) Consult Palliative Care Team at next drop-in SMA about ways to decrease fatigue.</p>	<p><b>b) Pros (+)</b> • Can get answers from experts and other people who have same problem.</p>	<p><b>b) Cons (-)</b> • Might be embarrassing to admit fatigue.</p>
<p>c) Regular exercise, especially walking, even when I don't feel like doing it.</p>	<p><b>c) Pros (+)</b> • Will have more energy.</p>	<p><b>c) Cons (-)</b> • Hard to do it every day.</p>
<p>d) Make sure I eat breakfast and lunch every day to boost energy.</p>	<p><b>d) Pros (+)</b> • Makes sense and good for general health.</p>	<p><b>d) Cons (-)</b> • I often don't feel like eating.</p>
<p>e) Take a 20 minute nap at noon and review sleep hygiene rules on page 68.</p>	<p><b>e) Pros (+)</b> • Likely to boost energy in the pm.</p>	<p><b>e) Cons (-)</b> • Will waste time I would rather spend with family. • I never had to take a nap before—hate to give in.</p>
<p><b>5) Choice of solution:</b> C—regular exercise</p>		
<p><b>6) Steps to achieve solution:</b> a) Contact a friend who likes to walk and who will join me. b) Buy a pedometer to help me keep track of distance and increase gradually. c) Get good walking shoes. d) Define a route outside to walk; and one inside for bad weather days.</p>		

\* In weighing the Pros and Cons, consider the amount of effort, time, money, emotional impact, and who else may be involved as you compare solutions.

## Example of Problem Solving

<p><b>1) Problem:</b>                  Difficulty scheduling family activities &amp; responsibilities around medical appointments. Specifically finding time with grandchildren, childcare for grandchildren.</p>		
<p><b>2) Achievable Goal:</b>                  Set aside at least six hours during the week for family.</p>		
<p><b>3) Solutions:</b>                  a) Negotiate treatment schedule with oncology team.</p>	<p><b>4) *Pros (+)</b>                  • Treatment scheduled conveniently for me and family.</p>	<p><b>4) *Cons (-)</b>                  • Might not be possible or convenient for team.                  • I am worried that the team might get annoyed that I asked.</p>
<p>b) Plan family time ahead during high energy times (morning).</p>	<p><b>b) Pros (+)</b>                  • Will enjoy family time more.</p>	<p><b>b) Cons (-)</b>                  • Energy level is sometimes unpredictable.</p>
<p>c) Call friend (Ted) to mow lawn while I spend time with grandkids.</p>	<p><b>c) Pros (+)</b>                  • More fun/less work                  • Ted will enjoy helping me.</p>	<p><b>c) Cons (-)</b>                  • Feel like I am imposing.</p>
<p>d) Turn off phone during family time.</p>	<p><b>d) Pros (+)</b>                  • Able to really use time well if not interrupted.</p>	<p><b>d) Cons (-)</b>                  • Might miss important call.</p>
<p>e) Get calendar/day timer to plan week in advance for treatment and family.</p>	<p><b>e) Pros (+)</b>                  • Better planning ability.                  • Feel in control of something.</p>	<p><b>e) Cons (-)</b>                  • Planning takes time.                  • To much work.</p>
<p><b>5) Choice of solution:</b>                  Will start with solutions A and E.</p>		
<p><b>6) Steps to achieve solution:</b>                  a) Buy calendar at store today.                  b) Call oncology team tomorrow and ask for specific treatment times. If not available, then ask what times are available and pick out best ones for me.                  c) Talk with daughter to plan out family times, especially with grandkids.                  d) Put all treatments and family plans in calendar.</p>		

\* In weighing the Pros and Cons, consider the amount of effort, time, money, emotional impact, and who else may be involved as you compare solutions.

## Problem Solving Worksheet

<b>1) Problem:</b>		
<b>2) Achievable Goal:</b>		
<b>3) Solutions:</b>	4)*Pros (+)	4)*Cons (-)
a)		
b)	b)Pros (+)	b)Cons (-)
c)	c) Pros (+)	c) Cons (-)
d)	d)Pros (+)	d)Cons (-)
e)	e) Pros (+)	e) Cons (-)
<b>5)Choice of solution:</b>		
<b>6)Steps to achieve solution:      Tasks that have been completed:</b>		
a)		
b)		
c)		
d)		

\* In weighing the Pros and Cons, consider the amount of effort, time, money, emotional impact, and who else may be involved as you compare solutions.

## Problem Solving Worksheet

<b>1) Problem:</b>		
<b>2) Achievable Goal:</b>		
<b>3) Solutions:</b> a)	4) *Pros (+)	4) *Cons (-)
b)	b) Pros (+)	b) Cons (-)
c)	c) Pros (+)	c) Cons (-)
d)	d) Pros (+)	d) Cons (-)
e)	e) Pros (+)	e) Cons (-)
<b>5) Choice of solution:</b>		
<b>6) Steps to achieve solution:</b> <b>Tasks that have been completed:</b> a) b) c) d)		

\* In weighing the Pros and Cons, consider the amount of effort, time, money, emotional impact, and who else may be involved as you compare solutions.

# Communication & Social Support Module

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## COMMUNICATION & SOCIAL SUPPORT MODULE

People with cancer have many questions, fears and hopes. Response to their illness will evoke many emotions such as denial, fear, anger, loss and hope. These feelings can pose many questions and concerns about the present, the future and the meaning of life. It is important to take the time to think about how you can take care of yourself during this difficult time.

### Taking Care of Yourself

An important first step is to realize you have a serious illness. By doing this you will be better able to live in the present and more easily accept the future.

Many persons with cancer find it much more helpful to:

- Understand (your) limits and what you can reasonably expect of yourself.
- Take time to sort things out.
- Talk over important problems with others.
- Learn as much as possible about what is happening now and what may happen in the future.
- Eat as well as you can.
- Exercise, within the limits of your illnesses.
- Get adequate rest.
- Do the things you enjoy.

While it may help you to talk with others about your feelings, it is important for you to remember there is no right or wrong way to talk—or NOT talk. Talk when you are ready. It is normal to have a need for silence some of the time. You may not want to talk about your illness at all. Or it may be that you are really not ready and need time before you can talk with others.

People with cancer find different ways to get help. Family members and friends as well as support groups and trained counselors can help. There are also excellent resources in libraries, bookstores and the Internet that can help guide you. It is important for you to find a way to live with your illness.

## Family and Friends / Caregiver Communication

### Communication Skills

The emotional, financial and physical stress of serious illness on the patient and family can often seem overwhelming. Despite the stress, many families discover inner strengths and courage they never knew they had. An essential element to consider when there is an ill person in the family is good communication.

Good communication skills can help manage stress not only for the ill person but also for the other members of the household. Gregory Bateson, a psychologist who studied families, said, “you cannot *not* communicate.” In other words, even when we are not talking to others, our behavior sends messages for others to interpret. Being aware of how we act and speak is vital to communicating effectively. Thus, good communication skills involve active listening, non-verbal and verbal communication. Remember,

### **Communication involves both talking and listening.**

Some guides for good communication for the patient are:

- Be clear. Typically you don’t need help with everything. Let people know what you need help with and what you can do yourself. As your situation changes, you may need more help, so keep people informed.
- When we are upset, talking helps, even if we don’t expect others to have a solution. It is okay to let people know that you don’t expect them to have answers, you just want them to listen.
- Sometimes the most helpful thing is for people to do what they always did (stop by for a cup of tea, watch a ballgame with you). Let people know that this is one way of helping.
- Remember, helping makes others feel good, so let them help.

Some guides for good communication for the family and caregiver are:

- Listen carefully to what someone is telling you. Listening is very healing.
- Offer any practical assistance that you feel comfortable giving.
- Be honest about your own thoughts, concerns, and feelings. However, use statements such as “I feel”, “I believe”, “I would want”, rather than, “you should”, “that’s wrong”, “everything will be OK.”
- When in doubt ask questions.

- Good listeners invite others to talk or say more. A way to do this is to use simple expressions and encouragement to continue. Some examples include:
  - “Can you tell me more about it?”
  - “I’d like to hear about it.”
  - “Would you like to talk about it?”
- People usually need to know they have decision-making power. Help them see choices.
- Stay in the present as much as possible. Don’t dwell on the past.

## **Asking for Help – Building a Support Network**

In addition to communicating, supporting yourself and your family are equally important as well. The following questions will help you consider how your illness may change things that matter to you and your family. After you answer the questions, you and your family should talk about ways to keep the illness from getting in the way of sharing, supporting and loving.

### **The Ill Person**

- What roles are you giving up?
- What childrearing activities are present?
- Who is affected by the illness?
- What changes need to be made?

### **The “Family”**

- Who are your close friends and family?
- What are the expectations of these friends and family members?
- What else do they have to deal with?
- Who will help in decision-making?

### **Resources**

- What are your economic resources? One-half of ill persons feel that they are an economic burden.
- What are your spiritual and religious resources?
- What, if anything, do your spiritual or religious beliefs tell you and your family about death and dying?

## Activity – Identifying a Support Team

Many of us forget that we are part of a network of support. We may spend a fair amount of our time helping others and we may need to remind ourselves that others are happy to help us out when we need it. In times of challenge and stress, it may be our turn to accept that help and support.

We encourage you, and perhaps a member of your family or a friend, to take a little time to consider the support network that you have created for yourself. It is helpful to see whom you can count on for a variety of needs, and friends and family members who might become a support.

This is an activity that can be shared with a family member or friend. Each of you can complete separate support networks.

### Instructions:

Use a blank sheet(s) of paper and whatever pens and pencils you might have (it is helpful to have a variety of colors). Place yourself in the center of the page and identify those people and/or pets in your life who do support you, or who might support you if you invited them to help in some way. Use colors and shapes to describe the relationships of these individuals with you and with each other. Use colors to get in touch with the “feelings” you have about these people and their relationships to one another. Be imaginative and see what you can learn about the network of support you can count on.

### Reflection: Now take some time to consider what you have learned about your support network.

- What surprised you as you played with shapes and colors, and people and relationships?
- Who else would you like to have support from?
- Are there individuals or caregivers you forgot to put on your page?
- Do you need to tell some relatives or friends that you could use their support, or to see how they might be of help to you at this time?
- How easy is it for you to ask for and receive support?
- If more than one of you did this exercise, were there differences between your perceptions of a support network?

The next table will help you list the people that could help you, and the time that it might take to complete different tasks.



## Talking with Your Health Care Provider

It is important to talk with a health care provider not only about a serious illness, but also about any fears and concerns you have. Although it is difficult for some people to speak up during a clinic visit, it is important to take an active part in making decisions about your care.

### Preparation:

- Bring someone with you if you think you will have trouble understanding, hearing, or remembering what is being said.
- Bring a pen and notepad to take notes.
- Write a list of one or two of your most pressing concerns.
- Focus on the symptoms/problems that are new.
- Write down questions you want to ask.
- Make a list of all the medicines, herbal and nutritional supplements you are taking. Be sure to include: name of medication, herb or supplement (you may also want to put them in a bag and bring them to your visit), the strength of the medicine, the number you take each time and what time of day you take the medicines/supplements.

### At the Office:

Your health care provider expects to answer “tough” questions such as:

- Will you talk openly and candidly with my family and me about my illness?
- What type of decisions will my family and I have to make? What can you give us to help make these decisions?
- What will you do if I have a lot of pain or other uncomfortable symptoms?
- How will you help us find professionals with special training when we need them? What about Hospice?
- Will you let me know if treatment stops working so that my family and I can make appropriate decisions?
- Will you still be available to me even when I’m very sick and close to the end of my life?

It also helps to tell the health care provider if you don’t understand or can’t hear what is being said. Additionally, repeat the information back in your own words.

**Leaving the Office:**

- Ask what the next step in your care is.
- Ask for written information about your medications, condition, illness and treatment.
- Ask if there are ways to keep in contact easily by phone or email.

## Problem Solving Worksheet

You can use this sheet to address problems related to communication and social support.

<b>1) Problem:</b>		
<b>2) Achievable Goal:</b>		
<b>3) Solutions:</b>	4) *Pros (+)	4) *Cons (-)
a)		
b)	b) Pros (+)	b) Cons (-)
c)	c) Pros (+)	c) Cons (-)
d)	d) Pros (+)	d) Cons (-)
e)	e) Pros (+)	e) Cons (-)
<b>5) Choice of solution:</b>		
<b>6) Steps to achieve solution:                      Tasks that have been completed:</b>		
a)		
b)		
c)		
d)		

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# Symptom Management Module

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## **SYMPTOM MANAGEMENT MODULE**

### **Introduction**

Symptoms are physical, psychological, social, or spiritual effects that are bothersome. People with serious illness often have symptoms from the disease and its treatment. Some symptoms may be new while other symptoms they have had for a long time. As a general rule, new symptoms should be discussed with a health care practitioner as soon as possible.

The alphabetical list of symptoms on the previous page commonly occurs in people with serious illnesses. Some, like sexual issues and sleep problems, occur early in an illness, whereas confusion may be a later occurring problem. Nausea, eating problems, and diarrhea frequently accompany treatments for cancer.

Some symptoms can be easily managed with medicines that are available over-the-counter, while others may require a prescription. Most symptoms will require a combination of medicine and non-medicine approaches. In the latter case there are many things that will make you feel better that you can do alone (self-care) or with the help of family or friends.

This section of the manual outlines some of the more common symptoms faced by many people with cancer, and provides a brief definition of the symptom (What is the problem?), some helpful hints (What you can do to help yourself), issues to bring to your health care provider (When to get help from a professional), and other resources. There are books and web pages devoted to some of these topics, so we'll only list some essentials about each topic. Additionally, your nurse educator can help you if you wish to delve into an area further.

One important point that applies to any symptom is noticing it, and keeping track of how it feels so that you can give your health care provider information that will help them to help you! The nature of a symptom is that it is usually something that you feel or experience—in general there are no blood tests or x-rays that can tell us what is going on. For instance, there is no blood test to tell us how much pain or nausea you are feeling. For this reason it is important to keep notes or a journal about your symptoms so that you can report them to your health care provider with details and specifics. Some people find it helpful

to use a 0-10 scale to report “how much” they feel of something. Other important points are:

- When did it start?
- What makes it better?
- What makes it worse?
- How long does it last?

Keeping track of these simple issues will help your appointment or phone call with your health care provider to be more effective. The activity below can assist you with tracking your symptoms.

Another important point about symptoms is to let the doctor or nurse practitioner know which symptoms are the most **BOTHERSOME** to **YOU**. Although ill people may have many symptoms, it is important for your health care team to know **YOUR** priorities so that they can discuss those symptoms that in your opinion are most important to address. Even though your doctors and nurses may ask you about whether you are having problems all throughout your body and person—it is critical that you bring up the ones that are the biggest problems to **YOU**! We hope these two simple points will help you to successfully manage and live every day to its fullest.

## Activity – Identifying and Managing Your Symptoms

The symptoms of cancer and the treatment for it can be as confusing as they are overwhelming. We often feel lost in the midst of the pain and discomfort. In order to be sure that we have done all we can to manage these symptoms, it is a good idea to be very clear about them. It is helpful to keep a journal, noting your experience of pain or other symptoms as they happen and recording their intensity along with the date and time of day when you are first aware of them. It is also useful to record what eases those symptoms and the time at which they are relieved.

To begin this process, we suggest that you note below the history of your symptoms, as best you can remember. Just make a list of all the symptoms you can remember since your diagnosis in the first column. In the second column, jot down what you did or what medications you took to relieve them and how successful they were.

Symptoms	What Relieves These Symptoms?

### Next Steps:

When you next visit your doctor or nurse specialist, take along a copy of this list to be kept in your file. Continue to keep a record of pain and your symptoms - and what relieves them. Be sure to share this important information with your physician.

## Problem Solving Worksheet

You can use this sheet to address problems related to symptom management.

<b>1) Problem:</b>		
<b>2) Achievable Goal:</b>		
<b>3) Solutions:</b>	<b>4) *Pros (+)</b>	<b>4) *Cons (-)</b>
a)		
b)	b)Pros (+)	b)Cons (-)
c)	c) Pros (+)	c) Cons (-)
d)	d)Pros (+)	d)Cons (-)
e)	e)Pros (+)	e)Cons (-)
<b>5)Choice of solution:</b>		
<b>6)Steps to achieve solution:</b>		<b>Tasks that have been completed:</b>
a)		
b)		
c)		
d)		

\* In weighing the Pros and Cons, consider the amount of effort, time, money, emotional impact, and who else may be involved as you compare solutions.

## **Symptoms - Activities of Daily Living/Managing Self-Care**

### **What is the problem?**

When people become ill they can have physical and emotional challenges that can interfere with performing all of the normal activities they did to take care of themselves, in their job, or with their family. Some activities can be modified slightly while others may need to be changed or eliminated. It can feel like the person is losing independence. There are strategies and resources that can help whether these limitations are temporary or permanent.

### **What are some things that you can do to help with personal care and hygiene?**

- See Fatigue section of this book for specific bathing and activity energy conservation strategies. (p. 53)
- Have your home evaluated by an occupational therapist from the local visiting nurse agency or hospital for customized assistive devices and strategies that can reduce the energy needed for dressing, bathing and toileting.
- Have a commode or urinal nearby for nighttime use: If incontinence is a problem, consider adult pads for nighttime and/or daytime to reduce accidents and soiled laundry.
- Wear comfortable clothing that will make dressing easier.
- Obtain the assistance of visiting nurses or hospice agency to assist if dependence is increasing.
- Even if you are bed-ridden you can do movements or exercises in bed alone or with help to improve strength and well-being. A physical therapist can create a program for you to follow.

### **What are some things that you can do to help with work responsibilities?**

- Discuss your situation with your supervisor or your employees.
- Negotiate for a reduced workload or part-time responsibilities for a short time (if possible).
- Discuss disability status with your Benefits Office or a Social Worker.
- Family members may need to consider taking a "Family Leave". Learn what their employers' policies are concerning this.
- If self-employed, consider hiring a temporary person who can oversee business responsibilities.

### **What are some things that you can do to help with family responsibilities?**

- Discuss the situation as a family and come up with a plan together that can help reduce your responsibilities for a short time.
- Enlist the help of extended family, friends, church members, or others in the community to assist with family responsibilities (e.g. car-pooling, child care, lawn care, etc.). Friends often wish to help but don't know how or don't want to intrude.
- Do not let "pride" or "wanting to be independent" interfere with asking for help.

### **When to get help from a professional:**

- When you are unable to problem solve how to overcome limitations.
- When you are facing a new situation/limitation from disease or treatment.
- When you are using all of your energy to take care of yourself and don't have time for enjoyable activities.
- Before you are "at wit's end" — discuss your limitations with your doctor or nurse so they can help with strategies to make life a little easier. Your doctor or nurse can't be aware of all of the ways the illness has affected how you function at home or at work. They can provide advice or assistance if they realize these are issues for you.

### **Other helpful resources**

- Your doctor, nurse, or visiting nurse, and hospice agency
- American Cancer Society local office (e.g. for transportation to treatments)

## **Appetite and Eating Problems**

### **What is the problem?**

Persons with a serious illness often have trouble getting enough nutrition. Surgery, chemotherapy, radiation therapy, immunotherapy, and the cancer itself can all lead to a decreased food intake. Some causes include difficulty swallowing, nausea, vomiting, changed sense of smell or taste, feeling full, pain, tumor growth, or depression. The loss of smell reduces taste, which may reduce appetite. Taste and smell may also be changed by medications, oral infections, poor oral care, and a very dry mouth or sinus infection. Malnutrition occurs when not enough food is eaten to nourish the body. Malnutrition can lead to progressive wasting, weakness, exhaustion, lower resistance to infection, and problems taking treatments. Although reduced food intake can be temporary, it may also be a permanent problem due to an inability to control the cancer. In the case of advanced illness food and liquids may only be recommended to increase your comfort and to satisfy feelings of hunger or thirst.

### **What you can do to help with general nutrition:**

- Eat as much as you want of foods that are appetizing to you.
- Start the day with a good breakfast.
- Try to get some light exercise before meals.
- Eat small frequent meals, or “graze” throughout the day on snacks that are easy to have nearby and are high in calories (e.g. crackers, cheese, fruit, nuts, protein/ granola bars, pudding, ice cream, etc.).
- Eat high-protein and high-calorie foods and drinks, including snacks.
- Avoid preparing foods with strong odors that can turn you off.
- Eat with family or create pleasant settings for your meals. Try new recipes.
- See your dentist regularly to be sure your teeth and gums are in good repair.
- Drink liquids with calories with meals rather than filling up on water.
- If recommended by your health team, try a glass of wine or beer before or with meals.
- Keep track of what you eat.
- Consult a nutritionist or dietician.

### **What you can do to help with chewing and tasting/food aversions:**

- Use plastic utensils, instead of metal.
- Cook poultry, fish, eggs, and cheese instead of red meat.
- Marinate meats with sweet marinades or sauces.

- Serve meats cool instead of hot.
- Avoid strong odors by using boiling bags, outdoor grill, kitchen fan, order take-out foods, or serve cold food instead of hot.
- Rinse your mouth with water before eating.
- Instead of meat, try high-protein substitutes such as cheese, soy foods, milk shakes, puddings, and ice cream.
- Use lemon-flavored drinks to stimulate saliva and taste; use very little sweetener.

### **What are some things you can do to help with hiccups:**

- Breathe slowly and deeply into a paper bag for 10 breaths.
- Drink water slowly.
- Hold a teaspoon of sugar in the mouth, and then swallow it.
- If the hiccups persist and the source of hiccups cannot be relieved, ask your health care provider about medicines that will help to lessen them.

### **What are some things you can do to help with indigestion:**

- Avoid spicy or tomato-based foods.
- Eat bland foods such as custards, puddings, ice cream, hot cereal, eggs, etc.
- Avoid alcohol, caffeine and nicotine products.
- Notice which foods or medicines in particular cause indigestion and report these to your health care provider.
- Take an over-the-counter antacid to relieve new or intermittent indigestion. Report results of this at your next appointment.
- Take prescribed medicines for causes of indigestion (e.g. for acid reflux).

### **What you can do to help when you have difficulty swallowing:**

- Try different foods and liquids.
- Sit upright when eating.
- Eat frequent, small portions of food you like.
- Eat foods high in protein and calories (e.g. nutritional supplements like Ensure or Boost).
- Keep your mouth moisturized with sprays of water mixed with a few drops of vegetable oil, lemon drops or foods such as fresh pineapple.
- Use smaller utensils if your mouth is sore or dry.
- Keep your head elevated.
- Drink thickened liquids in small amounts and frequently.
- Eat only soft foods.
- Avoid spicy, acidic, salty, sticky and excessively hot or cold foods.
- Avoid alcohol.

**When to see a professional:**

- You notice a major change in appetite.
- You are losing weight rapidly, for example, 3 pounds in a week.
- If you notice bleeding gums or loose teeth, consult your dentist.
- If you have pain when you eat.
- If you have not seen a cancer dietician ever or for some time.
- If you can not afford proper food.
- If you do not have energy to prepare your own food or shop for groceries.
- If you experience signs of an ulcer, such as gnawing stomach pain, bloody vomit, or bloody, black tarry stools.
- If hiccups persist for 24 hours.
- If your family member is distressed by your food intake and this has become a source of distress and concern for you and them.

**Other Resources:****Websites**

National Institutes of Health Eating Hints for Cancer Patients Before, During & After Treatment: [http://www.thebody.com/nih/eating\\_hints/eatingwellintro.html](http://www.thebody.com/nih/eating_hints/eatingwellintro.html)  
 Consult the following patient education website on anorexia (i.e. excessive weight loss): [www.cancersymptoms.org](http://www.cancersymptoms.org)

**Books**

Eating Well Through Cancer by Holly Clegg and Gerald Miletello MD  
 Betty Crocker's Living with Cancer Cookbook  
 The Cancer Survival Cookbook by Donna Weihofen

**What about tube feedings?**

In the largest study of seriously ill persons in hospitals, tube feeding did no good (except perhaps for some persons in comas). Before beginning tube feeding it is very important to understand the benefits and harms it might cause.

**If you have false teeth (dentures),** you should keep them clean and free of food deposits. Food on dentures can cause permanent staining, bad breathe, and gum irritation. Once a day, brush all surfaces of the dentures with a denture-care product. Before going to sleep, remove your dentures from your mouth and place them in water or a denture-cleansing liquid. It is also helpful to rinse your mouth with a warm saltwater solution in the morning, after meals, and at bedtime. Partial dentures should be cared for in the same way as full dentures. Bacteria tend to collect under the clasps of partial dentures. It is important that this area be cleaned well.

## **Appetite and Eating Problems: Nausea and Vomiting**

### **What is the problem?**

Nausea is feeling sick to your stomach or queasy. Vomiting is throwing up or expelling stomach contents. Nausea can come on even when you are not thinking of food. Or may come on when you think of or smell certain foods or odors. Vomiting can come on even if you haven't eaten recently, it can happen even if you are not nauseous, or it can happen if you've eaten too much food. You can have nausea and/or vomiting if something you ate disagrees with you, from the treatments, or from your disease process. However because many medicines can prevent nausea and vomiting many people that have cancer treatments do not experience nausea and vomiting.

Some causes of nausea and vomiting are:

- Medications
- Cancer treatments
- Uncontrolled pain
- Bowel blockage

### **What are some things you can do to help with nausea:**

- Medicines called anti-emetics may help. Ask your health care provider about taking these on a regular schedule to prevent nausea and vomiting.
- Frequently drink small amounts of fluids during the day except after meals.
- Avoid fatty, fried and strong smelling foods (some people will develop distaste for red meat or meat broth).
- Eat foods that are cold or at room temperature to avoid strong smelling foods that can trigger nausea.
- Frequently eat small amounts of crackers, foods, fresh fruits, chicken soup or broth, jello, bland or soft foods.
- Chew gum or hard candy, especially lemon flavored.
- Sniff a lemon.
- Eat 3-4 hours before treatment and drink fluids for several hours after treatment.
- Try relaxation techniques and a cool cloth over the face at the first sign of nausea.
- Keep your mouth clean: brush at least twice a day.

### **What are some things you can do to help with vomiting:**

- Lie on your side if you are in bed to avoid inhaling or swallowing vomit.
- Take medicines in suppository form.

- Take liquids in small amounts, such as ice chips at first until your stomach has had a chance to settle.
- Rinse your mouth and teeth after each vomiting episode.

**When to get help from a professional:**

- If it has been 24 hours since you have kept food down without vomiting.
- If you vomit bright red blood or coffee ground colored material.
- If vomiting last for more than 4 hours, is persistent, or you vomit more than 3 times in an hour.
- If you vomit in a sudden, forceful way without preceding nausea.
- If you think you have inhaled vomit.
- Bloating stomach or pain relieved by vomiting.
- Onset of nausea and vomiting that lasts for several days should be checked by health care provider.
- If you have signs of dehydration (loss of fluids):
  - Severe thirst
  - Urinating less than usual
  - Very dark urine
  - Dizziness/weakness
  - Fever greater than 100.5°F (38°C).
  - Jerking movements of head, neck, arms or legs (very rare).

## Confusion/Delirium

### What is the problem?

When the thinking process is disturbed or a person cannot think and act appropriately, this is often called confusion. Most often confusion is caused by medications or the late stages of a serious illness. Occasionally, it may come on suddenly—in that case, dehydration, imbalances of electrolytes (like calcium or blood sugar), infection and a fever, heart or lung trouble, or a new medication (starting a new pain medicine) or unrelieved pain may be the cause. Confusion can become worse at night or when a person is in a new or strange environment. Most times, confusion is reversible. Whatever the cause, it is important to determine the cause (if possible) to treat confusion when it is unexpected and to make sure that the confused person does not hurt him or herself. Confused people often respond well to having familiar people and belongings near by.

### What family can do to help manage a confused loved one:

- Use safety precautions, such as side rails on a bed.
- Provide for safe administration of all medicines.
- Administer prescribed medications to decrease confusion.
- Use oxygen, if necessary.
- Stay close to the person when communicating.
- Speak in soft, low tones, first telling the person who you are.
- Orient the person, keeping a clock and calendar nearby.
- Keep the room well lit during daytime hours and periods of confusion.
- Provide explanations for all that you are doing, **prior** to doing it.
- Do not leave the person alone for long periods.
- Keep stimuli of radio or television to a minimum.

### When to get help from a professional:

- If confusion pattern changes or the person becomes very agitated or violent.
- If the person is at risk of harming him/herself.

## Complementary and Alternative Methods/Therapies (CAM)

### What is the problem?

Many people hear on the news or in popular magazines or from friends about substances call “Complementary or Alternative Methods/Treatments” also called CAM. Some examples of these include herbs, certain “vitamins”, tonics, and teas. Some CAM are “physical methods” such as Reiki, Healing Touch, Massage, Acupuncture, and Relaxation therapies, however, these treatments have been more thoroughly researched and are used more frequently as a part of “traditional medical treatment”. There are many types of treatments and the information available can feel overwhelming. Don’t feel pressured by well-meaning friends or family to explore every “natural” treatment that they learn about.

### What are some things that you can do to help:

- Always tell your doctor or nurse about any treatments you are using or considering as they could interact with your other medically prescribed treatments.
- Be skeptical of treatments or people who claim their treatment will provide a cure and/or are seeking large sums of money for treatments.
- Learn all you can about the practitioner of the treatment.

In an effort to clarify all of your present treatment alternatives, from vitamin supplements to chemotherapy, take the time now to list them. It would also be a help to write down what results you are aware of from using them.

### Medications and Treatments

### Results

Medications and Treatments	Results

We suggest that you share this information with **all** of your providers.

## Learning How to Relax

Relaxation exercises are useful techniques to help relieve tension, decrease worry, improve sleep, and make you feel generally more at ease. These exercises use physical and mental activities, which focus attention on calming the body and mind, creating feeling of comfort.

Provided are descriptions of different relaxation exercises. It is not necessary to use all the forms of relaxation that are described. Instead, you should choose a form that is easiest and most comfortable for you. It is a good idea to try each and decide which you like best. However, all relaxation should begin with relaxed breathing. Once you master relaxed breathing, you can continue to add other relaxation exercise to your routine. You can also combine a few relaxation exercises, such as beginning with relaxed breathing, doing some muscle relaxation, and then using imagery.

## Relaxed (Diaphragmatic) Breathing

Since breathing is second nature to us, we rarely think about the way that we breathe. Learning to breathe abdominally (through the diaphragm) can promote relaxation, which improves physical and mental health. Over time, most people begin to breathe by moving their chest and/or shoulders. However, if you watch a baby breathe, you will see that they breathe by moving their belly, which is the most efficient way to take in oxygen and remove carbon dioxide with the least effort. The diaphragm is the muscle that controls breathing. It is dome-shaped muscle that sits beneath the lungs, above the abdominal cavity. When a breath is taken, the diaphragm flattens out, allowing the lungs more room to expand with air. When air is exhaled from the lungs, the diaphragm returns to its domed shape. Though breathing is an automatic function, the movement of the diaphragm can be controlled voluntarily with training. Learning how to control the diaphragm and the way we breathe can be beneficial in many ways:

- Allows the most efficient exchange of oxygen and carbon dioxide with the least effort.
- Promotes general relaxation.
- Improves circulation.
- Removes waste products from the blood.
- Slows down heart rate and breathing rate.
- Frees the mind.

## Relaxed Breathing

The best way to begin relaxed breathing is lying down on your back. Once you are comfortable breathing in this position, you can then try it sitting and standing.

- 1)** Find a comfortable place and lie down on your back, or sit in a chair.
- 2)** Breathe in through your nose slowly, in a natural, gentle way.
- 3)** At the same time that you take in each breath, gently expand your belly to fill with air. Keep your shoulders and chest as still as possible. Imagine that you are filling a small balloon inside your belly with air each time you inhale.
- 4)** Breathe out through your mouth, emptying your belly and letting it relax. As you breathe out, purse your lips to create a little resistance to the exhale to keep it slow, like gently blowing on a candle to make it flicker. Breathe out as slowly as you can make each exhale last.
- 5)** When you finish your exhale, wait quietly until your body naturally takes its next breath. Take your time
- 6)** Each time you breathe in, imagine a balloon filling with air, and each time you breathe out, imagine the balloon deflating.
- 7)** Be sure to breathe in a slow, gentle, and natural way. If you become dizzy or light-headed, take smaller breaths and slow down.
- 8)** It may help to put one hand on your stomach (over your belly button) and one hand on your breastbone. Watch to see which hand is moving more when you breathe in and out. Try to get the hand on your stomach to move more as you breathe, without forcing it.

You should practice diaphragmatic breathing frequently for short periods of time. At first, maybe 10-15 times per day for 1-2 minutes each time. Try to practice in different situations, such as lying down, sitting, and standing, on a bus/subway, etc. With practice, relaxed breathing can become a quick and easy tool to combat stress.

## Muscle Relaxation

Muscle tightness/tension is the body's signal that we are under stress. When we experience stress for prolonged periods of time, we may develop chronic tension in our shoulders, back, head, or other areas of our bodies. However, because we are so focused on external concerns, most of us are not usually aware of the tension in our bodies, unless it becomes painful.

Learning to relax your body not only helps prevent muscle tension from turning to pain, but can calm you mentally as well. Muscle relaxation trains you to be aware of tension in your body and control tight muscles that respond to stress. Relaxing your muscles is a skill that takes practice, but once you know how to do it, you can use it to reduce your emotional and bodily tension quickly and easily.

### **There are two types of muscle relaxation:**

*Passive relaxation* involves relaxing different muscle groups by thinking about them, while *progressive muscle relaxation* allows you to focus on and relax your muscles by first tensing them, which automatically forces your muscles to relax. The following is a relaxation exercise that you can use to relax the muscles in your body. You may want to have someone else read it to you, or you can tape yourself reading it, so that you can concentrate on relaxing.

### **Body Scan (Relaxation Exercise)**

- Begin by getting into a comfortable position and closing your eyes. Use some relaxed breathing to calm yourself. Take about 4 slow, deep breaths.
- Relax your whole face. Start with your jaw and tongue. Are you clenching your teeth? Are you pressing with your tongue? Let all the muscles of your jaw and tongue relax. Allow your teeth to be slightly parted in a natural, unforced way. Your tongue should be loose inside your mouth, resting against the back of your teeth. Next, pay attention to your eyes and forehead. Make sure that you are not squeezing your eyes shut or furrowing your eyebrows. Let your eyes close so your eyelids barely touch. Your whole face is completely relaxed.
- Now, relax your shoulders. Let go of all of the tension in your shoulders and let them drop. Let any feelings of tension in your neck flow away. Let your shoulders and neck muscles sink into a pleasant state of comfortable relaxation.
- Relax your arms, hands, and fingers. Are you flexing a muscle? Are you gripping anything with your hands? Let your arms feel heavy and relaxed, like a floppy rag doll.
- Let any feelings of tension in your back, chest, or abdomen dissolve and flow away. Let yourself become more and more limp and relaxed with every breath you take.
- Relax your legs, feet and toes. Let go of any tension from your legs. Let your leg muscles sink into a deeper and deeper state of pleasant comfort. Make sure you are not pressing your feet or toes. Let your feet and toes become completely relaxed.
- For the next minute or so, let your entire body become more and more

relaxed. Enjoy this feeling of comfort and relaxation, and when you are ready, open your eyes slowly and remain quiet for another moment or two.

## **Imagery/Visualization**

Imagery, or visualization, is a technique that uses your imagination to create mental pictures. It is used to focus your mind on something pleasant and comforting in order to ease stress and anxiety, and reduce muscle tension and pain. Imagery incorporates all of your 5 senses –sight, smell, hearing, taste, and touch. You should try to practice visualization 1 -2 times per day until it becomes natural for you. If you are a very visual person, this may only take a few practice sessions. For others, you may need to practice for a couple of weeks before you feel comfortable with it. The easiest way to practice imagery is in bed in the morning when you wake up and at night before you go to sleep. With practice, you will be able to go to your special place just by closing your eyes. Try it using the following exercise.

### **Your Special Place (Imagery Exercise)**

To begin, lie down, get comfortable, and close your eyes. Use some relaxed breathing to calm yourself. Take about 4 slow, deep breaths.

Now, picture yourself in a quiet, special place. A place that is very beautiful and feels peaceful, and safe. You are all by yourself and feel totally relaxed, safe, and at peace in this quiet, special place. It can be a place in nature, such as a beach...a lake... a forest...a field...a mountain. Or it can be somewhere else, like a garden... a church...a favorite room... somewhere you have been in the past.

Picture yourself in this quiet, special place as vividly as you can, using all of your senses. Look around. Notice what you see. The colors...shape...what the light is like. Perhaps the blue of the sky, or the reflection of the light upon the water. Notice what you see in your special place.

Notice the sound that you hear. Perhaps the lapping of water against the shore, or the sound of wind rustling in the leaves. Listen to the sounds in your quiet, special place.

Notice the smells in the air. Perhaps the smell of the salt water...or the fresh clean smell of country air...or the smell of pine needles in the forest. Notice the smells.

Feel how warm or cool the air is against your skin. And picture where you are. Are you lying down?...sitting?...leaning against something?...standing?

Use all of your senses to make this special place as vivid and real as you can. Memorize the smells, sounds, and sights. Continue to enjoy being in your special place for a minute or two longer. Allow yourself to relax even more deeply. Remind yourself that you can come back and relax here whenever you want. When you are ready, open your eyes slowly and continue to remain still and enjoy your relaxation for another moment or two.

### **Meditation**

Mediation is the act of focusing your attention on one thing for a period of time. This is done by repeating a certain syllable, word, or phrase (mantra) silently or out loud, or focusing on a fixed object or action. It does not matter what word, object or action you choose to focus on. It can be a relaxing word, such as "peace," an object, like a flower or candle, or an activity, such as concentration on your own breathing. Meditation allows you to see that you can choose to ignore thoughts that pop into your head and control your emotional responses to your thoughts. Like other relaxation exercises, meditation can decrease your heart rate, slow your breathing, and ease your mind by concentrating on one thing for very long. Other thoughts will pop into your head that can distract you from the meditation. The point of this exercise is to attempt to keep your mind on the chosen word or object, and when your mind wanders, to bring the focus back to the original object of your attention. The more time you spend practicing meditation, the more you will get out of it. You should try to practice at least once per day.

### **Meditation Exercise**

- Sit comfortably in a chair with your legs apart and your hands in your lap.
- Keep your back straight and keep your head up with your chin tucked in slightly.
- Close your mouth and breathe through your nose. Position your tongue softly on the roof of your mouth.
- Close your eyes or focus on a spot on the floor about 4 feet away.
- Take deep abdominal breaths, but do not force them. As you breathe, focus completely on your breathing. Pay attention to the feelings of the inhale, the point at which you stop inhaling, the pause between inhaling and exhaling, and the exhale.
- As you exhale, say "one" to yourself. Continue counting each time you

exhale by saying “two...three...four.” Then begin again with “one.” If you lose count, start over with “one” again.

- When you notice that your mind has wandered, note this, and then gently return to counting your breathing.
- If a particular sensation in your body catches your attention, focus on the sensation until it goes away. Then return your attention to breathing and counting your breaths.
- When you first begin to practice, maintain the meditation only for as long as it is comfortable, even if this is only for 5 minutes per day. As you practice and meditation becomes easier, you will find your self wanting to extend your time. In terms of relaxation, 20-30 minutes once or twice a day is adequate.

There are many other forms of muscle relaxation, visualization, and meditation that might be right for you. If you would like more training in any of these techniques, you can ask your physician for a referral to a cognitive behavioral psychologist or therapist. You can locate classes on meditation and stress management in the community. Or you can learn some more on your own through self-help books.

(Adapted from Davis M., Eshelman E., & McKay M. *The Relaxation and Stress Reduction Workbook*. Oakland, CA: New Harbinger Publication, 1988. )

### **Other helpful resources**

Patients and their doctor or nurse can learn about complementary and alternative therapies from the following government agencies:

**National Center for Complementary and Alternative Medicine** is the Federal Government’s leading agency for scientific research on complementary and alternative medicine. NCCAM’s mission is to explore complementary and alternative healing practices in the context of rigorous science, to train CAM researchers, and to inform the public and health professionals about the results of CAM research studies. The NCCAM Clearinghouse offers fact sheets and other publications, and responds to inquiries from the public.

#### **NCCAM Clearinghouse**

Post Office Box 7923

Gaithersburg, MD 20898–7923

Telephone: 1–888–644–6226 (toll free)

301–519–3153 (for International callers)

TTY (for deaf and hard of hearing callers): 1–866–464–3615

Fax: 1-866-464-3616

E-mail: [info@nccam.nih.gov](mailto:info@nccam.nih.gov)

Web site: <http://nccam.nih.gov>

**NCCAM** and the **NIH National Library of Medicine (NLM)** jointly developed **CAM on PubMed**, a free and easy-to-use search tool for finding CAM-related journal citations. As a subset of the NLM's PubMed bibliographic database, CAM on PubMed features more than 230,000 references and abstracts for CAM-related articles from scientific journals. This database also provides links to the Web sites of over 1,800 journals, allowing users to view articles in full-text. (A subscription or other fee may be required to access full-text articles.) CAM on PubMed is available through the NCCAM Web site at <http://nccam.nih.gov>. It can also be accessed at <http://www.ncbi.nlm.nih.gov/PubMed> by selecting "Limits" and choosing "Complementary Medicine" as a subset.

The **National Cancer Institute (NCI)** has an Office of Cancer Complementary and Alternative Medicine that coordinates the activities of the NCI in the area of complementary and alternative medicine. OCCAM supports CAM cancer research and provides information about cancer-related CAM to health providers and the general public via its Web site at <http://cancer.gov/occam> on the Internet.

**Booklets** - The Upper Valley Guide to Complementary and Alternative Health Services: Healthy Resources for Body, Mind & Spirit: The Guide, PO Box 221, So. Strafford, VT 05070 or email [guide@valley.net](mailto:guide@valley.net)

## Constipation

### What is the problem?

Persons who say they are “constipated” are bothered most by straining and hard bowel movements. “Regularity” may be twice-daily bowel movements for some or two bowel movements a week for others. Many persons worry that if they only have a few bowel movements a week, they are “constipated”. However, 15% of persons who otherwise never feel constipated have two or fewer bowel movements a week. But a person who eats a poor diet, drinks too little fluid, or misuses laxatives can easily become constipated.

Ask yourself these questions to decide if you are really constipated: Do you have difficulty passing stools? Are they usually hard? Do you have difficulty emptying? Is there pain? Are there other problems such as bleeding? The following issues are common causes of constipation:

- Lengthy bed rest, after an accident or illness, and lack of exercise.
- Certain medications: antidepressants, some anti-nausea medicines, heart medications, antacids containing aluminum or calcium, antihistamines, diuretics, some pain medicines, and anti-parkinsonian drugs.
- Overuse of mineral oil - a popular laxative - may reduce the absorption of certain vitamins (A, D, E, and K). Mineral oil may also interact with drugs such as anticoagulants (given to prevent blood clots) and other laxatives, causing undesired side effects.
- Occasionally constipation may be caused by something abnormal or by a blockage of the digestive system. Muscles or nerves that create normal bowel movements can be affected. Your doctor can perform a series of tests to find out if constipation is the symptom of an underlying (and often treatable) disorder.

### What are some things that you can do to help:

- Increase the amount of high fiber foods in your daily diet.
  - Try to eat about a cup of fruit and vegetables (peas, strawberries), either cooked or raw, each day. Dried fruit such as apricots, prunes, and raisins are especially high in fiber. A bowl of whole grain cereals (All-Bran, Puffed Wheat) and breads can be very helpful as well.
  - Try adding small amounts (a tablespoon or two) of unprocessed bran (“Miller’s Bran”) to baked goods, cereals, scrambled eggs, soups, and fruit as a way of increasing the fiber content of your diet. Start with one

or two tablespoons and increase to five tablespoons of bran a day. Unprocessed bran is usually sold in health food stores or the health food section of supermarkets. It should not be confused with the packaged cereals that contain large amounts of bran or bran flakes. If you do use unprocessed bran, remember that some people suffer from bloating and gas for several weeks after adding bran to their diets.

- Drink as much fluid as you can each day. Drink warm liquids first thing in the morning or before bed in the evening to help trigger bowel activity. Warm teas, lemonade or stimulant herb teas (e.g. “Smooth Move ®” Tea).
- Stay as active as you can—light exercise can stimulate the muscles in your intestines.
- Don’t ignore the natural urge to have a bowel movement. Some people prefer to have their bowel movements only at home. But holding a bowel movement can cause problems if the delay is too long.
- Develop a regular bowel habit (e.g. attempt to have a bowel movement shortly after breakfast or dinner).
- Take prescribed laxatives regularly, especially if you are taking constipating medications (such as most pain medicines). Lactulose, sorbitol (least expensive), wetting agents (docusate) soften stool. Irritant laxatives (senna) and milk of magnesia stimulate the bowel. Enemas should only be used once in a while.
- Do not expect to have a bowel movement every day or even every other day. If your bowel movements are usually painless and occur regularly (whether the pattern is three times a day or three times each week), then you are probably not constipated.
- Avoid constipating foods, e.g., chocolate, eggs, cheese.

### **When to get help from a professional:**

- If you suddenly become constipated and it is not relieved by your usual laxative regimen.
- If you don’t have a bowel movement for 3 days.
- If you do not have a bowel movement after 2 days of laxative use.
- If you have persistent cramps or vomiting.
- Blood on toilet paper.
- Bright red blood or tar-colored stools; may indicate bleeding somewhere else in the digestive system.
- Loose grainy diarrhea-like stools when constipated (may indicate stool is stuck, known as “impaction”).

**Other helpful resources:**

For once-in-a while use, try a mixture of apple sauce, prune juice, and bran (so-called “black magic”).

## Diarrhea

### What is the problem?

Having three or more loose or watery bowel movements a day with or without discomfort is diarrhea. Continuous diarrhea that lasts more than a few days can cause weakness, weight loss, skin soreness and poor nutrition.

Some causes of diarrhea include: bacterial or viral infection, radiation therapy to abdomen or pelvis, chemotherapy, antibiotics and other medications, anxiety, tube feedings containing large amounts of vitamins, minerals, electrolytes, and sugar, and other abdominal conditions.

### What are some things that you can do to help:

- Try a clear liquid diet, (water, weak tea, clear broth, Popsicles, gelatin) to increase your fluid intake to two - three quarts of non-carbonated fluids a day.
- Eat small frequent meals.
- Avoid high lactose (milk) foods, alcohol, caffeine and tobacco.
- Avoid spicy or greasy foods and very hot or cold foods.
- Avoid carbonated drinks such as soda and beer and sugary sport drinks such as Gatorade.
- Drinks like Ricelyde and Pedialyte may help.
- Add pectin and rice to your diet.
- When diarrhea improves, if possible, eat foods that are high in protein and calories and low in fiber (low fiber foods include: rice, bananas, applesauce, yogurt, mashed potatoes, low-fat cottage cheese, and dry white toast).
- Apply protective ointments or anesthetics (A&D ointment, hydrocortisone or tucks) to clean toilet paper and place it on the sore area to decrease irritation.
- Take medicine for diarrhea as prescribed.

### When to get help from a professional:

- If you have 6-8 bowel movements per day with no improvement.
- If you notice blood in your stool or around your rectum.
- If you lose 5 pounds after the diarrhea starts.
- If you don't urinate for more than 12 hours.
- If you have a fever.
- If you can't drink liquids for 2 days.
- If your abdomen suddenly becomes bloated or puffy or painful.

## Emotional Symptoms

### What is the problem?

Persons who have serious illnesses are often bothered by emotional problems. The most common problems are anger, anxiety/nervousness/fear, depression/sadness, and worry.

### Anger

Anger is one of the first emotions people experience after learning they have a serious illness. They often feel that life is not fair and that this should not have happened to them. Anger is a normal stage of grief and loss. You may not be comfortable with these feelings of anger. But it is normal and should be talked about. In fact, about 3 in 10 persons who are very ill have “temper tantrums.” If you feel your anger is beyond your ability to control, seek help from your family and health care practitioner.

### Anxiety/Nervousness/Fear

Everyone feels anxious when they are uncertain about what will happen in the future. Feelings of fear and anxiety may be due to changes in your ability to do all the “normal” things you did before your illness. People with cancer often feel fear or anxiety about things like pain, an unknown future, death, uncertainty, and the unknown. People often first feel disbelief when they learn that they have a health problem that makes the future unclear. By taking control of the problem, they get control of their anxiety. If you cannot control the frequency and intensity of your anxiety, talk to your health care practitioner about treatment. You do not need to suffer from excessive anxiety. Answers to questions that concern you and your family is the best defense against fear.

### Sadness/Depression

Depression is a common feeling for persons who have serious illnesses or who are uncertain about their future. Sadness is a normal feeling when disappointments or losses occur. It is time to take action when feelings of extreme sadness or despair last for at least two weeks or more and interfere with working, eating, or sleeping. Other symptoms include hopelessness, loss of interest in usually enjoyable activities, excessive crying, suicidal pre-occupation, guilt, lack of energy, inability to concentrate and irritability.

If you find yourself withdrawing from family and friends, feeling overwhelmed, exhausted, helpless, hopeless and blaming yourself for having these feeling then you need to ask for help. Depression is highly treatable and not seeking treatment can lead to needless suffering. It is often not possible to simply “snap out of it.”

### **What are some things that you can do to help:**

- Don't keep your feelings inside; talk to family, friends or a trained professional about your feelings and fears. It's ok to feel negative, fearful, and frustrated at times.
- Listen carefully to each other.
- Seek out sources of reassurance and support.
- Use prayer or seek out spiritual support.
- Use deep breathing or relaxation exercises to help with anxiety.

The following are some things you can do when you suspect, or family members suspect, that you are depressed:

- Tell your health care practitioner that you are depressed and ask for help. Depression is not a sign of weakness.
- Review all your medications with your health care practitioner to make sure none of them are causing depression.
- Eat a balanced diet, get rest, and exercise when possible.
- Avoid alcohol.
- Stick with a treatment for depression and discuss any side effects

### **When to get help from a professional**

- If you are feeling that life isn't worth living or are having thoughts of suicide.
- If you have hurt yourself or others.
- If you are using alcohol or illegal "street drugs" to overcome difficult feelings.
- If you are feeling "panic" or having trouble breathing or being in groups of people.

### **Other helpful resources**

There are many resources available to answer your questions. Your health care practitioner, family, friends, and other patients can help you find the information you need. The Internet is a great source. Begin with **[www.healthfinder.gov](http://www.healthfinder.gov)** or **[medlineplus.org](http://medlineplus.org)**. There are also cancer support groups and on-line cancer help groups (See Appendix).

## Fatigue/Tiredness

### What is the problem?

Fatigue means that a person has less energy to do the things he or she normally does or wants to do. Cancer fatigue is different from the fatigue experienced in everyday life by a person without cancer. Tiredness or fatigue can be mild or complete—“feeling all worn out”. Fatigue and tiredness may be caused by: serious illness, stresses involved in living with a serious illness, pain, decreased nutritional intake, sleep problems, medicines, cancer treatments like chemotherapy, radiation or surgery. Eliminating the causes of your fatigue may not be possible, but there are things you can do.

### What are some things that you can do to help:

- See the list on the next page for, “Energy Conserving Strategies”.
- Avoid over-working yourself, especially when you are feeling better than usual.
- Prioritize activities - carry out the essential ones first.
- Combine essential activities with those that are uplifting and pleasurable.
- Plan shorter activities.
- Schedule regular rest periods after each activity.
- Use assistive devices to help you get around and in the bathroom.
- Avoid low-slung chairs and beds that require a lot of effort to get out of.
- Place medicines, phone, drinking water, toilet chair and other essentials close by.
- Sit rather than stand for activities such as showering, shaving, brushing teeth, and preparing food.
- Let others do things for you.

### When to get help from a professional

- You should call your health care practitioner or a visiting nurse if you are not able to dress, move, bathe or go to the bathroom without getting tired.
- Dizziness (severe or frequent), falling that causes injury, or being unable to wake easily.

## Energy Conserving Strategies<sup>1</sup>

### Activities of Daily Living

- Sit down to bathe and dry off. Wear a terry robe instead of drying off.
- Use a shower/bath organizer to decrease leaning and reaching.
- Install grab rails in the bathroom.

- Use extension handles on sponges and brushes.
- Use an elevated toilet seat.
- Organize time to avoid rushing.
- Gather needed clothes and toiletries before dressing so that you don't have to make multiple trips to get things.
- Minimize leaning over to put on clothes and shoes.
- Bring your foot to your knee to apply socks and shoes. Fasten bra in front then turn to back.
- Modify the home environment to maximize efficient use of energy.  
Example: Place chairs to allow rest stops (e.g. along a long hallway).
- Wear comfortable clothes and low-heeled, slip on shoes. Wear button front shirts rather than pullovers.

### Housekeeping

- Schedule household tasks throughout the week instead of doing many large chores in one day.
- Do housework sitting down when possible. Use long-handled dusters, dust mops, etc. Use a wheeled cart or carpenter's apron to carry supplies.
- Delegate heavy housework, shopping, laundry, and child care when possible.
- Drag or slide objects rather than lifting. Use proper body mechanics. Use your leg muscles not your back when working. (An occupational or physical therapist can show you how to protect your back and joints when doing activities.)
- Sit when ironing and take rest periods.
- Stop working **before** becoming tired.

### Shopping

- Organize list by aisle.
- Use a grocery cart for support.
- Shop at less-busy times.
- Request assistance in getting to the car.
- Purchase clothing that doesn't require ironing.

## Meal Preparation

- Use convenience foods/easy-to-prepare foods.
- Use small appliances (they take less effort to use).
- Arrange the preparation environment for easy access to frequently used items.
- Prepare meals sitting down.
- Soak dishes instead of scrubbing and let dishes air dry.
- Prepare double portions and freeze half.

## Child Care

- Plan activities to allow for sitting down (e.g., drawing, pictures, playing games, reading, and computer games).
- Teach children to climb up on the lap or into the highchair instead of being lifted.
- Make a game of the household chores so that children will want to help.
- Delegate childcare when possible.

## Workplace

- Plan workload to take advantage of peak energy times. Alternate physically demanding tasks with sedentary tasks.
- Arrange work environment for easy access to commonly used equipment and supplies.

## Leisure

- Do activities with a companion.
- Select activities that match energy level.
- Balance activity and rest (don't get overtired).

<sup>1</sup>Note. Based on information from Donovan, E. (1995, October 25). "Energy conservation." In Fatigue Initiative through Research and Education (FIRE<sup>®</sup>) course. Educational program sponsored by Oncology Nursing Society and Ortho Biotech Inc., Phoenix, AZ.

## Fever

### What is the problem?

Fever is a body temperature greater than 100.5°F (38°C) orally. It is normal for body temperature to fluctuate by a degree over or under the “normal” temperature of 98.6°F. This may occur over the course of a day or a person may have a normal body temperature that is a little over or under this reading. Fever can be caused by an infection that is from bacteria, viral, or fungal in origin. These organisms can come from the environment, or in some cases if the immune system is low, a person’s own body organisms can cause infections. Sometimes dehydration, tumor, drug reactions, or inflammatory conditions can cause a fever.

### What are some things that you can do to help:

- Check your temperature with a reliable thermometer whenever you are feeling bad.
- Keep track of your temperature readings.
- Drink plenty of fluids.
- Avoid getting overheated.
- Avoid people (especially children) who are ill, or are coughing and sneezing.
- Wash your hands regularly after contact with another person.
- Avoid cleaning litter pans or birdcages.
- Use cool compresses to the head and face if hot.
- Treat fever with medicines like acetaminophen (Tylenol) or ibuprofen only after reporting a fever to your health care provider and being told to take these medicines.

### When to get help from a professional

- Temperature greater than 100.5°F (38°C) or a combination of two of the below:
  - Chills and shivering
  - Muscle aches and weakness
  - Runny nose, coughing and sore throat
  - Burning while urinating
  - Burning in anal area
  - Sores that don’t heal
  - Diarrhea that persists
  - Headache
  - Rash
  - Feeling confused

## Mouth Sores/Dry Mouth

### What is the Problem?

**Mouth sores** are like small ulcers in the mouth. The sores can be red and raised, or sunken like a small cavity. You may have white patches or blisters (“cold sores”). They can sometimes bleed. Sores can be present on the tongue, lips, gums, or inside of the cheeks. Mouth sores are most common a week or two after chemotherapy or during radiation to the head or throat area, due to poor mouth care, infections, alcohol, tobacco use, and sometimes due to poor nutrition. Healing may occur on its own after a week or two, but sometimes you will need to see your health care provider to obtain a specific treatment.

A **dry mouth** can occur with or without sores. It occurs when there is not enough saliva to keep the mouth moist. This is common when a person breathes only through their mouth, when using oxygen (that is not humidified), or following surgery or radiation treatments to the head and neck area.

### What are some things that you can do to help:

- Avoid alcohol and tobacco
- Avoid very hot, spicy or acidic foods.
- Drink lots of fluids.
- Before starting treatment, get all needed dental work done.
- Use a soft toothbrush
- Use unwaxed dental floss daily very gently. But *don't* floss when platelets are low because bleeding is more likely.
- Rinse with non-alcoholic mouthwash orally or a mixture of table salt (1 tsp) in a glass of water at least 4 times a day.
- Use lip balm.
- Suck on ice cubes during chemotherapy sessions.
- Use inexpensive “toothpaste” made of a mix of baking soda and hydrogen peroxide. Just pour the peroxide on a flat tablespoon of baking soda and dip your toothbrush into it. Plaque removal toothpaste is not necessarily better than regular fluoride toothpaste, or peroxide and baking soda.
- Keep a bottle of water handy and take small sips regularly.
- Add liquids or sauces to solid foods to add moisture and help with swallowing.
- Use artificial saliva or medicines that increase saliva (a prescription is needed).

### **When to get help from a professional**

- Fever of 100.5°F (38°C).
- Any early signs of irritation or sores.
- Difficulty chewing, taking in adequate food and fluids, or painful swallowing.
- Sores that don't heal after a week.

## Pain

### What is the problem?

#### Cancer Pain

When people are having pain it usually means they have an uncomfortable feeling or hurt somewhere in their body. Sometimes it means that they just feel bad in general and not in any particular location. Some people believe cancer always causes pain but this is not the case. Feeling tired, upset, or depressed can increase the feeling of pain and similarly pain can increase feelings of depression and anxiety leading to exhaustion. Each person expresses pain differently. Because of how we were raised, some people are very verbal about having pain, while others try to be “stoic” and minimize pain or don’t report it to their health care provider. There is no right or wrong way to express pain. However it is always important to bring a new pain, unrelieved pain, or any discomfort to the attention of your team. Pain is not an inevitable consequence of cancer. It is not a “normal” part of aging.

#### Neuropathic Pain

*Tingling, burning, or “electric-shock” like pain*, also called neuropathic pain, is a specific kind of uncomfortable feeling which many people don’t necessarily call “pain”. When nerves are injured from chemotherapy, radiation, surgery, infections like “shingles”, or compressed by tumor, specific uncomfortable sensations can occur. Some will feel like burning, numbness, pinpricks, or electric. These types of sensations can occur in the hands and feet, or at different sites on the chest, back arms or legs. When these types of pains occur a person may have difficulty with buttoning clothes, walking, or may have uncomfortable sensations from clothing or bed sheets. There are specific pain medicines (described below) that can help with this type of pain.

#### Learning about Pain Management

In most cases, severe pain and discomfort can be managed with medical treatments, such as medications, surgery and nerve blocks, and non-medical means, such as relaxation therapies, biofeedback, massage and good nursing care.

#### Reasons that persons suffer from unnecessary pain and suffering include:

- Failure to tell others about their pain.

- Failure of health care practitioners and family to accept what they are told about the severity of pain.
- Lack of knowledge among some health care practitioners about the best use of medications and other tools to control pain.
- Lack of money to pay for medications.
- Fear that pain medicines will not work “later when I really need them”.
- Fear that providing or taking opioids (prescription pain medicines or analgesics) will lead to addiction.
- Lack of access to sufficient amounts of medications for patients on very high doses of opioids.
- Fear of a hastened death by taking higher doses of pain medicine.

People with a serious illness may require very large doses of opioids to control their pain. Specialized doctors and nurses are able to prescribe medicines to diminish pain without causing excess drowsiness or other unpleasant side effects. ***Almost never do patients become addicted to these medicines. Fears of pain treatments causing death are also wrong.*** Pain treatments are given simply to keep the seriously ill persons comfortable and increase their quality of life when pain can't be eliminated through anti-cancer treatments.

**Getting Good Pain Management:** Describe your pain using the pain scale below.

Pain Scale										
0	1	2	3	4	5	6	7	8	9	10
No Pain		Mild		Moderate			Severe			Pain As Bad As Can Be

Let your health care practitioner know:

- How pain is affecting your ability to do things.
- When it is better or worse.
- If you have ever had problems with alcohol or substance abuse or illegal drug use.

Ask your health care practitioner about the plan for pain management. They should have a plan in mind or see that you have access to appropriate pain specialists. Consider what you are willing to trade for pain management. Some people would rather endure more pain if it meant they would be more alert and less sleepy.

## **What are some things that you can do to help with pain management:**

### **Medications**

There are many medicines available for treating pain. They work differently for different people so it is important to work closely with your health care practitioner in choosing the medication that is right for you. If you have tried pain medications in the past, you should let your health care practitioner know what they are and how they worked. It is important to let your health care practitioner know about any allergies that you have, particularly to any medicines.

- Non-opioids are usually used for mild to moderate pain. These include aspirin, Tylenol (acetaminophen), and non-steroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen. Most of these can be bought over the counter without a prescription. Common side effects include upset stomach.
- Opioids such as morphine, oxycodone and codeine are used to treat moderate to severe pain. A prescription is needed for these medications. Common side effects include feeling sleepy or constipated. Long acting opioids are often used to reduce the need to take medicine frequently.
- Antidepressants and anticonvulsants are two other types of medicines used for symptoms of tingling and burning. Some common antidepressants used are amitriptyline, imipramine, doxepin and trazadone. Common side effects of these drugs include sleepiness, dizziness when standing, or dry mouth. The anticonvulsants are gabapentin (Neurontin), carbamazepine and phenytoin. A prescription is needed for these medicines.
- Steroids such as prednisone and dexamethasone are used for pain caused by swelling. A prescription is also needed for these. Common side effects are bad dreams and body swelling.

## **What are some things that you can do to help with neuropathic pain management:**

- Take care to prevent injuries to numb hands and feet.
- Exercise numb limbs by flexing and stretching four times per day.
- Take short walks, to help numbness in legs and feet.
- Ask your health care team about medications that are helpful.

### **What are some things that you can do to help with non-medicine approaches to pain management:**

- See the Fatigue section of this manual for Energy Conservation strategies.
- Practice progressive muscle relaxation exercises or visualizations (the nurse educator will provide you with more information)
- Ask your health care provider about complementary treatments including massage, acupuncture (see CAM section of this manual).
- Use both medicine and non-medicine approaches together.
- Attend a support group to help deal with feelings of loss of function.

### **When to get help from a professional**

- When a new pain arises.
- When you are not getting relief from your medicines.
- When you cannot afford medicines prescribed for pain.
- When your pain feels like muscle aches, followed by painful tingling, sensitivity to light touches, heat, or cold, numbness or burning in hands or feet, feeling clumsy using hands or fingers.
- Increases in current symptoms, or new symptoms.
- If you are feeling overly drowsy, confused, constipated or are having other uncomfortable side effects from medicines.
- Get a second opinion or ask for a referral to a pain specialist if you feel as though your pain is not being taken seriously by your health care provider.

### **Other helpful resources**

Websites: <http://www.stoppain.org> and [www.cancersymptoms.org](http://www.cancersymptoms.org)

## Sexuality Issues - Women

### What is the problem?

The loss of sexual intimacy may result in feelings of loss, loneliness, and uselessness. Medications and illness may make sex unappealing or uninteresting.

### What are some things that you can do to help:

- Talk about sexual concerns and intimacy with your loved one and your health care practitioner.
- Realize there may be no “cure” for the problem.
- Explore other ways to be intimate with your partner.
- Consider sexual counseling when needed.
- Increase vaginal lubrication:
  - Use water-based lubricants during sex.
  - Avoid petroleum jelly.
  - Use vaginal moisturizers 4 times per week.
  - Continue having sexual intercourse on a regular basis.
- Try different positions.
- Spend extra time kissing and touching before intercourse.
- Use relaxation techniques.
- Set the scene for lovemaking.
- Try other ways of expressing affection.
- Raise your energy level by doing the following:
  - Taking naps.
  - Avoid heavy meals and alcohol.
  - Getting gentle exercise.
- Empty and tape any bags or tubes out of the way.
- Empty your bladder beforehand.
- Treat pain and nausea.
- Treating depression and anxiety can improve sexual relations.

### When to get help from a professional

- Intercourse is still painful, despite trying the steps above.
- Sexual issues are causing you physical and emotional distress.
- Sexual issues are affecting your relationship with your partner.

## **Sexuality Issues - Men**

### **What is the Problem?**

The loss of sexual intimacy may result in feelings of loss, loneliness, and uselessness. Medications and illness may make sex unappealing or uninteresting.

### **What are some things that you can do to help:**

- Talk about sexual concerns and intimacy with your loved one and your health care practitioner.
- Realize there may be no “cure” for the problem.
- Explore other ways to be intimate with your partner.
- Consider sexual counseling when needed.
- For problems with erections explore treatment options such as:
  - Pumps
  - Medications
  - Implants
  - Work with your care team to find the best treatments for your situation.
  - Explore other ways to experience sexual pleasure.
- Raise your energy level by doing the following:
  - Taking naps.
  - Avoid heavy meals and alcohol.
  - Getting gentle exercise.
- Empty and tape any bags or tubes out of the way.
- Empty your bladder beforehand.
- Treat pain and nausea.
- Treating depression and anxiety can improve sexual relations.

### **When to get help from a Professional**

- Physical or emotional distress because of sexual problems.
- Continue to have problems with erections despite taking measures.
- Sexual problems that are affecting your relationship with your partner.

## Shortness of Breath

### What is the problem?

Difficulty with breathing can occur when there is not enough oxygen in the blood, or when the lungs cannot take in enough oxygen to deliver it into the bloodstream. Shortness of breath is usually very bothersome and tiring. It has many causes including: chronic lung conditions, tumor, pneumonia, or fluid blocking air passages, pain, stress, anxiety, fatigue, anemia, or obesity.

### What are some things that you can do to help:

- Stop smoking.
- Rest to conserve energy.
- Avoid things that make it worse, for instance cold, humidity, tobacco smoke.
- Sit up in a chair, or rest your head on several pillows. Elevate your head in bed. Sleep in a recliner or on several pillows.
- Ask your care team about medication or oxygen.
- Morphine or other opioids can be helpful (you will need a prescription).
- Practice deep breathing every 4 hours (while awake).
- Have a fan blow on your face.
- Pace your activities – don't do too much at once!
- Decrease anxiety with relaxation exercises, and meditation.
- Mild exercise may help.
- Eat soft foods if shortness of breath interferes with eating.
- Keep the mouth moisturized with sprays of water, lemon swabs, or foods such as fresh pineapple.
- Oxygen therapy or inhalers may help (you will need a prescription).

### When to get help from a Professional

- If you notice any changes in your breathing.
- If you have a persistent cough.
- Fever greater than 100.5°F (38°C).
- If you have thick, green, yellow, or bloody sputum.
- If you feel cool or clammy, or have bluish fingertips or skin color change.
- If you are wheezing or have a sudden pain in the chest with breathing.

## Skin Problems-Color changes/Dry skin

### What is the problem?

**Changes in skin color** can be a sign of a problem or can occur as a result of cancer treatments. For instance, if the skin takes on a yellowish hue it could be due to jaundice (a condition indicating a problem with the liver or bile system). Bluish coloration can be due to not enough oxygen in the blood. Pale skin can be due to anemia. Bruises or red, pinpoint dots can arise if blood counts are low.

**Dry, flaky, or itchy skin** occurs when there is not enough moisture in the skin either due to dehydration, skin infections, and effects of cancer treatment, heat, or cold.

Sometimes **skin will become irritated and sores** can result from pressure on bony parts of the body, such as the buttocks, elbows, heels, or ankles. People who are bedridden can have a serious condition called pressure sores or “bed sores”.

### What are some things that you can do to help:

(Changes in skin coloration should be brought to the attention of a health care provider—For other skin problems consider the following):

- Use soft beds and special surfaces, such as sheepskin, or foam “egg crate”. Keep clothes, jewelry, or other skin from rubbing on affected area.
- Avoid rough sheets, tape, vigorous drying with towels, and too much heat.
- Wash skin gently with non-irritating soap and warm water.
- Shave with electric razors only (regular blades can “nick” the skin).
- Take showers instead of baths, or use soaps with emollients or skin moisturizers
- Prevent pressure sores with frequent position change and good nutrition.
- Assess high-risk areas - pelvic area, heels, ankles and hips - daily.
- Do passive range of motion exercises if bedridden. (A physical or occupational therapist can customize a program for you.)
- Treat itchiness with a cool bath with baking soda, moisturizing lotions, or medicated lotions. Avoid scratching.
- Avoid sun exposure and don’t use heating pads or ice bags over treatment area.
- Keep up good nutrition – it helps with healing.
- If you are bedridden consult your health care provider or visiting nurse for special strategies to help prevent pressure sores.

### **When to get help from a professional**

- Report any signs or symptoms of skin infection, including pain, redness, swelling, drainage, odor, or red streaks under the skin.
- Fever greater than 100.5°F (38°C).

## Sleep Problems

### What is the problem?

There are many reasons why people may have problems sleeping such as pain, medication side effects, and difficulty breathing or worrying about your condition. Sleeping problems range from difficulty falling asleep and staying asleep to waking up too early in the morning. If you don't get a good night's sleep, you may become irritable, unable to concentrate, and tired.

- **Leg Cramps:** Can occur at night causing frequent awaking & morning tiredness. A good treatment for restless legs and leg cramps is to perform stretching exercises. To do this stand two feet away from a wall and lean forward against it keeping your feet flat to the floor. Hold and repeat. Quinine works well for leg cramps and clonazepam pills may help restless legs. A physician must prescribe these medications.
- **Sleep Apnea:** Is a condition in which breathing stops intermittently through the night causing the person to awake multiple times during the night. Because of this sleep disturbance the person will feel tired in the morning. This condition is usually diagnosed by a specialist. Treatments for sleep apnea include devices to be worn at night (troublesome), continuous air pressure using a device through the nose (bothersome), and even surgery (50% effective). The cheapest and safest first approach is to reduce weight when necessary and avoid alcohol.

### What are some things that you can do to help:

- Go to bed only when sleepy. There is no need to sleep eight hours every night and there is no benefit from staying in bed when you can't sleep. Staying in bed more than five hours a night is of no value if you are not sleeping.
- Use your bedroom only for sleeping. For safety your bedroom area should have a smoke alarm, a lamp that's easy to turn on, and a telephone by your bedside. After turning off the light, give yourself about 20 minutes to fall asleep. If you are still awake, or if you lose your drowsiness, get up and go into another room until you feel sleepy again.
- Follow a regular schedule. Get up at the same time. Don't have one schedule for the workweek and one for the weekend. A regular routine at bedtime, like reading a book or taking a warm bath, will tell your body it's time to sleep.
- Write down what you are doing each day. See if you are pushing yourself too hard.

- Avoid daytime naps. If you take daytime naps, you are likely to stay awake at night. If you must nap, take a short nap before 3 PM. If you usually feel so tired during the day that you fall asleep without planning to nap, please talk to a doctor.
- Try to exercise regularly. Brisk walking four times a week improves sleep. Moderate exercise several hours before bedtime will also help you sleep.
- Learn relaxation techniques. (An occupational therapist can help you customize a relaxation program.)
- Avoid drinking caffeinated (coffee, cola) beverages late in the day. As a stimulant, caffeine can keep you awake. Don't drink alcohol to help you sleep. Drinking even small amounts of alcohol can make it harder to stay asleep. This is a very common occurrence.
- Smoking is not only dangerous (starting a fire by falling asleep with a lit cigarette), but nicotine is a stimulant and will keep you awake.
- If you are in pain, consult your health care provider about better pain management.
- Avoid excessive use of sleeping pills.
- If you still have difficulty, try these "tricks:" Try not to worry about your sleep. Some persons find that playing mental games is helpful. For example, think black—a black cat on a black velvet pillow on a black corduroy sofa, etc.; or tell yourself its five minutes before you have to get up and you're just trying to get a few extra winks. A warm bath with a drink of warm milk or herb tea may help. However, beverages taken before bedtime may increase the need to go to the toilet. Your doctor may recommend that you visit a sleep clinic. Sleep clinics may be used to make diagnoses and recommend treatments for persons who have sleep apnea or severe sleeping problems not responding to any of the above described approaches.

### **When to get help from a professional:**

- Talk to your health care provider about any medications you are using for sleep. Prescription sleep medicines are often habit forming and may build up in your body. Sleep medicines you can buy without a prescription usually contain antihistamines. These medicines are generally not harmful if used only a few times a year, but they can make you drowsy and more likely to have accidents the next day.
- If you experience sleep problems for more than 3 weeks or if you regularly wake in the middle of the night.
- If sleepiness is a risk to safety (e.g. driving), or if sleepiness interferes with work or other activities.

## Swelling/Edema

### What is the problem?

Swelling (or edema) is a build up of fluid under the skin or in different areas of the body, for instance in the legs or arms (lymphedema), scrotum, abdomen (ascites), or in the chest (pleural effusion). Common causes are blockages of the lymph system that normally drains this fluid (by tumor or damage to the vessels), and water accumulation due to medication side effects (especially chemotherapy drugs, hormones, and steroids). Decreased intake of protein and lowered blood protein can also lead to fluid accumulating under the skin. Kidney or liver failure can cause an accumulation of fluid in the abdomen or lower limbs.

### What are some things that you can do to help?

- For feet and legs, get measured for support hose and apply before lowering legs out of bed in the morning.
- Keep legs elevated when sitting.
- For arm/finger swelling: avoid wearing tight fitting rings, consider a sling or arm compression sleeve.
- Consult with a physical therapist specializing in lymphedema for compression devices and exercises to decrease swelling.
- Limit salt intake by avoiding the use of table salt, or eating salty foods.
- Take medicines prescribed by your health care team to get rid of excess fluids.

### When to get help from a professional:

- When fluid accumulation interferes with breathing.
- When fluid accumulation is painful or leads to skin irritation.

### Other helpful resources

#### Sleep Problems

[www.cancersymptoms.org](http://www.cancersymptoms.org)

#### Swelling/Edema

The National Lymphedema Network (NLN) is an internationally recognized non-profit organization to provide education and guidance to lymphedema patients, health care professionals and the general public by disseminating information on the prevention and management of primary and secondary lymphedema. A toll-free recorded information line: 1-800-541-3259 or website [www.lymphnet.org](http://www.lymphnet.org).

# Advance Care Planning Module

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## ADVANCE CARE PLANNING MODULE

### Unfinished Business

Everyday most of us have a lot of things that we want to do and have not yet done. We get some of those things done each day and feel some sense of accomplishment. There are other things that we just seem to “put off” for another day. Those things stay on our list – a real list or a list in our heads – and seem to hang over our heads. Some of those are just routine things, like making the bed, cleaning out closets or labeling photographs. Others are important things that are difficult to approach, like resolving troubled relationships or writing our wills. Still others are simply things we want to do, like traveling to a particular area or visiting with friends and family members.

A health care challenge may remind us of our personal “unfinished business”, those things that we want to do and have not done. We may become anxious to take care of some of these things. Or we may just want to do some of the things we want to do but have put off until now.

Take some time to think about some of the “unfinished business” in your life. What are those things that you want to do, or mean to do, or wish you had done? What are those things that, if you do not accomplish or do them, you would be sorry you had not?

You can use the next page to write your answers to the above questions and to record any other thoughts you have on “unfinished business”.

The following section will help you explore advance care planning in more detail, as well as you and your family’s thoughts around spirituality, loss, and grief.

## Unfinished Business

- a. Which items are most important to you? Maybe you want to highlight those in some way.
- b. Which of your items involve other people? What do you have to ask of them?
- c. What can others do to help you accomplish these things?

Use the problem-solving model worksheet at the end of this chapter to identify steps you could take to deal with your unfinished business.

### My “unfinished business”:

- 1) \_\_\_\_\_
- 2) \_\_\_\_\_
- 3) \_\_\_\_\_
- 4) \_\_\_\_\_

## Advance Care Planning

Advance care planning allows you and your family members to think and talk about health care choices, and based on your wishes, to plan for future health care decisions. It helps others know what you want by putting what you want in writing.

The Advance Directive documents, a Living Will and a Durable Power of Attorney for Health Care (DPOAH), are two legal documents that give you an opportunity to verify your own wishes about medical care and to make those wishes known to your family, physician, and to others who care about you.

Years ago, we did not have the choices in medical care that we have today. Seriously ill people, old and young, were more likely to die quickly of natural causes than they are today. Now, medical technology can extend the life of seriously ill people for longer periods of time. It can even keep permanently unconscious people alive for many years. This has created choices that just a few years ago would not have seemed possible. Sometimes, the new technology seems truly miraculous in its ability to restore health to someone who is seriously ill. At other times, it only seems to prolong suffering and the dying process.<sup>1</sup>

### **In completing Advance Directives, you should consider:**

- Your rights as a patient.
- Common treatments in critical and end-of-life care.
- Your own values and wishes in relation to medical care and treatment as your illness progresses.
- How you can use Advance Directives to leave instructions for your care if you become unable to speak for yourself.

Thinking about these issues now, and sharing your thoughts with your physician as well as with those who care about you, gives you and your loved ones the opportunity to prepare. Your interest might be a catalyst for others in your family to complete the same forms; we all should have Advance Directives on file in case of a medical crisis that could happen to anyone at any time. The Advance Directives Vermont: Taking Steps to Plan for Critical Health Care Decisions, along with the Values Questionnaire gives helpful information as you consider what treatment and care is right for you. Copies are available from your physician, your hospital, or The Vermont Ethics Network website.

<sup>1</sup>Advance Directive Vermont: Taking Steps to Plan for Critical Health Care Decisions. A publication of the Vermont Ethics Network. 2002. 802-828-2909 or [www.vtethicsnetwork.org](http://www.vtethicsnetwork.org).

The Durable Power of Attorney for Health Care (DPOAH) is a legal document that allows you to appoint someone to make a broad range of health care decisions for you if, for any reason, you become unable to make those decisions for yourself. The DPOAH can cover any health care situation in which you are incapable of making your own decisions. You can use the DPOAH to instruct your agent to request all available care or to limit the types of care you will receive.

The Living Will, also called a Terminal Care Document, is a legal document that directs your health care team with regards to your choices for the type of medical care in the event that you can't speak for yourself. This medical care may or may not include extraordinary measures, comfort care, and artificial nutrition and hydration.

## Activity - Decision Making and Planning

With this manual you will have received two worksheets:

### 1) Five Wishes and (2) An Advance Care Planning Guide.

We suggest that you, and anyone who is working through this material with you, complete these worksheets to give you an opportunity to consider your own values as they relate to medical care decisions.

The *Five Wishes* may assist you completing the Advance Directive materials. After reviewing the *Five Wishes*, complete the Advance Directive materials distributed by your state of residence.

Once you have completed these worksheets, be prepared to discuss them with the nurse educator. You may also wish to provide copies to your health care team and other caregivers, family, friends, and your attorney. If you have a Living Will or Durable Power of Attorney for Health Care Decisions, you may wish to attach a copy of these forms to those documents.

## **Spiritual Issues**

Spirituality refers to more than just going to church. Spirituality includes ideas that come from organized religion as well as the deeper questions we all have about why we are here and where we are going. When people face life-threatening illnesses, spiritual issues can be both a source of concern and comfort.

### **Definition of Spirituality**

There are at least three components to this spiritual dimension. First, spirituality is an expression of how a person relates to a larger whole, be it God, a higher power, nature or the human family. Second, personal spirituality provides a source of meaning and understanding about the significance of being human. Third, personal spirituality often contains habits, rituals, gestures, and symbols that provide ways in which the person can interpret and manage existence.

Some physicians and other providers become quite nervous during any discussion of spirituality in medicine. They might fear that spirituality means enforcing particular religious beliefs. However, spirituality and religion are not synonymous. Religious belief is one very important way in which many people express their spirituality. But a person can be spiritual without explicit religious belief. Individuals have a variety of ways to find meaning in life and may come to an understanding of their choices and behaviors. It is not uncommon to discover a poem, or a piece of music or a good meal in the company of friends can provide a context by which one can grow, endure, or, even accept diminishment. Forms of religious practice frequently express personal spirituality. Faith provides a variety of personal and communal resources to handle serious illness. Serious illness causes believers and non-believers alike to face loss, fears, grief, personal mortality and questions of meaning. These are the kind of issues that appropriately are identified, at least partially, as spiritual.

### **Physicians and Spirituality**

Why should doctors bother with spirituality? A doctor who inquires about a patient's spirituality gains a deeper insight into the patient's experience. Knowing all the chapters of a patient's story and gaining insight into that person's spiritual journey can provide a context for making medical decisions. As a person faces the end of life, the context can be especially crucial. For all the discussion and interest in informed consent, advance directives, and patients' rights, attempts to care for individuals at the end of life are often filled with poor communication and with the inappropriate use of technology. This might well reflect the inability of doctors and patients to speak the same

language. Doctors ask about ventilators, CPR, intubations, and feeding tubes. Patients and their families talk about death with dignity, refusing to give up, hopes for miracles, and requests to be left alone. If a physician understands a person's spiritual response to illness, better communication might result. Two examples may help illustrate the point. A person frightened about death, concerned about what will happen to a spouse and children, and despairing at the loss of hopes and dreams may cling to illusory hope about technology, or focus on the possible life-prolonging aspect of a particular therapy. The result could be an extensive period of aggressive care, the end result of which is increased suffering and death. A doctor who can ask about fears, hopes and despair might be able to find the tools to ease the spiritual pain without blindly resorting to invasive treatments that will not bring the patient the peace he or she seeks. Likewise, an individual who has come to the end of an illness can communicate to a physician spiritual acceptance of mortality. The doctor is in a better position to discuss care that is compatible with the person's view of the dying process.

### **Giving Meaning to the End of Life**

Some people are not interested or not comfortable in discussing spiritual issues with their health care practitioner. Whatever your religious or spiritual beliefs are it may help to take some time to consider the following "Four Rs for the Spirit"

- **Remembering** - Take time to reflect on your life and its events. What were your accomplishments? What must be left undone? Who influenced you, for better or worse, and whose lives did you influence? Who did you love? Who do you love? What do those relationships mean to you now?
- **Reassessing** - Take time to see your life as a whole. You may ask what your life really added up to or who you really were. You might even share your thoughts with those who know and love you.
- **Reconciling** - Try to be at peace with yourself. You may need to reconcile yourself to not having done the things you always wanted to do. You may need to forgive yourself for your shortcomings, or forgive those who hurt or disappoint you. You may need to ask others to forgive you. Reconciliation with your imperfections - and those of others - can help you find peace.

- **Reuniting** - Try to be at peace with those you love. Most of us have various relationships disrupted over our lifetime from death, anger, relocation, and the many forces that push people apart. As serious illness threatens, it is important to come together with family and friends, when you can, and to have the chance to say farewells. Don't wait too long to try to see that long-estranged sister or son, or even to sit awhile with a friend from long ago. If you believe in some kind of hereafter or heaven, that afterlife can also be where our souls will be reunited with those who have died before us.

### **Talking with Your Clergy**

If you wish to talk to Clergy, they will expect to be asked questions such as:

- If I have negative feelings like frustration, sadness, despair, anger at God or life, will you listen?
- Will you help me if I have problems communicating with family or friends?
- Will you visit with my family and help them with their spiritual concerns about my illness?
- Will you just sit and be with me, even if I don't want to talk?

## Loss and Grief

Loss is defined as the state of being deprived of or being without something you once valued. Coping with serious illness may cause a sense of loss. As you navigate from diagnosis through treatment to periods of physical limitation it is important to be aware of the effects of these losses and the difficulty you may have in accepting them.

Coping with serious illness may cause a sense of loss for some people. These are significant losses, and we will experience some difficulty in accepting them. Each person grieves in her/his own time, according to his/her own way. There is no formula for grief and no way around it. Grief is a country we all must visit, and it helps to know what it's like there how others have survived the journey, the maps they followed, the setbacks, and what they learned along the way. Grief can occur many times in the course of an illness, both before and after the death of a loved one. A life threatening illness can give you time to say good-bye to people you love and care about. You have time to make plans for how you want to be cared for at the end of your life, and, perhaps, how you want to be remembered. You may, if you feel well enough, find time to do things you have always wanted to do, or you may wish to resolve old hurts and grievances.

It was a Swiss psychiatrist, Elisabeth Kubler-Ross, whose 1964 book, *On Death and Dying*, helped us to see that the experience of grieving is a universal and natural one, and that it has some predictable emotions. She observed that most of us will experience denial, anger, bargaining, and depression as well as a state of acceptance or peace with each significant loss in our lives. There is no steady progression or pattern to our experience; at one moment we might feel overwhelmed by sadness over our situation, and in the next may feel just as overwhelmed with anger. Just when we think we have accepted our situation and feel some peace, we may find ourselves trying once again to bargain with the powers beyond us to take the illness away if we become more perfect in some special way. All of these feelings are natural, and it is important to let ourselves experience and express all of these feelings.

## Types of Grief

Grief describes a person's response to a potential or actual loss. There are many types of grief.

**Anticipatory grief** is the process by which friends and family come to terms with the potential loss of an important person in their life. As people with serious illness progress toward the end of their own life, they may also

experience anticipatory grief related to concerns about leaving loved ones, loss of their ability to work or function at the same level, unmet life goals, and the reduced ability to participate in previously enjoyable activities. Common feelings representing anticipatory grief are anger, fear, guilt, anxiety, irritability, sadness, and feelings of loss.

**Acute grief** is a sudden, often dramatic reaction to the actual loss of a significant person. Acute grief can result from a sudden death or from an expected death in which there was a phase of anticipatory grief. Acute grief is characterized by intense crying spells, anxiety, denial, “numbness,” a sense of a lack of reality, and physical symptoms.

**“Normal” grief** is a period of time during which a person gradually adapts to a loss. Since death often changes people, a return to pre-loss state is not always possible. Instead, a more realistic goal is an altered life in which the person has adapted to the loss.

There is no defined period of time within which people are expected to “recover” from grief. Though guidelines are difficult to determine, some progress in the person’s grief should occur within the first 1 to 2 months. Clear improvements in at least some areas of the person’s grief should show by the 4<sup>th</sup> month after the loss.

**Complicated grief** is marked by a failure to return to pre-loss level of performance, or state of emotional well being, after the loss of a significant person. Complicated grief may be difficult to identify because grief experiences vary significantly among individuals. However, a person suffering from complicated grief usually does not show marked improvements at the 1 to 2 month or 4 month marker.

**Complicated Grief Versus Depression Grief** can be a significant source of distress. People experiencing grief are at risk for health problems, suicide, and death from other causes. Overall, estimates of depression in the first year after the loss of a loved one range from 20-30%.

It is often difficult to distinguish between depression and complicated grief. Both conditions can have similar symptoms such as feelings of guilt, thoughts of death, and slower thinking and movement. However depression symptoms usually begin later, after 1 to 2 months of grief, and persist for several months after the loss. Depression is also the more likely diagnosis when symptoms are constant. Some markers of depression include frequent suicidal thoughts, large changes in sleep and appetite, or large decreases in physical and emotional function.

## Treatment

Effective grief treatment and intervention is essential for maintaining the health of the grieving individual. Though the grieving individual may receive some emotional support from their physician, a vast majority of support that people receive after a loss comes from friends and family. In all stages and forms of grief, emotional support and counseling are helpful.

If the grief is severe or complicated, medications may also be helpful. Please talk to your regular doctor or nurse. Additional counseling, psychotherapy, and referral to a psychiatrist may be needed for both depression and complicated grief.

### Activity - Identify your Strengths & Resources

In your life to date, you have met with countless losses of many kinds. You probably have endured, and coped well. You may have even reached a measure of peace with some losses. Earlier in your experience of those losses, you did not know that you could recover.

In an effort to bring your own history to bear on your present situation, we suggest that you recall earlier significant losses in your life, allowing yourself to remember the feelings around those experiences as you list them. Then we ask you to remember the resources in yourself and outside of yourself upon which you learned to depend on in order to cope with those losses. These are the same strengths, of course, that you bring to your present situation.

In the activity below identify your past losses and then some of the strengths and resources you were able to gain from these experiences.

Losses	My Strengths & Resources

### Reflection

Think about the following:

- a.** Who is a good listener with whom I can talk about my experience and feelings?
- b.** How well do I listen to others who wish to confide in me?
- c.** When have I come to peace with a loss that at an earlier time seemed overwhelming?
- d.** How do I express anger when I feel it?

## Problem Solving Worksheet

You can use this sheet to address problems related to advance care planning.

<b>1) Problem:</b>		
<b>2) Achievable Goal:</b>		
<b>3) Solutions:</b>	4) *Pros (+)	4) *Cons (-)
a)		
b)	b) Pros (+)	b) Cons (-)
c)	c) Pros (+)	c) Cons (-)
d)	d) Pros (+)	d) Cons (-)
e)	e) Pros (+)	e) Cons (-)
<b>5) Choice of solution:</b>		
<b>6) Steps to achieve solution:      Tasks that have been completed:</b>		
a)		
b)		
c)		
d)		

\* In weighing the Pros and Cons, consider the amount of effort, time, money, emotional impact, and who else may be involved as you compare solutions.

# Appendix-Resources

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## **APPENDIX - RESOURCES**

This appendix is full of resources to meet a variety of needs. Resources will give you a place to start looking and ask questions that will help to resolve a concern or problem you have or may be faced with in the future. You will find interesting and educational references to different organizations, community supports, and internet websites. Websites may be accessed from a number of different locations at DHMC including the Hematology/Oncology Waiting Room (2 computers), the Radiation Oncology Waiting Room (near the fish tank; ask the receptionist if you can't find it), or at the Matthews-Fuller Sciences Library on 5<sup>th</sup> Floor (above the rotunda/information desk) at DHMC (ask reference desk for help). Have fun exploring!

## **Social Support & Communication Resources**

### **NCCC Cancer Help Line**

The NCCC Cancer Help Line gives information about cancer treatment, prevention, support groups, programs and events, and other resources related to cancer. The Help Line is staffed from 9 a.m. to 5 p.m. on weekdays. At other times, you may leave a voice mail message; your call will be returned as soon as possible. To reach the Cancer Help Line, call: 1-800-639-6918.

### **DHMC Support Groups**

There are many more support groups at DHMC than the ones listed below. We thought you might be interested in the groups listed below.

#### **Coping with Cancer, A Support Group for Adults**

Support for patients and for their families and partners  
First Monday of each month, 1:30 to 3:00 p.m.  
Room L3A off Main Mall of DHMC

#### **Women with Breast Cancer: "Turning Points"**

2nd Thursday of each month, 6:00 - 7:15 pm  
Women's Health Resource Center, on the Lebanon Mall  
Call 603-650-2233 for more information.  
Margie Cole, MSW and Jill Butler, MSW

#### **The Women's Group - A Support Group for Women with Metastatic Cancer**

This group is offered for women with any type of metastatic cancer.  
3<sup>rd</sup> Thursday of each month, 12:00 - 1:00 pm  
Held at DHMC. Call 603-650-2233 for room locations.  
Margie Cole, MSW and Briane Pinkson, LPN, Healing Arts Practitioner,  
DHMC

#### **Healing Journey Circle - A Free Support Group for Women with Chronic Illness**

Whether you find yourself living with chronic stress, MS, cancer, diabetes — any illness with or without a medical diagnosis — you will find this group a welcoming and supportive community. The group will explore the issues of everyday living and use the methods of drumming, Reiki, energy psychology, imagery, ritual and other techniques for emotional healing.  
3<sup>rd</sup> Sunday of each month, 3:00 - 4:30 p.m.

Women's Health Resource Center at the Lebanon Mall  
Charon Burford, Shamanic Counselor & Reiki Master

### **Look Good, Feel Better**

A how-to class for women who have skin and hair change due to cancer treatment by women teaching makeup, wig and scarf styling.

1<sup>st</sup> Tuesday of each month. No Charge.

10:00am – 12:00pm

Room DMS 2E on the 4<sup>th</sup> floor of the Cancer Center

Contact Doris at 603-448-1793

### **The Caregiver Resource Directory: A Practical Guide for Family Caregivers.**

This guide is intended to help family caregivers feel less alone and overwhelmed. It offers resources, facts, and advice about caring for a loved one, as well as the caregiver. The guide is an interactive 3-ring binder with pockets and ample writing space so that caregivers can organize all the resources and medical information in one place. Available from the Beth Israel Medical Center at 877-620-9999 or [http://www.stoppain.org/caregivers/resource\\_form.html](http://www.stoppain.org/caregivers/resource_form.html). *The guide is **available free of charge to patients, family caregivers, health care professionals, and the public.***

**DHMC Libraries:** There are Patient and Family Libraries located in the Hematology/Oncology Waiting Room, the Radiation Oncology Waiting Room (just outside the treatment area), and the Matthews-Fuller Health Sciences Library (Consumer Health Collection) at DHMC (speak with a reference librarian for assistance). The libraries include a collection of reliable and understandable information about cancer. Computers in all of the libraries are linked to the Internet and can be used to find, research, and print information you may find helpful.

**Religious/Spiritual** resources are available in your local community and at DHMC. Your local telephone directory lists a variety of religious and spiritual affiliations that are available in the area. To contact a chaplain at DHMC, ask your nurse or call the Chaplaincy Office at 650-7939 during regular business hours (8:30 a.m. to 5:00 p.m. M-F). A chaplain is available for emergencies 24 hours a day. The chapel is located on level 3 in the Patient Towers. It is open and available to everyone regardless of faith. Scheduled services include:

- A non-denominational worship service at 10:00 a.m. on Sundays.
- A Roman Catholic Mass at 11:00 a.m. on Sundays and noon on

Tuesdays and Thursdays. Masses are also offered on Holy Days of Obligation and on Ash Wednesday.

- A Jewish Shabbat Eve Prayer Service on Friday at 4:30 p.m.

**On-line Websites** may provide you with information and support. The amount and scope of information available on the Web is both amazing and bewildering. You should evaluate research and be aware of the information you find. Start by going to reliable, well-known sources such as government research institutions (e.g., National Cancer Institute or the Center for Disease Control), highly respected advocacy groups (American Cancer Society or the American Lung Association), and academic institutions. You may also consider, "Is this information widely accepted or is it a subject of debate among scientists and cancer prevention experts?"<sup>1</sup>

AARP	<a href="http://www.aarp.org">http://www.aarp.org</a>
American Cancer Society	<a href="http://www.cancer.org">http://www.cancer.org</a> 800-ACS-2345
Americans for Better Care of the Dying	<a href="http://www.abcd-caring.org">http://www.abcd-caring.org</a>
Cancer Care Inc.	<a href="http://www.cancercare.org">http://www.cancercare.org</a> 800-813-HOPE
CancerNet	<a href="http://cancer.gov/cancerinformation">http://cancer.gov/cancerinformation</a>
Dying Well	<a href="http://www.dyingwell.com">http://www.dyingwell.com</a>
ElderWeb	<a href="http://www.elderweb.com">http://www.elderweb.com</a>
Family Caregiver Alliance	<a href="http://www.caregiver.org/">http://www.caregiver.org/</a>
Five Wishes	<a href="http://www.agingwithdignity.org">http://www.agingwithdignity.org</a>
Guides to living wills and legal issues -	<a href="http://www.nolo.com">http://www.nolo.com</a>
Health Insurance Association of America -	<a href="http://www.hiaa.org">http://www.hiaa.org</a>
National Breast Cancer Organization Y-ME	<a href="http://www.y-me.org/">http://www.y-me.org/</a>
National Cancer Institute	<a href="http://www.nci.nih.gov/occdocs/cis">http://www.nci.nih.gov/occdocs/cis</a> 800-4-CANCER
National Coalition for Cancer Survivorship	<a href="http://www.canceradvocacy.org/">http://www.canceradvocacy.org/</a> 888-650-9127
National Family Caregivers Assoc.	<a href="http://nfcacares.org">http://nfcacares.org</a>
National Hospice Organization	<a href="http://nho.org">http://nho.org</a> 703-243-5900
National Hospice Foundation	<a href="http://www.hospiceinfo.org">http://www.hospiceinfo.org</a>
OncoLink	<a href="http://oncolink.upenn.edu">http://oncolink.upenn.edu</a>
Today's Caregiver Magazine	<a href="http://www.caregivers.com/">http://www.caregivers.com/</a>
Well Spouse Foundation	<a href="http://www.wellspouse.org">http://www.wellspouse.org</a>

<sup>1</sup>From: Newsletter of the Harvard Center for Cancer Prevention.

**On-line support includes chat rooms:**

American Cancer Society

<http://www.cancer.org/docroot/home/index.asp> (look for message boards)

Breast Cancer Support

<http://bcsupport.org/>

Cancer Support Chat

<http://www.cancerpage.com>

Growth House – Improving care for dying

<http://www.growthhouse.org/chat/>

What you need to know about Cancer

<http://cancer.miningco.com/mpchat>

**Local Senior Citizens Centers/Councils on Aging:**

Charlestown Senior Citizens Center. 223 Old Springfield Road, Charlestown, NH (603) 826-5987.

Claremont Senior Center. 24 Tremont Square, Claremont, NH (603) 543-5998.

Hanover Senior Center. 42 Lebanon Street, Hanover, NH (603) 643-5531.

Lebanon Grafton County Senior Citizens Council, Inc. P.O. Box 433, Lebanon, NH (603) 448-4897. E-mail: [gcsccl@gcsccl.org](mailto:gcsccl@gcsccl.org)

Mascoma Area Senior Center. Church Street, Canaan, NH (603) 523-4333.  
Email: [gcsccl@gcsccl.org](mailto:gcsccl@gcsccl.org)

Bradford Orange East Senior Center. 21 Upper Plain, Bradford, VT (802) 222-4782.

Norwich Senior Action Center. Main Street, Norwich, VT (802) 649-1800.

Randolph Senior Citizen Center. 6 Hale Street, Randolph, VT (802) 728-9324.

Springfield Senior Center. 139 Main Street, Springfield, VT (802) 885-3933.

Upper Valley Senior Citizens Center. 603- 448-4213.

White River Junction Bugbee Senior Center. 262 North Main Street, White River Junction, VT (802) 295-9068.

Woodstock Senior Center. 1141 Senior Lane, Woodstock, VT (802) 457-3277.

**Interest Groups** including bird watching, quilting, bridge playing, volunteer activities, and outdoor recreational activities may be considered. Volunteer job listings are published about once/month in the Sunday edition of Valley News or are available online at <http://www.vnews.com>

**Local town Recreational Departments:**

Lebanon Recreational Dept. 603-448-5121 offers volunteer-led walks in the area

Hanover Conservation Council 603-643-3433

Upper Valley Events calendar - <http://calendar.valley.net/>

**Symptom Management Resources**

**The Upper Valley Guide to Complementary and Alternative Health Services: Healthy Resources For Body, Mind & Spirit:** The Guide, PO Box 221, South Strafford, VT 05070 or [guide@valley.net](mailto:guide@valley.net). This is a community resource booklet that offers local resources on alternative/holistic therapy, exercise, meditation, stress reduction and many more categories.

Managing the Side Effects of Chemotherapy and Radiation Therapy, by Marilyn J. Dodd. 2001; ISBN: 0943671205

Complete Bedside Companion: No-Nonsense Advice on Caring for the Seriously Ill, by Rodger McFarlane and Phillip Bashe. 1998; ISBN: 0684801434

Handbook for Mortals: Guidance for People Facing Serious Illness. Joanne Lynn and Joan Harrold. 2001. ISBN: 0195146018

You can also refer to the symptom management module in this manual for further symptom-specific resources.

## **When to call your doctor or care team**

It can be difficult deciding whether a problem is serious enough to notify your care team right away or whether the problem can wait a bit, say until the next morning or until your next visit. There are some things that require an urgent response by your care team – things like infection, difficulty with breathing, or signs of bleeding problems.

The following is a list symptoms, which, should they occur you should contact your care team as soon as possible:

- Fever greater than 100.5° degrees (38°C).
- Shaking and chills – that you can't control, that's not related to being cold.
- Can't take in or hold down food or fluids for 24 hours.
- Diarrhea – more than 5 bowel movements per day, for more than 1 day.
- Bright red or dark, tarry stool.
- Vomit bright red blood or brown flecks ("coffee grounds").
- Sudden intense pain anywhere in your body.
- Shortness of breath not related to exercise.
- Cough, especially if greenish or brownish sputum is produced.

If you have serious concerns, it's better to go ahead and contact your care team and let them decide.

## **Who Do I Call? Members of your health care team.**

\*\*Please be sure to include their business cards, if handy, on the following page.

**Oncologists:**

Name: _____	Name: _____	Name: _____
Specialty: _____	Specialty: _____	Specialty: _____
Phone# _____	Phone # _____	Phone # _____

**Fellows:**

Name: _____	Name: _____	Name: _____
Specialty: _____	Specialty: _____	Specialty: _____
Phone# _____	Phone # _____	Phone # _____

**Nurses/Nurse Practitioners:**

Name: _____	Name: _____	Name: _____
Specialty: _____	Specialty: _____	Specialty: _____
Phone# _____	Phone # _____	Phone # _____

**Physician Assistants:**

Name: _____	Name: _____	Name: _____
Specialty: _____	Specialty: _____	Specialty: _____
Phone# _____	Phone # _____	Phone # _____

**Social Workers/Psychologists:**

Name: _____	Name: _____	Name: _____
Specialty: _____	Specialty: _____	Specialty: _____
Phone# _____	Phone # _____	Phone # _____

**Care Managers:**

Name: _____	Name: _____	Name: _____
Specialty: _____	Specialty: _____	Specialty: _____
Phone# _____	Phone # _____	Phone # _____

**Physical Therapists:**

Name: _____	Name: _____	Name: _____
Specialty: _____	Specialty: _____	Specialty: _____
Phone# _____	Phone # _____	Phone # _____

**Occupational Therapists:**

Name: _____	Name: _____	Name: _____
Specialty: _____	Specialty: _____	Specialty: _____
Phone# _____	Phone # _____	Phone # _____

**Other Helpful People:**

Name: _____	Name: _____	Name: _____
Specialty: _____	Specialty: _____	Specialty: _____
Phone# _____	Phone # _____	Phone # _____

## Advance Care Resources

When preparing an advance care plan you should think about how you would like your short and long term care needs to be met. Needs may include nutrition, pain control and symptom management, self-care needs (e.g., home health care, nursing home, and hospice), and emotional and financial support. The Office of Care Management at DHMC has Advanced Care booklets, depending on the state that you live in, and resources that may be helpful.

Inability to do self-care is a real concern for most persons as they age. Family members and friends can often give needed help, at least for a few weeks. Although most persons in need of assistance are cared for at home, it is estimated that as many as 40% of Americans who turned 65 in 1990 will spend some time in a nursing home. For most, it will be a short stay.

### Alternative Care: Nursing Home and Hospice Care

Hanover Terrace Healthcare	(603) 643-2854
Kendal at Hanover	(603) 643-8900
Lebanon Center Genesis Eldercare	(603) 448-2234
DHMC Office of Care Management for other Nursing Homes and Hospice Care	(603) 650-5789

Some persons with serious illnesses are eligible for Hospice care. Eligible persons:

- Are eligible for Medicare Hospital Insurance (Part A); AND
- Are likely to live six months or less, according to their doctor and the Hospice medical director, if the disease runs its expected course; AND
- Sign a statement choosing Hospice care instead of standard Medicare benefits for the illness.

For more information on Medicare approved hospice programs in your area contact your state hospice organization, or call the National Hospice Organization Hospice Help line. (800) 658-8898 or on the WEB go to <http://www.hospicenet.org/html/medicare.html>

Once in Hospice, persons receive:

- Physician's services.
- Nursing care (intermittent with 24 hour on call).
- Medical appliances and supplies related to the illness.
- Outpatient drugs for symptom management and pain relief.

- Short-term acute, in-patient care, including respite care.
- Home health aide and homemaker services.
- Physical therapy, occupational therapy and speech/language pathology services.
- Counseling, including dietary and spiritual counseling.

### **Home Support Services**

Some patients and caregivers may feel they can manage at home and just need additional support at home. The following services may be helpful in this manner.

- Home Health Care - Visiting Nurses Alliance of Vermont and NH 800-858-1696 or 802-295-2604
- Medical equipment – check with VNA for loan, then Lion’s Club, or Keene Medical Supplies (800 447-0028 or 603 448-5290 - PO Box 439, 240 Meriden Road; Lebanon, NH 03766-0439)
- Help with cleaning your house (homemaker services) or preparing meals - Meals on Wheels contact Upper Valley Senior Center, 10 Campbell Street, Lebanon, NH: Telephone: 603-448-4213 or Visiting Nurses Alliance of Vermont and NH 800-858-1696

### **Office of Care Management, DHMC**

Social workers that specialize in cancer care can provide assistance and information about financial and legal assistance, advance directives, support groups, transportation, and other resources. Short-term counseling for patients and families is offered. Call (603) 650-5789 for more information. The OCM is located on the 3rd (Main) floor of the Medical Center in the North Mall. Hours are from Monday through Friday 8:00 a.m. to 5:00 p.m.

## **Memoirs**

### **Shared Decision Making Service, DHMC**

Shared Decision Making Service helps patients, the public and professional staff with the process of making health care decisions. They offer counseling appointments for any decision and loan out videos and other decision aids about specific decisions. Located at DHMC, on the Level 3 Mall, and open Monday-Friday from 8 a.m.-5 p.m. Call (603) 650-5578 or email Shared-Decision-Making@mailbox1.hitchcock.org for an appointment.

**Leaving a Legacy** – writing, video, or audio taping a message for anyone, but especially for seniors or those with a serious illness. The purpose of A Legacy to Remember® (<http://www.alegacytoremember.com/HowTo.html>) is:

- An activity that is worthwhile and promotes creativity
- An activity that enables them to reflect back on life

Additionally, **Life Chronicles**, a nonprofit organization ([www.lifechronicles.org](http://www.lifechronicles.org)) produces recordings for people in health crisis or experiencing bereavement. To assist individuals in communicating with loved ones by recording messages of comfort, reassurance, and lifetime memories. They are based in California, however if the patient is out of state and does their own videotaping, they can send the tape and Life Chronicles will edit and put in music.

## Financial Support and Services

Financial stress may also be a factor in your everyday life. When someone is ill, money often becomes very important. They worry about day-to-day costs, such as medications and home help, and unexpected costs such as hospitalization.

You should contact your insurance company and ask them direct questions about what the benefits/limits of your insurance coverage for the following types of services: hospital care, emergency ambulance, sub-acute care in nursing home, long term care in nursing home, medications, home health nurses, and home health aides.

If you think you can figure out the answers yourself, review your insurance materials and benefits packages. Additionally, the Office of Care Management at DHMC (see below) has care managers and resource coordinators who can assist you in answering your questions.

Some things to do:

- Think about your needs and write down your questions.
- Contact your plan to find out if you have a case manager and write down his or her name.
- Have someone join you if you have an appointment.
- Ask what support/advocacy your case manager or plan can provide to you.
- Keep a record of your contacts and answers to questions.

*Understanding the different types of medical insurance and benefits is confusing.* There are different insurance types that include:

- Private (Managed Care Plan/HMO/Federal/etc.) – call the phone # listed on your plan ID cards or brochure.
- Medicare Supplements or primary/secondary insurance.
- Medicare - contact number should be in your local phonebook.
- Medicaid - contact your local District Office (NH-Health Human Services, Vt. Dept. of Social Welfare) to speak with caseworkers.
  
- Ask the hospital/clinic if they have assistance programs. DHMC does have a program based on income eligibility.
- Apply to Catastrophic Illness Program through the State of NH. 1-800-852-3345 ext. 4495 or 603-271-4495. This is a state funded program that provides financial assistance to low-income NH residents who require medical treatment for several medical conditions including cancer.

- If you do not have medical insurance then contact the Office of Care Management at DHMC and find how/where/to whom can I turn to get coverage?

For additional financial resources, supports, and services to consider contacting include:

- Social Security and Social Security Disability/SSI - contact Local Social Security office first and then National Social Security office (toll free number-800-772-1213).
- What is the family Medical Leave policy for my or caregiver's place of employment? Family and Medical Leave Act <http://www.dol.gov/esa/whd/fmla/>.
- Where else can I turn? What is in my own community? For example, Town Clerk Town Clerk or Welfare/Support Officer, Regional Community Action Agency, Religious Community, Service Clubs (Lions, Elks, etc.), Salvation Army, and Senior Citizens Centers/Councils on Aging.

Office of Care Management, DHMC - Social workers that specialize in cancer care can provide assistance and information about financial and legal assistance, transportation, and other resources. Short-term counseling for patients and families is offered. Call (603) 650-5789 for more information. The OCM is located on the 3rd (Main) floor of the Medical Center in the North Mall. Our normal operating hours are Monday through Friday 8:00am to 5:00pm.

COVER Home Repair (Corps of Volunteers Effecting Repair) is a small home repair group based in Lebanon that addresses the urgent home repair needs of low-income, elderly and disabled members of the Upper Valley community. Projects focus primarily on the repair or restoration of preexisting structures: wheelchair ramp construction, pitched roof construction/repair/restoration, interior weatherization/insulation and window or cabinet installation. COVER minimizes the cost of repair by using salvaged, at-cost materials to benefit homeowners who are physically or financially unable to complete the repair themselves. Contact COVER at 158 South Main Street, White River Junction, VT 05001; 802 296-7421 / Fax 802 296-7380; Project Director - Simon Dennis ([simon.dennis@dartmouth.edu](mailto:simon.dennis@dartmouth.edu))

## **Other Financial Concerns including Food, Housing, Transportation, etc.**

If you are having difficulties paying for necessities such as food, housing and clothing, you may need to check on income assistance programs. Usually a social service helper, or the following community support groups, will be able to answer your questions and have resources that are helpful.

- Town clerk or welfare/support officer.
- NH Division of Human Services – 800-852-3345
- Vermont Agency of Human Services - 802 241-2400
- Regional community action agency.
- Central Vermont Community Action – Randolph – 802-728-9506
- Southern Vermont Community Action (SEVCA) – 800-639-1053 or 802-295-5215
- Religious Community – see Churches and/or Synagogues in your local telephone book
- Service clubs (Lions, Elks, etc.).
- Salvation Army – At Listen 603-448-4553 or at Thrift Store 603-298-8724.
- LISTEN (financial and housing resources) – 603-448-4553.
- Haven (temporary, emergency housing) – 802-295-6500.
- Senior Citizens Centers/Council on Aging – listed under “Social Support and Communication Resources” in this Appendix.
- Meals on Wheels – 603-826-5139 (Charlestown), 603-542-9526 (Claremont), and 603-863-3177 (Newport, NH).

Transportation difficulties can be addressed with the Office of Care Management. See above listing.

If your spouse or caregiver is having problems with volunteer jobs, work, or caregiver support, there may be an Employee Assistance Program (EAP) at their place of employment. EAP can provide short-term counseling and support.

For problems with housing arrangements contact Office of Care Management or the Haven (802-295-6500).

If you're having problems with paying for medications, contact the Office of Care Management for suggestions on how to resolve this.