

The American College of Physicians
Home Care Guide
for
Advanced Cancer

When Quality of Life is the Primary Goal of Care

For family, friends, and hospice workers caring for persons
with advanced cancer at home.

Edited by Peter S. Houts, Ph.D.

How To “Speed Read” Chapters in This Guide

1. Read the Overview.

This a road map of what is in each chapter.

2. Read the “Understanding the Problem” section.

This tells what the problem is, who is likely to experience it, and what can be done about it.

3. Read only the **bold** type in the rest of the plan.

This will tell describe the basics of what you can do.

With these three steps, you will quickly understand what is in the plan. Later, you can read the regular type, which will explain why you should do the various recommendations.

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Editor

Peter S. Houts, PhD

Associate Editors

Julia A. Bucher, RN, PhD
Balfour M. Mount, MD
Susan E. Britton, RN
Arthur M. Nezu, PhD
Christine Maguth Nezu, PhD
Harold A. Harvey, MD

Contributors

Ellen Jaeger, ACSW, LSW
Dale B. Schelzel, RN
Sandra J. Poljaric, RN
Kathy B. Kambic, RN
Elise M. Givant, RN
Georgia L. Trostle, RN
Glenda M. Trumpower, MSW

Project Coordinator

Carole A. Bean

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Acknowledgments

The American College of Physicians Home Care Guide for Advanced Cancer builds on an earlier book for caregivers of people receiving treatment for cancer titled *The Home Care Guide for Cancer*. The many people who contributed to that book, and who are listed in its acknowledgments section, have indirectly contributed to this work as well.

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Preface

Almost half a century has passed since the philosophy underlying “Hospice Care” was succinctly stated in the plea of a dying patient, David Tasma, who told his young social worker, Cicely Saunders, “I only want what is in your mind and in your heart.” Significantly, this agnostic Polish Jew from the Warsaw ghetto, who was to become an important catalyst for Dame Cicely’s thinking, feelings, and subsequent actions, had given force to the twin pillars of Hospice Care. Those dying need the friendship of the heart, with its compassion, acceptance, and reciprocity. They also need the skills of the mind, embodied in competent medical care. Neither alone is sufficient.¹ North American health care has found it much easier to deliver the skills of the mind than the friendship of the heart. The teachings of Cicely Saunders, embodied in hospice care, have helped to redress this balance. A fundamental component of hospice care is the empowerment of both those who are ill and their families, thus enabling them to be active participants in caregiving rather than merely passive recipients.

As the millennium approaches, we face increasing pressures from shrinking health care budgets, an aging population, and an increasing need for palliative care. Never have skilled home care, volunteerism, and the enhancement of individual coping skills been more important. *The American College of Physicians Home Care Guide for Advanced Cancer* has been designed for use by family caregivers, hospice workers, and other health providers. Its aim is to support effective problem-solving by all involved: the patient, family members, and other caregivers.

Confronting advanced illness brings to the surface an awareness of our transience, our fears, our beliefs, our quest for meaning, and our need for community. This work recognizes that most of us are assisted toward adaptation and an improved ability to cope with life’s problems when we are helped to confront our fears and assisted in being proactive in addressing the problems that face us. For most, uncertainty breeds anxiety, and anxiety paralyzes coping mechanisms. *The American College of Physicians Home Care Guide for Advanced Cancer* provides a rich array of information and problem-solving strategies that decrease our uncertainty and promote our ability to help both ourselves and those we care for.

Balfour M. Mount, MD

Director, Palliative Care Service

Royal Victoria Hospital

Montreal, Quebec, Canada

1. duBoulay S, Saunders C. *The Founder of the Modern Hospice Movement*. London: Hodder and Stoughton; 1984:172.

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A Dying Person's Guide to Dying

Roger C. Bone, M.D.

The central theme of the Home Care Guide for Advanced Cancer is that planning near the end of life is helpful. By thinking ahead about what could happen - and about how you will deal with problems if they do happen, you can create a better life and a better quality of life for yourself and for the people who love and care about you. What I have to say is for the person who, like myself, is dying. We, too, need to plan - to think ahead in order to fashion, out of the time remaining, the best of what is possible.

As I am dying from cancer, I have learned some things that I think are important for a dying person to know in order to plan. I am a physician, but what I have learned has little to do with my medical training. I have learned this as a person; perhaps my medical experience was helpful because I have paid close attention to the actions and reactions of people around me.

First, it is likely that you will be surrounded by persons who mean well but, in the end, you must die your own death. Dying can be considered a journey one takes alone with a crowd. Family and friends are the first to gather around you, and they offer the most comfort.

Here are some pieces of advice to remember in those first few days after you learn the bad news.

1. One or two people - probably family members - will make enormous personal sacrifices to help you. If you are married, your spouse is likely to do this, but don't be surprised if others - a daughter, a brother-in-law, or even a friend, step forward to offer extraordinary help. Be grateful, and accept help, from whatever source, graciously.
2. Some family members, but especially friends, will treat you differently. Even before you show signs of serious illness, people will have a different look in their eyes as they talk with you. You might consider this patronizing or over bearing. It may be difficult, but it is best to ignore their attitudes and treat them as you always have. They will come around to their normal selves when they get over the shock.
3. Happily accept all gifts from family and friends. It makes them feel better and you might

receive something you really like and appreciate.

4. Don't be afraid to ask to be alone. We need time to be by ourselves. Some family and friends may feel driven to fill your every waking moment with activities; perhaps they are trying to 'take your mind off' your impending death, but they may also be doing the same thing for themselves.
5. Be your own counsel. No one, including your physician, religious counselor, spouse, or friends can understand 100% what you want and need. It surprised me that some people seemed to "bully" me with advice when they learned that I was terminally ill. We should remember Immanuel Kant's advice to avoid accepting someone else's authority in place of our own powers of reason. We are the ones who should be considering alternatives and making choices. We can, and should, ask for advice. Make telephone calls and read books - but ultimately, we should decide.
6. Slow down and ask your family and friends to slow down. There may not be a lot of time, but there is sufficient time in all but the most extreme cases to think, plan, prepare.

There are things you need to know from your doctors and other health care staff. You need not ask all of the following questions or ask them in this order. Still, these questions deal with crucial issues that need to be addressed and, hopefully, resolved.

1. What is my disease?

You should find out as much as possible about your disease. What is it? How will it affect me? And very importantly, how will it cause my death? First, ask your physician. Additionally, many popular books are available in bookstores and libraries which can give you a basic sense of your disease process and disease terminology. National organizations, such as the American Cancer Society, and often local hospitals can provide brochures, video tapes, or even lay experts to help you and your family understand your particular disease. Ignorance is not bliss; the more you and your family know, the better able everyone will be able to cope with what is happening.

2. Should I seek a second opinion about my disease and my condition?

Seek a second opinion! A second opinion will relieve your mind and resolve doubts one way or another that a major mistake has not been made. More importantly, a second opinion will offer a slightly different perspective that may help everyone's understanding. Don't be embarrassed about asking for a second opinion or think that you will make your physician angry. Second opinions are perfectly acceptable, and many physicians are happy when their patients seek second opinions. The original diagnosis is usually confirmed, and you are then more prepared to follow prescribed treatments.

3. What health professional do I especially trust?

Search for and then trust in a single individual. This does not mean you should not listen to all health professionals and follow reasonable directions and advice. But focus on one individual as the final helper. This normally will be the specialist physician in charge of your case. However, you may know your family doctor better than you know your cancer specialist. If this is the case, your family doctor may be the one to choose. But, if you do, make certain that your family doctor knows that he or she is serving that role.

4. Why am I going into the hospital?

There are four basic reasons why a terminally ill person would be hospitalized, but not all four necessarily apply to every patient. They are: (1) to confirm the diagnosis and analyze how far the disease has progressed; (2) to provide treatment that can only be given in the hospital, (3) to treat a severe worsening of the disease; and (4) to treat the final phases of the disease, if this cannot be done at home or with hospice. You should know which applies to you so that you can understand why things are done to you and what benefits you can expect.

5. What are the hospital rules about terminally ill patients?

Hospitals and medical centers have written rules and procedures that outline in detail how the hospital will deal with terminally ill patients. These are not 'treatment' rules. These protocols or guidelines, as they are called, deal with how to handle end-of-life issues, such as whether the patient (or the patient's family speaking for the patient) wishes extraordinary "heroic" measures to be used to keep the patient alive. Hospitals are obligated, and very willing, to share these protocols or guidelines with patients and families. Consider getting a durable power of attorney in which you name one or two people to make decisions or choices on your behalf if you should be incompetent or incapable of making decisions yourself. Read the 'Do Not Resuscitate' policies of the hospital. Death should be peaceful, and you should not ask for anything that gives you prolonged agony.

You should be aware that nurses and other hospital staff may not know that you are terminally ill. This fact may not be written in your chart, which can lead to conflicts between families and hospital staff. The family may assume that everyone in the hospital shares their grief, and will not understand the work-a-day attitude of nurses, dietitians, or others. It is okay for the family to tell the hospital staff that you are dying since they may not know.

6. What resources are available from the health care community?

Most hospitals have many services available to patients and families to help with nonmedical aspects of your care. These include social services and psychological, financial, and religious counseling. For example, a visit, before hospitalization, to the hospital financial counselor by a family member to check on insurance and payment plans is a wise move. In the rush to admit a patient, important information may not get recorded. A 15 minute meeting with counselors can avoid stress and anger over incorrect bills. Similarly, meeting with the hospital social worker may be very helpful in arranging home care. Use these

services! The chapter on “Getting Help from Community Agencies and Volunteer Groups” has many useful ideas and strategies to help you get the help and resources you need.

7. What can I do if it seems that nothing is being done or if I don't understand why certain things are done to me?

Hospitals, clinics, and doctors' offices can be confusing places. You can begin to feel you have no control over what is being done to you, and you may wonder if anyone really understands your case. This is the time to call the health professional who is your primary contact - the one you decided you fully trust - your physician specialist or family physician. Ask this person to explain what is going on. Have him or her paged or even called at home if your situation is very upsetting. It is the physician's responsibility to help you, and he or she will not be angry that you called. There are also some useful suggestions in the chapter titled “Getting Information From Medical Staff” to help you and your family deal with this problem.

8. How will I and my family pay for my treatment?

Financial professionals employed by hospitals understand billing and what may or may not be covered by Medicare, Medicaid, or private insurance. Consult them and be sure to ask every question to which you and your family need an answer. It is important that you and your family do not panic over billing. Ask for advice and help. There is additional information on this subject in the chapter on “Getting Help from Community Agencies and Volunteer Groups.”

Sometimes the hardest part about dying is the effect it has on your family and friends. Helping them deal with your death helps you find peace and comfort. If you are not at peace with your death, ask the health professional you especially trust to help you find peace. That person will help or will get whatever help is needed. After all, it is the goal of all health professionals, to give you comfort and health during life and peace to you and your family at death.

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*The American College of Physicians Home Care Guide for Advanced Cancer:
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Using This Guide to Solve Caregiving Problems

This guide is for the family, friends, and hospice workers caring for those patients with advanced cancer who are living at home. It provides the information they need to deal with caregiving problems while working cooperatively with a team of health professionals, such as nurses, physicians, and social workers who are members of a hospice, home health, or oncology care team. The book is written for use in “palliative care,” in which the primary goal of treatment has shifted from extending the patient’s life to ensuring the best possible quality of life. The World Health Organization has defined palliative care as:

- ⇒ Integrating the psychologic and spiritual aspects of patient care;
- ⇒ Affirming life, and regarding dying as a normal process;
- ⇒ Neither hastening nor postponing death;
- ⇒ Offering a support system to help patients live as actively as possible until death; and
- ⇒ Offering a support system to help the family cope during the patient’s illness and their own bereavement.

The American College of Physicians Home Care Guide for Advanced Cancer was written and edited by nurses, physicians, social workers, and psychologists who work in palliative care with help from family caregivers and hospice volunteers. A companion work, *The American College of Physicians Home Care Guide for Cancer*, which discusses how to solve caregiving problems when the primary goal of treatment is to

extend life, also is available.

How the Guide Is Organized

Each individual plan (or “chapter”) in this guide deals with a problem that may occur during palliative care in the home, and each is organized into five major topics:

1. Understanding the problem (*what is the problem, who is most likely to have it and when, what can be done to help, what is a realistic goal*);
2. When to get professional help (*when to call immediately and when to call during office hours, what information to have when you call and what to say*);
3. What you can do to help (*how to deal with the problem as well as how to prevent it*);
4. Possible obstacles (*misinformation that can interfere with carrying out the plan and how to deal with it*); and
5. Carrying out and adjusting the plan (*how to check whether you are making progress, how fast to expect any change, what to do if the plan is not working*).

This guide only deals with the most common problems of patients with advanced cancer and their home caregivers.

How To Use this Guide

Read key information headings first

The second page of each plan provides an overview of that particular issue. Individual topics are summarized in bold, with information about why the topic is important presented in regular type. Arrows indicate which topics are actions you can take or symptoms you should look for. By reading the overview, the “Understanding the Problem” section, and then the material in bold (especially when there is an arrow in front of it), you can quickly and easily understand the problem and what you can do about it. The information in regular type, which will give you the reasons for the recommendations, can be read later.

Read plans before problems develop

By reading these plans before problems develop or become severe, you will be prepared for them if and when they occur. Most problems can be dealt with more easily when they are just starting, so early intervention can prevent these problems from becoming serious. In addition, some plans also provide information on prevention.

Read plans again when problems persist

This guide contains many ideas and strategies for dealing with caregiving problems, and it is hard to remember them all. Therefore, re-read the information about problems that persist. Then, you can be sure that you are doing everything you can.

Use this guide as part of an orderly approach to problem-solving

By itself, this guide will not ensure effective problem-solving. You must develop your own plan to carry out the recommendations presented here.

Solving problems using this guide

Four key ideas will help you to be effective in solving caregiving problems. First, you need to make effective use of **expert information**—the kind of information that is included in *The American College of Physicians Home Care Guide for Advanced Cancer*. Second, you need to develop an orderly **plan**. Third, you must be **creative** in dealing with obstacles. And, finally, you need to be both **optimistic** and realistic when involving the person with cancer in the plan.

You can remember these four key ideas by thinking of the word *COPE* (which means to succeed in solving problems):

***C* for Creativity**

***O* for Optimism**

***P* for Planning**

***E* for Expert information**

Now, let's examine these four ideas in detail.

Be CREATIVE

As a caregiver, you will be challenged constantly to think creatively

Each person is unique, and so is each problem. Therefore, you must be creative in adapting your plans to fit each unique situation.

Most plans will run into obstacles. When your plans do not work out as you had hoped, you should see overcoming or sidestepping these obstacles as a challenge to your creativity.

Here are three things you can do to help yourself think creatively when dealing with obstacles:

1. See the obstacle from someone else's point of view. Put yourself in the shoes of another person who can look at your problem differently, and ask yourself what he or she would do.
2. Ask other people who have faced similar problems for ideas.
3. Ask how important or serious the obstacle really is. Does this obstacle truly stop you from carrying out your plan? Sometimes you can ignore or work around an obstacle.

Have an OPTIMISTIC attitude while being realistic about your problems

Have a positive attitude

One of the most important things you can do to help the person you are caring for is to have a positive attitude. People with advanced cancer need encouragement, and they need help noticing the good things that are happening around them. At the same time, it is important to be realistic about the seriousness of their problems. These patients must not feel that their problems are being ignored or belittled.

Expect to succeed

If you think there is a good chance of succeeding, then you will do your best. If you think the problem is hopeless and nothing will work, then it will be hard for you to carry out

your plans, and the people around you will become discouraged, too. If you do feel discouraged and negative, get help from someone who has a positive attitude and is a good problem-solver. This could be the person you are caring for, a friend or family member, or a health professional.

Take breaks from caregiving

Do things you enjoy so that you can have a positive outlook even when you feel stress. The Caregiving plan provides ideas and guidance for dealing with your feelings as a caregiver, and it should help you find the emotional strength you need to have a positive attitude when dealing with the problems of caregiving.

Develop an orderly and systematic PLAN

Problem-solving is done best in an orderly, systematic way. This means that you should:

Get the facts

Be clear about what is happening, and separate facts from opinions.

Review what you can do

Read this guide as well as other written information about the problem. Ask health professionals for their recommendations, and think back over your own experiences for ideas and strategies that have worked in the past. Ask what you can reasonably hope to achieve.

Decide on the best strategy

Compare the advantages and disadvantages of the different approaches you can take, then develop a strategy with a reasonable chance of achieving your goal.

Consider obstacles

Think of what could interfere with your plan, and think creatively about how you can deal with these obstacles.

Carry out and adjust your plan

Set deadlines for yourself to be sure things get done, and keep records of how the plan is working. This will help you to monitor progress and explain to professional staff both

what you have done and what the results have been. If the plan is not working or is not having as much success as you had hoped, ask yourself if you are expecting change too quickly and whether you should adjust your goals. Then, repeat the problem-solving steps to develop a new plan, paying special attention to maintaining a positive attitude and expecting success.

Get EXPERT INFORMATION about the problem and what you can do

The foundation of good problem-solving is knowledge about the problem and what can be done. This guide contains the information you need to solve many common problems that occur during palliative care. For others, you should collect the same kinds of information that appear in these plans:

- 1. Understanding the problem,**
- 2. When to get professional help,**
- 3. What you can do to help,**
- 4. Possible obstacles, and**
- 5. How to carry out and adjust the plan.**

Research shows that people who use the *COPE* technique are better problem-solvers. Research also shows that people who use this technique experience less stress when dealing with problems.

A Note about Spiritual Problems

During palliative care, and especially as death approaches, both patients with cancer and their caregivers often ponder spiritual problems and questions. Where did I come from? Why am I here? What is really important in my life? What happens after death? Each person must answer these questions within the framework of his or her beliefs, values, and experiences. Therefore, this guide contains no plan for solving spiritual problems. There is, however, a discussion of how to support someone who is pondering these very important issues in the Caregiving chapter.

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Caregiving

Overview

Understanding the Problem

- Caregivers are problem-solvers
- Caregivers work as a team members
- Caregivers work to have a positive attitude
- Caregivers take care of themselves

When To Get Professional Help for Yourself

- If you are experiencing severe anxiety or depression, feeling overwhelmed, or don't know whom to call for help
- If communication between you and the patient with advanced cancer has broken down
- If your relationship with the patient has a history of abuse, addiction, or conflict
- What You Can Do To Be a Supportive Caregiver
- Work and communicate effectively with the patient
- Support the patient's spiritual concerns
- Help to resolve the patient's unfinished business
- Work with health professionals
- Work with family and friends
- Take care of your own needs and feelings

Possible Obstacles

- "He doesn't want to talk about feelings."
- "What if she talks about things that I don't want to hear?"
- "She won't follow my advice."
- "I don't have time to take care of my own needs."
- "If I don't do it, it won't get done."
- "I hate asking other people to help me."
- "The person I'm helping doesn't want anyone else to help."

Carrying Out and Adjusting Your Plan

- Use the strategies in this guide
- Be realistic in your expectations for sharing feelings
- Be realistic in your expectations about yourself
- Ask for help before you feel overwhelmed

Topics with an arrow in front of them are actions you can take or symptoms you can look for.

Understanding the Problem

The information in this guide fits most situations, but yours may be different. If the doctor or nurse tells you to do something other than what is recommended here, follow what they say. If you think that there may be a medical emergency, see [When To Get Professional Help for Yourself](#).

Caregivers are problem-solvers

Caregiving involves solving problems. You have been solving problems throughout your entire life, but many of the problems that come with advanced cancer are new to you and the person you are helping. This guide will help both of you to solve these new problems, giving information and guidance that are organized into specific steps for you to take.

The individual plans in this guide are designed to help you solve problems, but you, the patient, and his or her family and friends will actually solve the problems yourselves. You decide what actions to take. You adjust the plans to meet your special situation. You carry out the plans, and you monitor how well they are working and make changes as they are needed. You also must develop new plans on your own to deal with any problems not mentioned here.

You and the person you are helping are in charge of dealing with your problems. You are not people simply following instructions; you are people making decisions and taking actions.

You are a member of a team

Good palliative care requires a team of people with different skills and perspectives. Nurses, physicians, social workers, and clergy make important and unique contributions to palliative care, but family members, friends, and hospice volunteers also are important contributors. You already have (or will develop) a close, personal relationship with the person who is ill-so you will play a key role when involving this person in his or her own care. Your relationship will help you to understand and interpret the feelings, desires, and needs of the person who is ill. You will be the first to become aware of many physical and emotional problems, the first to deal with those problems, and often the person who will carry out the plans that you and other team members develop.

As a team member, your job is to work cooperatively with other members to solve caregiving problems. To do this, you need to use the COPE problem-solving method.

You need to collect facts, get expert information and guidance about what to do, develop a plan for dealing with the problem, and then carry out that plan while keeping the other team members informed. You need to have an optimistic and a realistic attitude, and as much as possible, you need to keep the patient both informed and involved in what is done.

Work to have a positive attitude

Emphasize the positive parts of caregiving. For example, some successful caregivers see their work as helping someone they love and care for deeply. Others see caregiving in a spiritual way—"I think this is part of God's plan for me." Still others feel that caregiving has enriched their lives, and some see it as a challenge and want to do the best job they can. In addition, some people view caregiving as a way of showing appreciation for the love and care they have received from those who now need their help.

Caregiving can have important benefits. It can give you a sense of satisfaction and confidence, and families who perform caregiving often feel closer to each other and to the person who is ill. You also may discover inner strengths you never realized you had.

You can use the illness to open doors to new friends and relationships as well. This can happen through talking with other people who have faced the same problems, meeting people at a support group, meeting people who have volunteered to help with caregiving, and from family members and old friends who have grown distant but are drawn together again because of the illness.

Take care of yourself

Helping someone with advanced cancer can be difficult and stressful, but the more you take care of your own needs for rest, food, enjoyment, and relaxation, the better you will be able to help.

Your goals

To be an effective team player working not only with the patient but with health professionals, family members, and friends in solving home care problems.

To care for your own needs during the illness so that you will have the emotional strength to be an effective caregiver.

When To Get Professional Help for Yourself

Many people need help with caregiving. Some prefer family and friends for this, but others want hired help from local agencies or private duty services. Even with additional helpers, however, you may find that keeping someone with advanced cancer at home is not the best idea. Ask health professionals, clergy, or other professionals for help if any of the following conditions exist:

⇒ **You are experiencing severe anxiety or depression.**

⇒ **Communication between you and the patient has broken down or become painful and difficult.**

The stresses that come with advanced cancer-physical, psychologic, financial, and emotional-can hamper your ability to communicate with the person you are caring for. If the levels of anxiety and stress have risen to the point where you cannot talk openly about important issues, get professional help from a member of the clergy, a hospice staff member, home health staff member, counselor, or social worker.

⇒ **Your relationship with the patient is affected by a history of abuse, addiction, or conflict.**

Caregivers who have suffered through verbal, mental, physical, or sexual abuse from the person they are caring for, or for whom alcohol or drug addiction has affected their relationship, are likely to have serious problems in caregiving. They already have strong and deep-seated negative feelings, usually built up over many years, and this situation calls for professional help from the start.

⇒ **You feel overwhelmed and unsure if you can manage at home.**

This is a common concern. Ask for help from nurses or social workers at the hospice, clinic, or doctor's office you have visited. They can assist you in getting the help that you need.

⇒ **You don't know who to call for extra help at home.**

Call the hospice, home health agency, or department of social work at the hospital you use, and explain your concerns. They may refer you to a local agency or have a visiting nurse or social worker come out and speak with you.

⇒ **You want to know the pros and cons of moving someone to a nursing home or other setting.**

⇒ **You feel badly yourself, or very “down” and alone.**

What You Can Do To Be a Supportive Caregiver

Here are six steps you can take to be an effective caregiver:

Work and communicate effectively with the patient.

Support the patient's spiritual concerns.

Help to resolve the patient's unfinished business.

Work with health professionals.

Work with family and friends.

Take care of your own needs and feelings.

Working and communicating effectively with the patient

This is your most important and challenging job. The person you are caring for must deal with the physical effects of the disease and medicine as well as the psychologic and social challenges of living with advanced cancer. This may make it difficult for the patient to participate in the home care plan. Nonetheless, your job is to involve as much as possible the person you are caring for in making decisions and carrying out the plan. You should support the person's efforts to deal with the reality of the prognosis emotionally, and this includes efforts to:

⇒ **Help the person to accept that he or she has advanced cancer.**

Some people with advanced cancer deal with upsetting news by pretending that it

simply did not happen. This can be healthy when it helps them to live as normal a life as possible. It can be harmful, however, if they do things that make the illness worse, such as avoiding medicine or engaging in activities that are physically harmful.

Sometimes, what looks like “denial” is the patient’s attempt to protect loved ones from what is really happening. If this is the case, reassure the person that you are willing to listen and talk about all aspects of the illness—even though it may be hard for both of you.

Support the patient’s efforts to live as normal a life as possible, but if he or she is pretending that nothing is wrong, you need to be clear in your own mind about what is really happening. This is when your own objectivity is important in making sure that the patient is benefiting from his or her pretending and not doing things that could be harmful.

⇒ **Create a climate that encourages and supports sharing feelings.**

Talk about important or sensitive topics in a time and place that is calm and conducive to open communication—not in the midst of a crisis or family argument. If your family usually talks around the dinner table, that is the proper time. Think about when you have had important talks in the past, and try to recreate that setting.

Communicate your availability. One of the most important messages you can give to the person you are caring is this: “If you want to discuss this uncomfortable issue, I’m willing to do it.” Leave the timing up to the patient, however. To the greatest extent possible, leave decisions on what feelings to share as well as when, how, and with whom to share them up to the patient. By not pressing the issue, you allow the person with advanced cancer to retain control over part of his or her life at a time when many issues and decisions no longer are.

⇒ **Understand that men and women often communicate in different ways, and make allowance for those differences.**

Although there are many exceptions, women often express their feelings more openly than men in our society. If you are a male caregiver and the person you are caring for is a woman, be aware that when she shares her feelings, you may find yourself giving advice when she wants support and understanding instead. If you

are a female caregiver and the person you are caring for is male, be aware that he may express his feelings differently than you would, and pay special attention when he talks about things that are important to him.

⇒ **Be realistic and flexible about what you hope to agree on or communicate.**

People with advanced cancer want to share many things, but they may not share them all with just one person. Let the patient talk about whatever he or she wants with whomever he or she wants. If the patient isn't telling you everything, this is fine as long as he or she is telling somebody the rest. Also, remember that a person may have spent a lifetime developing a particular style of communication, and this will not change overnight. Some people, both men and women, have never talked about their feelings. Try to accept that this pattern most likely will not change even now.

Sharing does not always mean talking, either. The person with advanced cancer may feel more comfortable writing about feelings or expressing them through an activity. He or she may express feelings in other nonverbal ways as well, such as through gestures or expressions, touching, or just asking that you be present.

⇒ **Help the patient to deal with anxiety and depression.**

People with advanced cancer may become anxious because of worries about medical procedures, their cancer, or the future. Their anxiety also may be a side effect of medicine they are taking or even of the cancer itself.

Many people feel depressed at some time during their illness. Seek advice on how to control depressed thoughts and feelings, especially when they are just beginning.

When you and the patient disagree on important issues:

Remember that you and the person you are caring for do not always have to agree. You may disagree on issues such as when, how, and what to share, but remember that this is one of the patterns of life and cannot always be resolved. Then this is the case, the following suggestions may prove useful:

⇒ **Explain your needs openly.**

Sometimes, you may need to ask the patient to do something that will make your own life easier or your caregiving responsibilities more manageable; for example, you will want to know when any pain begins rather than when it becomes very severe. These situations can create conflict, and you should understand that conflict resolution does not always mean that everybody is happy. On some issues, you will have to give in. On others, you will have to ask the person you are caring for to give.

Suggest a trial run or time limit.

If you want the person you are caring for to try something, such as a new bed or a certain medication schedule, and he or she is resisting, ask the person to try it for a limited time, such as a week, and then evaluate the situation. This avoids making the patient feel locked into a decision. If the person resists writing a will or power of attorney, ask if he or she will at least read one over and discuss it.

⇒ **Choose your battles carefully.**

Ask yourself what is really important. Are you being stubborn on an issue because you need to win an argument or be in control? You can save both time and energy by skipping the minor conflicts and using your influence on issues that really count.

⇒ **Let the patient make as many of his or her decisions as possible.**

A good example of letting a patient make his or her own decisions is when adult children living some distance away from the person with cancer want to move him or her into a nursing home. Although moving to a nursing home may make the adult children feel better, it may not be what the person with cancer wants. If the patient understands the consequences, such as that no one may be around to help if he or she falls, then the caregiver should accept the patient's right to make that decision. Taking away someone's ability to make decisions can undermine his or her feelings of control, which in turn interferes with the person's ability to deal with other aspects of this stressful illness.

Support the patient's spiritual concerns

Spiritual concerns raise fundamental questions about life. Why are we here? What is a good life? What happens after death? These profound questions become

especially important as life nears its end. As a caregiver, you can support the patient in thinking about his or her own answers to these questions.

Spiritual questions are not answered easily, of course. For those people whose faith gives answers and comfort, your support of that faith will be both helpful and appreciated. For those who are troubled by uncertainty, you can help by sharing your own questions and uncertainties—showing that their concerns are normal and reasonable. If you can admit to the possibility, it may be helpful to say that not all spiritual questions can be answered. It also may be useful to ask about beliefs that were helpful to the patient before this illness and if they can be helpful again now.

Professionals such as clergy or counselors who have experience helping people with spiritual problems near the end of life can be very comforting to the person you are caring for—*provided that he or she wants their help*. Spiritual questions are very personal; therefore, the person with these concerns is the one who knows best who can help. Bringing in someone who is not wanted can backfire and *cause* rather than resolve problems. Let the person you are caring for know that you will be happy to arrange visits by clergy or others who could help—but that this decision is entirely up to him or her. Do not expect all clergy to be equally skilled in working with people during the last stage of life, however. If one is not helpful, keep looking until you find one who is. Hospice or palliative care staff can help you locate someone with the necessary skills, and hospital chaplains usually are experienced in working with people near the end of their lives and may be able to help.

If the patient is seriously depressed because of spiritual concerns, seek help from a mental health professional or clergy with training in mental health care. Also, be available to listen. Speaking with another person who is understanding helps to put one's thoughts in perspective and also to see that others appreciate and understand them. The person with advanced cancer may want to make sense of life his or her experiences—to reminisce, talk about the past, and look for meaning in what has happened. *As a caregiver, listening is the most important thing you can do to help*. Let the person you are caring for know about your willingness and availability for these discussions when and if he or she wants them. If you find it very difficult to listen to the patient's concerns, then find someone, such as a member of the clergy, family member, or friend, who can.

For people whose religion is very important and gives meaning to both their lives

and their dying, you can help by asking questions that allow them to tell you, if they wish, what about their faith has helped them through life and is helping them now. You must be careful to accept and respect views that are different from your own, however. Let them tell you if there are ways you can encourage and support them in their faith. Would they like to listen to a tape of hymns or other religious music? Is there a religious symbol that would bring them comfort? Would they like to share with clergy from their faith one of their traditions, such as a bedside prayer service?

Share your views and feelings when you are asked or think that he or she would like to ask. Hearing another person's thoughts and feelings can be helpful to someone who is troubled by spiritual problems, but always let the person you are caring for be your guide-never impose. Sometimes, reading together from spiritual writings can be comforting and may help to resolve unanswered or unresolved questions. These readings also can provide an opportunity to share how you feel about these issues as well.

You may be worried yourself about spiritual questions. Watching and helping someone who is dying sometimes can bring up very difficult issues. These may be about the unfairness of the situation, fear about what will happen to the person you are caring for after his or her death, fears about your own death, and general confusion and anxiety about what life is about. Talking with clergy, counselors, hospice staff, or health professionals who work with the family and friends of dying people can be very helpful. They have experience helping those like yourself. They will listen and help you to think through these issues. You may find it easier to talk to some people more than others, and you also may find that some are more helpful than others. If the first people you talk to cannot help you, keep looking until you find the person who can.

Help to resolve the patient's unfinished business

People near the end of their life commonly to want to take certain actions or have certain experiences before they die. Sometimes, it is to do or see something important or pleasant again, such as being with friends or visiting an especially meaningful place. Sometimes, it is to say things to someone that have been unsaid in the past or to resolve some old misunderstanding or conflict. Arranging for these experiences can be substantial undertakings, involving contacting other people and organizing long-distance travel.

Do not expect that the experiences you arrange will always be successful. Even with the best of intentions, things may not happen as you or the person you are caring for would like. The weather may be less than ideal for the trip. The people you work hard to bring together may not say helpful things once they arrive. When it is over, both of you may be disappointed. The fact that you tried, however, can be very important-and this may make all of the effort worthwhile.

Before committing to such a major undertaking, ask yourself how you and the person being cared for would feel if the experience is less than you hope. Would it still be worth the time and resources? If your answer is no, ask what you could do that would be less costly or stressful. If your answer is yes, then move ahead (with realistic expectations).

Working with health professionals

Here are some practical suggestions to keep in mind when you need information and help from health professionals:

⇒ **Be clear about what you want, and get to the point as soon as possible.**

Make lists of questions and concerns, and have them in front of you when you talk with health professionals.

⇒ **Have all the information that health professionals may need ready when you call.**

Many of the individual plans in this guide have lists of information you should have when you call for professional help. Try to think ahead about what information medical staff may need, and try to have it ready when you call.

⇒ **Write down the answers.**

This will ensure that you have the information correct and do not forget it. Have paper and a pencil ready when you call. It is good to keep your questions and answers together in a file or drawer where you can easily find and review them.

⇒ **Be firm and straightforward about getting the information and the help that you need.**

Health professionals are there to help you be a good caregiver, so make your requests with confidence that you will get the help you need. Feel free to tell them when you do not understand. Remain calm, and speak in a pleasant, polite voice. Being angry usually is not helpful. Being pleasant, firm, persistent, and showing your appreciation usually are the best strategies.

Working with family and friends

⇒ **Do not try to do everything yourself. Ask for help.**

Family members, friends, clergy, and people who belong to community organizations all can help you. Some can help with planning, and others can help with carrying out those plans and giving support.

People who live in the same household or are going to be very involved in carrying out a plan should help in developing it, and they should read and understand this guide. Then, they will be able to work with you and the patient as a team. If they have had a hand in its development, they will be more committed to carrying out the plan.

Others may want to help but need to be told how. It is important to be clear with these people about what you would like them to do as well as the limits of what is expected of them.

Taking care of your own needs and feelings

You need to be at your best if you are to provide the best care. Therefore, pay attention to your own needs as well as those of the person you are helping. Set limits on what you can reasonably expect yourself to do. Take time off to care for yourself, and ask for help before stress builds.

It is natural to have strong feelings when you are helping someone with a serious illness. Some common feelings that caregivers have as well as strategies for dealing with them if they become severe are:

Feeling overwhelmed

Caregivers as well as the person being cared for can feel overwhelmed and confused when they learn that the disease is not responding to treatment or is progressing. Here are

some ways to deal with feeling overwhelmed:

⇒ **Try not to make important decisions while you are upset.**

Sometimes, you must make decisions immediately, but you often do not have to. Ask the doctor, nurse, or social worker how long before a decision needs to be made.

⇒ **Take time to sort things out.**

⇒ **Talk over important problems with others who are feeling more level-headed and rational.**

If you are feeling very upset or discouraged, ask a friend, neighbor, or family member to help. They can bring a calmer perspective to the situation as well as new ideas, and they can help you in dealing with the problems that you face.

Anger

There are plenty of reasons for you to become angry while caring for a person with advanced cancer. For example, the person you are caring for may be demanding or irritating at times. Friends, family members, or professionals may not be as helpful or understanding as you would like. Some people grow angry because they feel their religion has let them down. It is natural to be angry when your life has been turned inside out, which often happens with a serious illness like cancer.

These feelings are *normal*. What is important is what you do *with* them, not that you feel them in the first place. The best way to deal with angry feelings is to recognize them, accept them, and find some way to express them appropriately. If you do not deal with your anger, it can get in the way of almost everything you do.

Here are some ways to deal with your anger:

⇒ **Try to see the situation from the other person's point of view, and understand why he or she acted that way.**

Recognize that other people are under stress as well, and that some people deal with stressful situations better than others.

⇒ **Express your anger in an appropriate way before it becomes too severe.**

If you wait until your anger is severe, it will impair your judgment, and you are likely to make other people angry in return.

⇒ **Get away from the situation for awhile.**

Try to cool off before you go back and deal with what made you angry.

⇒ **Find safe ways to express your anger.**

This can include beating on a pillow, yelling out loud in a car or closed room, or doing some hard and vigorous exercise. Sometimes, it helps to vent anger with someone who is “safe”- someone who will not be offended or strike back, like a friend or member of the clergy.

⇒ **Talk to someone about why you feel angry.**

Explaining to another person why you feel angry often helps you to understand why you reacted as you did, allowing you to see your reactions in perspective.

Fear

You may become afraid when someone you care for deeply has a serious illness. You do not know what is in store for this person or for yourself, and you may fear that you will not be able to handle what happens.

Here are some ways to deal with your fears:

⇒ **Learn as much as possible about what is happening and what may happen in the future.**

Knowledge can help to reduce fear of the unknown, and it can help you to be realistic so that you can prepare for the future. Talk with health professionals and other people who have cared for someone with cancer to see if you are exaggerating the risks.

⇒ **Talk with someone about your fears.**

It often helps to explain to an understanding person why you feel afraid. This allows you to think through the reasons for your feelings. Also, talking with an understanding person will show you that other people realize and appreciate how you feel.

Loss and sorrow

A serious, life-threatening illness can bring on a great sense of loss and sorrow. You may feel sad that plans you had for the future might not be fulfilled. You may feel the loss of the “normal” person and the “normal” things you did together before the illness. Memories of how he or she used to be may make you sad, and you may feel burdened by more responsibilities that you must handle alone.

Here is a way to deal with feelings of loss and sorrow:

⇒ **Talk about your feelings of loss with other people who have had similar experiences.**

People who have been caregivers for persons with a serious illness usually will understand how you feel. Support groups are one way to find people with similar experiences.

Guilt

Many people who care for someone with advanced cancer feel guilt at some time during the illness. They may believe they did something to cause the cancer or that they should have recognized the disease sooner. They may feel guilt about not doing a better job of caring for the person with cancer or because they are angry or upset with him or her. They also may feel guilt because they are well and a person they care for deeply is sick. Some people even feel guilt almost out of habit, having learned from childhood to feel that way whenever something goes wrong.

Although feelings of guilt are understandable, they can interfere with doing the best possible job of caregiving. Guilt makes you think only about what *you* did wrong. Most problems have many causes, and what you did most likely is only part of the reason (assuming it even has anything to do with the problem at all). To solve a problem, you

must look objectively at *all* of the causes and then develop a plan to deal with the entire situation. For example, if you feel anger toward the person you are caring for, this is partly because of what he or she did as well as what you did. To deal with the cause of that anger, you need to talk openly with the person you are caring for about what *both* of you did-not just feel guilt about what you did or feeling angry.

Your goal here is to work toward forgiveness, both for yourself and for the other person. Dwelling on feelings of guilt about the past will rob you of the precious energy you need to cope with the present.

Here are some ways to deal with feelings of guilt:

⇒ **Do not expect yourself to be perfect.**

Remember that you are human and will make mistakes from time to time.

⇒ **Do not dwell on mistakes.**

Accept your mistakes, and get beyond them as best you can. Repetitive, negative thoughts such as guilt can be controlled by pushing them aside with positive, constructive thoughts.

Possible Obstacles

Think about what could prevent you from carrying out your plan for being an effective caregiver.

Here are some obstacles that other caregivers have faced:

1. “He doesn’t want to talk about feelings.

Response: He is the best judge of that. Your job is to make sure that opportunities to listen are there when and if he decides to talk about his feelings.

2. “What if she talks about things that I don’t want to hear?”

Response: Even if what are hearing hurts you, consider it in the larger picture of what it means for the patient to be able to express it. Remember that you do not have to resolve everything. You are helping even if you only listen.

3. “She won’t follow my advice.”

Response: If you are feel frustrated because the person you are caring for will not follow your advice, try to understand how important it is for the patient to retain some control over her life. You may know what is best for her, but realize that your job is to support, not to make decisions for her. If you have a dominant personality or usually have been the one to make decisions in your family, be prepared to practice letting go.

4. “I don’t have time to take care of my own needs.”

Response: This is the most common reason that caregivers become exhausted. They become preoccupied with problems and do not pay attention to themselves. You will be a better caregiver in the long run if you take the time (especially when stress is high) to get help so that you can do things that you enjoy and relax you.

5. “If I don’t do it, it won’t get done.”

Response: Yes, it will. No one is indispensable. You also should sort out things that really need to be done versus those you would like to see done. It is perfectly acceptable to let some things, such as housework, slide a bit when you take on new responsibilities.

6. “I hate asking other people to help me.”

Response: There are two ways around this problem. First, you can get together socially with people who could help and let them volunteer. Second, you could have someone else ask for help for you. Try to make the times when others visit both pleasant and rewarding, then they will want to visit and help.

7. “The person I’m helping doesn’t want anyone else to help.”

Response: Suggest trying to get help for just a short time, after which you can talk over how it worked. Also, explain to the person you are caring for that *you* need the help, not him or her.

Think of other obstacles that could interfere with carrying out your plan

What additional roadblocks could get in the way of your being a successful caregiver? For example, will the person with advanced cancer cooperate? Will other people help? How will you explain your needs to other people? Do you have the time and energy to carry out these responsibilities?

You need to develop plans for getting around these road blocks. The four COPE ideas (creativity, optimism, planning, and expert information) can help, and see Solving Problems Using This Guide for a discussion of using them in overcoming your obstacles.

Carrying Out and Adjusting Your Plan

Carrying out your plan

Start using the ideas in this guide immediately. Do not wait until you feel overwhelmed. It is easier to develop good caregiving habits and attitudes early, before problems get out of hand.

Checking on results

Every week or so, take the time to think about how you are doing as a caregiver. Look through this plan, and ask yourself how closely you are matching the “successful caregiver” that is described.

If your plan does not work

Be realistic about what you expect from yourself. Do not expect to be perfect. Everyone makes mistakes, and learning to be a caregiver for someone with cancer takes time. If there are some parts of caregiving that are especially difficult for you, ask others for help.

Be realistic in your expectations about feelings being shared. Most people do not change their styles of communicating quickly.

If you cannot do the things that are essential for the person you are helping, talk with the doctor, nurse, or social worker about getting the help that you need.

If you become so upset that it interferes with your ability to do what needs to be done, or you are experiencing severe depression or anxiety, talk with the doctor, nurse, or social worker about getting help.

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*The American College of Physicians Home Care Guide for Advanced Cancer:
When quality of life is the primary goal of care.*

Cancer Pain

Overview

Understanding the Problem

The person with advanced cancer has a right to good pain control
Pain control takes time to achieve, so persistence is vital
Only the person with pain knows what the pain is like
Never assume that pain means the cancer is spreading
How doctors use the “pain ladder” to control pain

When To Get Professional Help

Symptoms that indicate an emergency
Information to have ready when you call for help
What to say when you call

When To Get Immediate Professional Help for the Side Effects of Pain Medicine

When to get immediate help
Symptoms that should be reported but do not indicate an emergency
Information to have ready when you call for help

What You Can Do To Help

Make the best use of pain medicine
Understand the medication plan
Prevent and control pain through methods other than medication

Possible Obstacles

“I’m afraid of addiction.”
“I want to ‘save’ the medicine until the pain is severe.”
“No one wants to hear about my pain.”
“Only people who are dying take morphine.”
“If I give him his medicine and he dies, would it be the drug that killed him?”

Carrying Out and Adjusting Your Plan

Keep track of pain levels
The patient must understand that you fully accept his or her pain ratings
Do not accept anything less than the best pain control
If necessary, ask for a referral to a cancer pain specialist

Topics with an arrow in front of them are actions you can take or symptoms you can look for.

The information in this home care guide fits most situations, but yours may be different. If the doctor or nurse tells you to do something other than what is recommended here, follow what they say. If you think there may be an emergency, see When To Get Professional Help.

Understanding the Problem

Every person with advanced cancer has the right to good control of their pain. As a home caregiver, your job is to make sure that happens.

It takes time to get good pain control, so be patient. Do not give up until adequate control has been achieved.

When many people think of cancer, they think of pain. Today, however, most cancer pain can be controlled or even eliminated. For example, even with advanced cancer, pain can be controlled in 90% to 99% of cases. In nine out of 10 cases, physicians can control pain by using pills alone; they do not have to use injections, operations, or other methods. In those few situations in which pain from cancer cannot be eliminated completely, it can be reduced so that the person with advanced cancer can live with it day to day and still accomplish activities that are important to him or her.

People with advanced cancer and their home caregivers must tell the doctors and nurses how pain gets in the way of their everyday activities, such as moving around or dressing. This information is useful to the doctors in evaluating the pain and developing an effective treatment.

It also is important that everyone be open and supportive. Family and friends should make clear that they believe the patient. *Those with pain are the only ones who really know how much pain they are feeling. No one else can do a better job.* If people in pain feel that others do not believe them, they become upset and may even stop reporting their pain accurately, which only makes controlling the pain more difficult.

Because the level of pain medicines takes time to build in the bloodstream, it also usually takes time to get the pain under control. The doctor may need to try different medicines or amounts to see which ones work best. The things you can do on your own to control pain take time to learn as well, but do not give up just because complete control does not happen immediately. Remember, most cancer pain can be controlled.

When the people with pain feel something new, many think it is a sign that the cancer is growing. The pain might not be from the cancer at all, however. For example, treatments can change tissues, either shrinking and swelling them, and this can cause pain. Weight loss or gain also changes tissues and muscles, which again can cause pain. Many things in addition to growth of the cancer itself can produce these new aches and discomforts.

How doctors control cancer pain

Physicians who treat cancer pain use the Three-Step Analgesic Ladder for Cancer Pain Management, which was developed by the World Health Organization and is shown below.

Doctors usually begin treatment as low as possible on the ladder, working their way up gradually until control of the pain has been achieved.

STEP 1: Pain - adjuvant	Non-opioid +/- adjuvant
STEP 2: Pain persisting or increasing adjuvant	Weak opioid +/- non-opioid +/-
STEP 3: Pain persisting or increasing adjuvant	Strong Opioid +/- non-opioid +/-
STEP 4: Freedom from cancer pain	

Step 1 for Mild Pain: Non-narcotic pain medicines

These drugs also are called:

1. *Analgesics*: Examples are acetaminophen or Tylenol.
2. *Nonsteroidal anti-inflammatory drugs*: Examples are aspirin and ibuprofen (Motrin or Advil).
3. *Adjuvants*: These medicines treat specific pain and ease other types of symptoms. Examples are antidepressants such as Elavil, anticonvulsants such as Tegretol or Dilantin, anti-nausea medicines, and anti-anxiety medicines such as Xanax, Valium, Ativan, and Atarax or Vistaril.

Step 2 for Moderate Pain: Weak narcotics with other pain medicines

If Step 1 drugs do not work or the pain is rated as moderate, the next rung is used. Weak narcotics are stronger pain relievers and often are prescribed with other medicines such as those listed in Step 1. Examples of weak narcotics are Codeine, Darvon or Darvocet, Empracet, and Wygesic. Darvon, Darvocet, and Wygesic can cause side effects after long use, however, so these generally are not used for long periods. Stronger medicines in this category include Tylox, Percocet, and Percodan.

Step 3 for Severe Pain: Strong narcotics with other pain medicines

The last rung on the ladder describes what category of medicines should be used to control severe pain. A strong narcotic can be either short-acting or long-acting. Morphine, Dilaudid, and Numorphan are examples of strong narcotics that carry an effect lasting from 3 to 4 hours. Methadone also is a strong narcotic, giving 4 to 6 hours of relief. These medicines are available in 12-hour time-release pills as well.

Your goals

Call for professional help during the following emergencies: 1) severe pain, and 2) reactions to pain medicine.

Call for professional help for non-emergencies.

Make the best use of pain medicine.

Understand the medication plan.

Ask about changing prescriptions when needed.

Manage the more common side effects of pain medicine.

Prevent and control pain through methods other than medication.

When To Get Professional Help

Emergency symptoms

Call the doctor or nurse if any of the following conditions exist:

⇒ **Actions to relieve “breakthrough pain” are not working, and pain continues to be a problem between doses of long-acting medicines (6 to 12 hours of relief expected).**

Breakthrough pain is pain that “breaks through” the relief achieved by regularly scheduled, around-the-clock medicines. This type of pain occurs in between the scheduled times for medicine to be taken.

⇒ **Inability to get up or walk because of pain.**

A tumor can press on a nerve and cause severe pain, especially when the person moves. Swelling or inflammation around a tumor also can push on tender tissues and nerves. In these cases, people with cancer will feel severe pain, usually complain, and be unable to get up when lying down or to walk without help.

⇒ **Inability to sleep because of pain.**

Not sleeping well because of discomfort, aches, and pains is a sure sign that something should be done to increase the patient’s comfort.

⇒ **Crying and getting upset about feeling pain.**

Look for physical responses to pain: tears, closed eyes, knitted eyebrows, wrinkled forehead, grimaced face, clenched fists, or a stiffened trunk (chest and back) that is held rigidly and moved slowly. When these occur or the patient complains of severe pain, call the doctor or nurse for help immediately.

⇒ **Unwillingness to move, or muscles that are very tense when moving.**

Even if the patient does not complain and tries to act as if nothing is wrong, watch how easily he or she moves. People in pain move with great difficulty, try not to move, and do not do normal, everyday things like getting dressed or out of bed.

⇒ **A bone sticks out in an unusual way.**

Bones can break or fracture more easily as a person ages, and bone cancer also increases the risk of a fracture. If a bone sticks out in a new way, report this even if pain does not immediately follow the event.

Have the answers to the following questions ready when you call the doctor or nurse:

1. How long has the pain been a problem?
2. Where is the pain located? Is it in more than one area?
3. How severe is the pain? Ask the patient to use a number from 0 to 10 to describe or rate the pain, where 0 = none, 5 = moderate, and 10 = worst ever.
4. Is the pain sharp and stabbing or dull and aching?
5. Does the pain burn or feel like an electric shock?
6. Is there any numbness or tingling?
7. How much has the pain interfered with normal activities?
8. Describe any current prescriptions for pain, including:
 - Name of medicine(s)
 - How much time should go by between doses
 - How many pills can be taken at one time
 - How many doses were taken in the last 2 days
 - How long does the medicine take to work

How much relief is achieved

How long does the relief lasts

Is the patient still able to swallow pills

9. What other medicines have been taken, or what else has been done to relieve the pain? What were the results?

Here is an example of what you might say when calling for professional help:

“I’m Mary Smith, the wife of John Smith. My husband sees Dr. Harvey. This morning my husband refused to get out of bed because his leg hurt so badly up at the hip, and it hurts even if he tries to move just a little in bed. He said his pain is an 8 on a scale of 1 to 10 and is sharp. At 6 a.m. he took two Percocets but didn’t feel any better. The next time for his medicine isn’t until noon. We tried a heating pad, but it didn’t help.”

When to Get Immediate Professional Help for the Side Effects of Pain Medicine

A drug reaction or narcotic overdose is a different type of emergency related to pain control. If the person with advanced cancer is allergic to a pain medicines or that medicine is too strong, professional help is needed.

Most of the symptoms on the following “call now” list indicate that a drug reaction is causing a problem with the central nervous system, gastrointestinal tract, urinary tract, or skin, and that the body’s normal functioning is being severely impaired. The medicine is too strong, or there is an uncommon allergic reaction.

Side effects like those on this list demand immediate action. When you call and report these symptoms, the doctor or nurse most likely will want to see the patient right away, or they will send help to you. After evaluating what is happening, they can give additional medicines to clear any drugs from the body. They also can prescribe other ways to calm the central nervous system and reverse an allergic reaction.

Problems with drug reactions are not very common. When they do happen, however, it is important to get help right away. *Call the doctor or nurse immediately if any of the following symptoms occur:*

- ⇒ **Disturbing hallucinations (hearing or seeing things that are not there).**
- ⇒ **ringing or buzzing in the ears.**
- ⇒ **Sudden confusion or being “out of it.”**
- ⇒ **Severe trembling, uncontrolled muscle movements, or convulsions (seizures).**

- ⇒ **Numbness or tingling in the feet or lower legs.**
- ⇒ **Unable to hold in urine or stool when this was not a problem in the past.**
- ⇒ **Unable to urinate despite feeling the need.**
- ⇒ **Unable to have a bowel movement for 2 or 3 days.**
- ⇒ **Nausea or vomiting with no relief.**
- ⇒ **Hives, itching, skin rash, or swelling of the face.**

Have the answers to the following questions ready when you call the doctor or nurse:

1. What pain medicine was taken over the last few days?
2. How much of the medicine was taken?
3. How often was this medicine taken?

Symptoms that should be reported but do not indicate an emergency:

Call the doctor or nurse if any of the following conditions exist:

- ⇒ **No relief after taking pain medicine three times as prescribed.**

Call and discuss the problem and continuing pain with the doctor or nurse.

- ⇒ **Some pain relief is achieved, but significant pain remains 1 or 2 days after starting the medicine or changing either the way it is taken or the amount.**

The physician or nurse needs to re-evaluate the amount or type of pain medicine being prescribed.

- ⇒ **A new type of pain, pain in new locations, or new pain when moving or sitting.**

Report any pain occurring in new locations. New pain may need to be evaluated before the next regularly scheduled visit.

- ⇒ **Numbness, tingling, or burning sensations that are new.**

These can signal an early problem with the nervous system or the amount of medicine being taken. Report them immediately so that the doctor or nurse can locate the cause and make any necessary changes in the treatment plan. These types of pain may need to be

treated with medicines other than the drugs and analgesics that are commonly prescribed. Reporting these sensations can help the doctor or nurse to understand that these pains differ from those reported in the past. When a tumor invades the nerves, there might be a feeling of numbness, tingling, burning, or of a short electrical shock. Low doses of antidepressants can help to relieve these problems, help the patient to sleep, and even readjust chemicals in the spinal cord, all of which result in better control of pain.

⇒ **Medicines for breakthrough pain are used more than three times a day in addition to the regular pain medicines.**

Report whether taking the patient's regularly scheduled doses, such as every 4 hours, does not hold back the pain. The doctor may change the medicine schedule or prescribe extra doses to be given "as needed" when breakthrough pain occurs.

⇒ **Tremors or involuntary jerking motions while awake or asleep.**

These motions can indicate a need for the doctor to adjust the pain medicine.

⇒ **More pain occurs with movement, such as being lifted or turned in bed.**

"Incident" or "event" pain comes either during or after a particular movement, such as getting out of bed, or during a treatment, such as a dressing change. It can be relieved by taking small amounts of the regularly scheduled drug. For example, hospice staff may advise you to offer morphine liquid every 2 hours as needed *20 minutes or more before the incident or event*. This way, the medication is already at work before any movements that will bring on pain are made.

What You Can Do To Help

Here are five ways to help relieve pain resulting from cancer:

Make the best use of pain medicine.

Understand the medication plan.

Ask about changing prescriptions, times, and doses.

Manage the more common side effects of pain medicine.

Prevent and control pain through methods other than medication.

Make the best use of pain medicine

If the pain is not an emergency but the patient needs medicine on a regular basis, be sure you are

using the medicine correctly and preventing pain before it becomes severe.

⇒ **Give the pain medicine at regular times, as prescribed by the doctor.**

When pain occurs regularly and not just once or twice a day, give the pain medicine on a consistent schedule. This will keep enough medicine in the bloodstream to control the pain.

Also, encourage the patient not to wait too long to taking the medicine. For example, suppose the pain medicine is prescribed “every 4 to 6 hours as needed.” You can give pain medicine anytime after 4 hours. Do not wait longer than 6, however, because the pain then may become so bad that the prescribed amount will not give full relief.

⇒ **Give the medicine before pain becomes severe.**

When pain occurs regularly and not just once or twice a day, control is more difficult. It also takes longer to achieve if pain is allowed to build to a severe level. People need to take pain medicine to avoid a “pain crisis” just like diabetics need to take insulin to avoid a “sugar crisis.”

Taking the medicine with the same amount of hours between doses prevents peaks and valleys and keeps a steady supply of medicine in the body. You may even find that you can decrease the amount of medicine given, because the person with pain is more confident that the pain can be controlled.

⇒ **Continue to give pain medicine during the night.**

Try not to go longer than 4 hours without giving medicine during the night, unless the person is taking a medicine like MS Contin (a time-release capsule), which is prescribed to be given every 12 hours, or a drug like Duragesic or Fentanyl, which lasts up to 72 hours. Too much time between shorter-acting pills means that the amount of medicine in the body keeps dropping and the level of pain keeps increasing. In this event, the patient will need *more* of the medicine to return to the right amount of pain control because he or she waited too long before taking the next dose.

Giving a pill on a regular schedule, even in the middle of the night, will help to prevent breakthrough pain. By adhering strictly to the medication schedule, you are not waiting too long for the next recommended dose.

Sometimes, a “night dose” method is ordered. This means that a larger dose of medicine is given at bedtime to help the patient sleep, but you will still have to give regular doses throughout the night.

⇒ **Do not suddenly stop the pain medicine if it has been taken for a number of weeks.**

If pain medicine is stopped suddenly, the body almost experiences a “shock.” It expects a steadier flow of these medicines into the bloodstream, and withdrawal symptoms can occur in the same way as if one suddenly stopped smoking cigarettes or drinking coffee. Increasing the length of time between doses and taking lower doses allow the body to be weaned off the medicines in a gentle manner. The discomfort of withdrawal, such as shakiness or headache, is less likely to occur or be a problem if the medicine is stopped slowly, over several days, and under the direction of a physician.

⇒ **Expect that giving pain medicine correctly also will help to relieve other problems that can increase pain, such as muscle tension, lack of sleep, and emotional distress.**

Because the patient no longer is battling pain, use of pain medicine restores comfort, helps the patient to rest, and reduces some anxieties. It also helps to relieve other problems that can increase pain, such as muscle tension, lack of sleep, and emotional distress.

⇒ **As the doctor or nurse what to do in the following situations:**

1. If the medicine wears off and pain returns (or if pain does not diminish even when the medicine is taken as prescribed) but it is *too early* for the next does to be taken.
2. If pain causes the patient to wake up at night.
3. If a dose of medicine is accidentally skipped.

⇒ **Find out whether the prescribed medicine can be crushed by a pharmacist or mixed in a liquid to make it easier for the patient to swallow.**

Some medicine, such as MS Contin, should not be crushed, because then all of the medicine will be absorbed at one time. This could be dangerous when the medicine is to be delivered in a time-release fashion. If the patient is having trouble swallowing, the hospice staff will show you other ways to give it.

Understand the medication plan

Understanding how and when the doctor and nurse want you to give pain medicine is the key to successful control and prevention. There are three basic plans that can be followed, and you should ask which the person you are caring for is on:

Plan 1: Take medicine as needed

⇒ **Know when to give a medicine that is prescribed as “give as needed” (or “give prn”).**

Pain medicines can be ordered “as needed.” For example, the bottle may be labeled “take every 3 to 4 hours as needed” or “take every 6 hours as needed.” This means that people with advanced cancer can decide when to take the medicine, but that they should not take it more frequently than the lowest number of hours listed on the instructions. If they need the medicine before this shortest time, discuss the problem with the doctor or nurse. Maybe the dose is not high enough, or maybe the medicine needs to be combined with another, such as Tylenol or aspirin, to prevent the pain.

For example, if the prescription is “take every 3 to 4 hours as needed,” people with pain can take the medicine every 3 hours and do so consistently, especially if the pain starts to come back 3 hours after the last dose. Writing down the times at which the person takes the pain medicine helps the doctor or nurse to understand what is happening. They can then see that the medicine is being taken every 3 hours—morning, afternoon, evening, and night—and that the patient is not waiting 4 hours for the next dose. This information is important.

Taking medicine “as needed” also means that the person can take a dose and then wait for the next until the first inkling of pain begins again or they begin an activity that stimulates pain. For example, some people learn exactly what brings on their pain, such as bending or turning for a bath. Taking pain medicine before these activities and 3 hours afterward prevents the pain that could follow these activities.

If pain begins to return after 3, 4, 5, or 6 hours and the medicine is ordered “take as needed,” the patient should try taking it with the same number of hours between pills for at least a 2-day period. For example, if the pain returns in 4 hours, he or she should take the pills every 4 hours and not “tough it out” by waiting until 6 or 8 hours have passed.

Plan 2: Take medicine with an equal number of hours between doses

⇒ **Know when to give a medicine ordered for a certain number of times per day.**

If medicine is ordered for a certain number of times per day (and not for a certain number of hours), start with the time that the patient wakes up and divide the 24-hour day into equal spaces. For example, if medicine is ordered as “take twice a day” and the person usually wakes at 9:00 a.m., give a dose at 9:00 a.m. and again at 9:00 p.m. The times do not need to be exactly right, but you should try to divide the day into even sections.

If the dose is ordered as “take 4 times a day” and the person wakes at 9:00 a.m., then make sure that a dose is taken at 9:00 a.m., 3:00 p.m., 9:00 p.m., and 3:00 a.m. (or

sometime in the middle of the night).

If the dose is ordered as “take 6 times a day” and the person wakes at 9:00 a.m., then make sure that a dose is taken at 9:00 a.m., 1:00 p.m., 5:00 p.m., 9:00 p.m., and during the night at about 1:00 a.m. and 5:00 a.m.

Plan 3: Take extra medicine when pain breaks through before the next dose is due

⇒ Treat breakthrough pain to prevent its return.

Usually, there is a prescription for just when this happens, or the doctor may advise the patient to take an analgesic medicine if pain returns before it is time to take the strongest pain medicine.

If breakthrough pain is occurring for the first time, make sure that the person is taking the pain medicine as frequently as ordered. Sometimes, taking the medicine more consistently (the same number of hours between doses) and more frequently (for example, if ordered every 4 to 6 hours, then take every 4 hours) will prevent breakthrough pain.

⇒ Treat incident pain to help with moving or treatments that cause pain.

Medicine for incident pain can be prescribed and taken only as needed between the normally scheduled doses. This dose usually is very small. For example, 2 mg of morphine sulfate can be offered every 2 hours while a patient goes back and forth between home and clinic appointments.

Ask about changing prescriptions, times, and doses

If the patient is taking the medicine as prescribed but still feels significant pain or is bothered by side effects from the current medication, ask the doctor about other medicines or ways of taking them that might be more helpful.

⇒ Ask about increasing the amount of medicine.

Sometimes, there is just too little medicine in the body to prevent pain. If so, the doctor may increase the dosage by small amounts until the right one is discovered.

⇒ Ask about shortening the time between doses.

Perhaps the right amount of medicine is not in the bloodstream because the medication is not being taken often enough. If so, the doctor may shorten the time between doses to increase the level of medicine in the body. Talk to the doctor before shortening the time between doses, however, and be sure to say when the medicine was taken and after how

many hours the pain returned.

⇒ **Ask about taking short-acting or immediate-release narcotics in between long-acting (time-release) narcotic orders (such as taking immediate-release morphine for breakthrough pain).**

Breakthrough pain can occur even when someone is taking a time-release narcotic. Doctors and nurses who know the latest information on pain control also know that faster-acting narcotics can be ordered to stop such pain; however, the dose of the long-acting narcotic must be increased if breakthrough pain occurs on more than two occasions. Some people need to have their narcotic dose (the long-acting pill) almost doubled to prevent breakthrough pain from happening again.

Ask about giving the same medicine in a different way.

Most pain medicine is given as pills. If taking pills is difficult or not possible, however, other ways can be used.

⇒ **Liquid pain medicine.**

If people with advanced cancer cannot eat solid foods, they may have trouble swallowing pills. Some pain medicines are available in liquid form. A pharmacist also can mix a liquid syrup containing one or more pain medicines that can be given with a measuring spoon, syringe, or eyedropper.

⇒ **Skin patches.**

A recent invention is the “transdermal” skin patch, which is placed on the body (chest or back) and delivers a medicine through the skin for up to 72 hours. There also are pills that give pain relief for a long time, such as 12-hour, time-release capsules of morphine.

⇒ **Rectal suppositories.**

Pain medicine can come as rectal suppositories as well. Once placed, they melt and are absorbed into the body.

⇒ **Single injections into muscles.**

Pain medicine can be received by injection, either into the muscle or just under the skin. If the idea of a needle scares the person you are caring for, however, very short needles can be used. Many people even learn to give shots to family members or friends.

⇒ **Subcutaneous needles attached under the skin for 3 days.**

A small needle can be placed just under the skin (called “subcutaneous”) by health care

workers, and medicine is injected through this line every few hours by a family member. These lines also can be hooked to pumps or simple battery devices that deliver the medicine at regular times. The needle must be changed and reinserted at a new site every few days by a nurse.

⇒ **Nasal sprays.**

The inside of the nose can become so dry that it hurts, and nasal sprays can give relief from pain and add moisture. Humidifiers or pans of water placed near radiators at home also help to moisten the air and ease the pain of dry nasal passages.

⇒ **Intravenous (IV) lines into large veins.**

You may have heard of Hickmans, Broviacs, or catheters, sometimes called *PICC lines*—peripheral inserted central catheters. These lines are placed into large veins. The tubing comes outside of the skin a few inches, and medicine is given through it. PICC line dressings are changed by nurses at the clinic or at home.

⇒ **Epidural catheters near the spine.**

Anesthesiologists can put epidural catheters near the spine to deliver medicine, and family members can give medicine through these.

⇒ **Implanted ports under the skin.**

Implanted ports are another way to get medicine into a large vein in the chest. These ports are circular, metal, and about 1-inch wide and 1-inch deep. They usually are surgically placed under the skin of the upper chest, and a nurse can find its exact placement by gently pushing on the skin and feeling the small round disc. Then, the nurse cleans the skin there with Betadine (a brown cleaning solution) and can draw blood from the site and give medicine into the port, which flows into the vein.

⇒ **IV infusing pumps attached to implanted ports.**

Small, portable pumps with IV lines can be carried on a belt. They are run by batteries and can deliver medicine evenly during the day and night. Home health nurses or home IV nurses give medicine through this and teach caregivers how to maintain the pump and the line. Some patients even learn to give themselves medicine through these lines as well.

Ask about adding other medicines

The doctor may combine several types of pain medicine that work in different ways to give relief. For example, an antianxiety or antidepressant can be added to decrease emotional tension,

which in turn improves pain control.

⇒ **Ask about changing pain medicine.**

If many of the suggestions in this plan have been tried but pain still persists, it is time for the patient, caregiver, and health care staff to discuss another medication plan. Do not give up on the relief of pain as a goal.

⇒ **Ask about use of radiation therapy for pain.**

Radiation sometimes is prescribed to shrink a tumor causing pain. Treatments usually are given daily and last from a few days up to 4 or 5 weeks.

⇒ **Ask about referral to a pain clinic or specialists in pain management.**

University and large hospitals often have special clinics to evaluate and treat chronic pain. Most pain clinics require that a doctor refer you to them and send the medical chart to their staff.

Doctors, nurses, counselors, and pharmacists at a pain clinic know about the special problems with pain, and they are interested in helping you. For example, an anesthesiologist can give a nerve block that stops the feeling of pain for a short time, until other methods are prescribed, or the nerve block can be given to last a long time. The staff at a pain clinic also might prescribe a combination of two or three medicines that relieve different types of pain.

If there is no pain clinic at your local hospital, ask the doctors there to refer you to a clinic at another. You also can call the pain clinic yourself and ask how referrals are handled.

⇒ **Use the hospice staff for help with pain control.**

Hospice teams include nurses and pharmacists who are specialists in pain control. Their experience and knowledge about the many types of cancer pain can make a big difference in getting (and keeping) pain under control.

Manage the more common side effects of pain medicine

Not all people react the same way to medicine; however, certain side effects are very common. Watch for these, and deal with them early.

⇒ **Prevent constipation with stool softeners and laxatives.**

Narcotics are dehydrating. They take water from the stool, which results in constipation. Stool softeners are pills that put the water back in, making the stool softer and easier to

pass. Some people take one or two stool softeners in the morning and one or two at bedtime to prevent this problem.

If stool softeners and laxatives do not work and the patient has not had a bowel movement in 2 or 3 days, give a product that is purely a laxative, such as Milk of Magnesia. You also may have to increase the number of stool softeners and stimulants taken each day. One Dulcolax rectal suppository every day can be very helpful. Problems with constipation mean that you need the help of hospice workers. If your family does not have help from a hospice, call the pain clinic or hospital and ask for a referral. These staff members know how to solve problems of constipation and pain, and they will help you with many aspects of caring at home for someone who has advanced cancer.

- ⇒ **Relieve a dry mouth with crushed ice, hard candy, and frequent rinses with water or products that do not contain alcohol.**
- ⇒ **Relieve painful, dry nasal passages by humidifying the air or breathing in moisture from a sink full of warm water.**
- ⇒ **Avoid an upset stomach by taking medicine with food or antacids unless instructed otherwise.**
- ⇒ **Expect drowsiness for a few days when pain medicine is started or increased.**

If sleepiness increases just after starting or increasing pain medicine, wait about 3 days. Sometimes, sleepiness happens because a person is finally getting relief from his or her pain and needs to catch up on missed rest, or the body just needs time to adjust to new medicines or doses.

Managing pain medicine

- ⇒ **Set an alarm as a reminder to take the medicine.**

An alarm reminds you to give the pain medicine. It also can remind the patient to take it.

- ⇒ **Use a tray with slots for the time of day to hold the medicine.**

These are plastic boxes with squares for each day of the week and slots for dose times. Many people fill the box for the entire week. If you are having trouble reading labels, remembering to give the medicine, or following the schedule, get someone else to fill the medicine tray. You also can use an egg carton and mark each slot with the day of the week and the time for the medicine to be given.

- ⇒ **Telephone the pharmacy before going to fill the prescription.**

Some pharmacies do not carry all pain medicines. They may have to “special order” it or send you to another store. Telephone at least 2 days ahead of time.

⇒ **Always use the same pharmacy if possible.**

If you use the same pharmacists, they will understand what the medication plan is, how it is working, and be able to suggest ways of handling any side effects. They also will know what pain medicines to keep on hand and can answer many of your questions about them.

⇒ **Keep at least a 3-day supply of pain medicine.**

Call the doctor for a new prescription before the last of the pain medicine is given. If it is the end of the week, you should have at least a 5-day supply on hand. If you are planning to be out of town, be certain to have a sufficient supply until your scheduled return.

Keep weather forecasts in mind as well. If a tropical storm is predicted and you live in Florida or a snowstorm is predicted and you live in the Wisconsin, travel may be disrupted, and you may be unable to get to your pharmacy for a several days. Stock up on medicine accordingly.

⇒ **Write the time and dose of pain medicine on a special form or tablet.**

Many caregivers forget when the last pill was given, or how much was given. Keep a special list handy to write down this information. An example of such a form appears at the end of this section.

Prevent and control pain through methods other than medication

⇒ **Use warm showers, baths, hot-water bottles, or warm washcloths.**

Heat relaxes the muscles and gives the patient a sense of comfort. Do not use heating pads on the high setting, however, because they can burn the skin. Wrap them in a towel, and do not place them over or near areas where radiation was given, even when the treatments are finished.

⇒ **Use cool washcloths or ice.**

Cooling the skin and muscles also can soothe pain, especially pain that comes from inflammation or swelling. For example, many people use a cool washcloth on their forehead when they have a headache.

⇒ **Position the person carefully with pillows and soft seat cushions.**

⇒ **Massage sore spots.**

⇒ **Avoid lifting or straining.**

⇒ **Encourage use of deep breathing exercises.**

Breathing deeply, slowly, and quietly helps the mind and body to relax, and this can decrease pain. Use tape recordings, or learn simple methods from books on relaxation. Ask the health care team about these techniques.

⇒ **Distract the patient with pleasant, involving activities.**

Doing pleasant, involving activities takes a person's mind off his or her pain. Different people are distracted by different activities, however. One may be distracted by watching television or going through a catalog. Another may be distracted by listening to music or visiting with friends.

⇒ **Remind the person to use pleasant and relaxing imagery, daydreams, or pictures in the mind to relax muscles.**

Remind people with advanced cancer about using images to relax their muscles. The patient needs to be in a quiet, restful place and to be comfortable, either lying or sitting down. Have the person close his or her eyes and picture a nice setting, such as a quiet, warm beach or a field full of colorful flowers. Then, tell the person to imagine being in that setting, feeling peaceful, and enjoying it. Tapes are available that walk people through pleasant scenes like this. They can go on "vacation" in their mind and relax, all of which helps to control pain.

⇒ **Ask about using biofeedback for muscle relaxation.**

Biofeedback has been used successfully by people with all types of pain, especially back pain. Professionals teach patients how to control their own muscles and to become more relaxed. Find out if this option is available in your area.

⇒ **Offer special foot rubs ("reflexology").**

Older forms of healing used pressure on the bottom of the foot and ankle. Rubbing these areas and pushing or pressing on them with a thumb and fingers can feel very good, and you may find that other parts of the body also can be relaxed through pressure on special spots. Try it. See what happens. Books are available on where to push to get relaxation in other parts of the body.

⇒ **Ask for help with tasks.**

Now is the time for both you and the patient to avoid "overdoing" it. Get others to lend a hand. Do not be shy about asking for help. It is part of your job as a caregiver to get

additional help when needed.

⇒ **Do activities when the patient feels most comfortable.**

Plan activities when the patient is feeling best and most awake. This might be a few days after a new pain medicine is started or after the dose has been increased.

⇒ **Keep a diary, rate the pain, and note what makes it worse or better.**

A diary can help you to inform the doctors and nurses of how well the pain treatments are working, and it can help you to judge what progress is being made at home. Writing down what makes the pain worse or better helps both you and the person with advanced cancer to think clearly about a plan to solve and prevent pain. Also, keep track of the times, amounts, and names of any pain medicines that are given. If you bring this diary with you to doctor appointments, it helps the staff to understand what you are doing, which helps them to make better recommendations about treatment.

⇒ **Avoid stressful events when possible.**

Emotional stress and anxiety increase pain, so if you can cancel certain events that you know to be stressful, do so. A “bad atmosphere” is not something the person you are caring for needs to struggle with right now.

⇒ **Consider going to a family-caregiver support group or educational session.**

To find out where and when local support groups meet, look in the telephone book, which usually has a large section called “Guide to Human Services.” Cancer support groups are listed under “Cancer,” and groups for family and friends who help anyone with a chronic illness are listed under “Caregivers.”

You also can ask medical staff about local support groups. Your local office of the American Cancer Society most likely has a list of support groups; their number is in the white pages of the phone book. In addition, you can ask the hospice staff. If you are not successful in finding a caregivers’ group, call the Cancer Information Hotline at the National Cancer Institute (1-800-4-CANCER).

Possible Obstacles

Here are some common obstacles that other caregivers have faced:

1. “I’m afraid of addiction.”

Response: *People who take narcotics for pain rarely become addicted.* In fact, if their

pain is treated effectively, it decreases the risk of addiction.

People who are “addicts” take drugs for a “high,” or an altered state of mind. People who take narcotics for cancer pain take them to get relief from physical pain. People who are not addicts *before* they take narcotics for cancer pain do not become addicts later. Remember, the medicine is being used for controlling pain, not for a psychologic “high,” and pain medicines can be stopped in such a way that the person does not experience the effects of withdrawal.

Even if you understand that the person you are caring for is not addicted, others may not. Do not spend a lot of energy trying to change their minds, however. Just tell them that this medicine is part of the medical treatment and is absolutely crucial to the patient’s quality of life and ability to do what is most important to him or her.

2. “I want to ‘save’ the medicine until the pain is severe.”

Response: Taking pain medicine for mild discomfort now does not affect how well it will work in the future, or when the pain gets worse. Do not hold back the pain medicine you should take today simply to “save up” if more is needed later. In fact, it takes more medicine to treat pain that is uncontrolled than it does to prevent the pain from building up in the first place.

People sometimes need to increase their doses, but this does not mean they are becoming “immune” to the medicine or need more and more to control the same level of pain. These people need more because the pain itself has changed. There is no real limit to the dose a person can take for most of these drugs, but if the patient ever does reach such a limit, the doctor can change to a different medicine.

If pain is controlled now, both you and the patient should be less worried about controlling it later, because you know that the medicine works. Also, taking enough medicine now helps the person with pain to relax and preserve his or her strength.

3. “No one wants to hear about my pain.”

Response: The person with pain should understand that family and friends may seem uninterested because they feel helpless. Doctors and nurses who specialize in pain, such as those in a pain clinic or hospice, understand. Talk to them if you are feel alone with these problems.

4. “Only people who are dying take morphine.”

Response: *Morphine is not reserved for those who are dying.* It is an effective medicine for many types of cancer pain, and taking it does not mean that a person is near death. Morphine is used to control chronic pain during all phases of the disease. Some people go

back to work and do their regular daily activities precisely because the morphine is so effective and lets them return to pain-free lives.

5. “If I give him his medicine and he dies, would it be the drug that killed him?”

Response: Pain medicine leads to comfort. When death comes, it is because of the disease, not the medicine. If a person gets “too much,” he or she usually will just sleep very deeply. Physicians also can order a drug that will cancel the narcotic in the blood and help to wake the person. Giving or not giving the pain medicine only changes the level of comfort, not the effects of the disease.

Think of other obstacles that could interfere with carrying out your plan

What additional roadblocks could get in the way of the recommendations in this plan? For example, will the person with advanced cancer cooperate? Will other people help? How will you explain your needs to other people? Do you have the time and energy to carry out the plan?

You need to develop plans for getting around these roadblocks. Use the COPE ideas (creativity, optimism, planning, and expert information), and see Solving Problems Using This Guide for a discussion of how to use them in overcoming your obstacles.

Carrying Out and Adjusting Your Plan

Carrying out your plan

Relieving pain and making the person you are helping comfortable is a challenge. If you follow the suggestions in this plan and work closely with hospice and home health staff, then you will be doing everything you can. Persist, and set the goal as being “pain free.”

Checking on results

Keep track of the level of pain. You can do this by asking the patient how severe the pain is, but use the same terms each time you do this. That way, you will be able to compare one time with another, and this will help you to evaluate how effective your pain control program is as well as to notice any changes. For example, you might want to use “worst ever,” “severe,” “bad,” “moderate,” “mild,” and “none at all,” and the patient can choose which fits best or even say that it is “between” (for example, “It is between ‘severe’ and ‘bad’”). Another way is to think of a 10-inch ruler, where 10 is the worst pain ever, 5 is moderate pain, and 0 is no pain; then, the person can give you a number to fit the pain.

If these ratings are to be meaningful, the patient must understand that you fully accept his or her ratings. Pain can be judged only by the person who has it. *The person with advanced cancer has to feel that you trust and accept what he or she says about the pain or the patient either will not*

cooperate or will give incorrect information.

If your plan does not work

If the pain is growing worse even after you have followed the strategies in this plan, speak with the doctor or nurse. Say what you have done to deal with the problem, and ask for guidance. Continue watching for symptoms that indicate immediate professional help is needed. Do not give up! Most cancer pain can be relieved, and the person you are caring for deserves to be comfortable.

If you feel the medical staff is not listening to your concerns or is unable to provide adequate pain control, ask for a referral to a cancer pain specialist. These are physicians who specialize in such pain and usually can be found at cancer centers, or they may be local physicians involved with hospice care.

Below is an example of how to keep track of pain medicines at home. Lists such as these inform health professionals about the amount and frequency of each drug administered. It is easy to forget what was given, especially if pain medicine or doses change frequently.

PAIN MEDICINE RECORD

DATE	TIME	PAIN MEDICINE	DOSE	RATING (0 to 10)
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*The American College of Physicians Home Care Guide for Advanced Cancer:
When quality of life is the primary goal of care.*

Shortness of Breath

Overview

Understanding the Problem

Shortness of breath can be caused by inability of the lungs and heart to get oxygen to the rest of the body, especially the brain

The patient's anxiety about shortness of breath often makes the problem worse

When To Get Professional Help

Symptoms indicating that professional help is needed
What information to have ready when you call for help
What to say when you call

What You Can Do To Help

Make the person being cared for as comfortable as possible
Ask the physician or nurse if oxygen or medicine will help

Possible Obstacles

“It makes me very upset when he can't breathe properly, so I get confused about what to do.”
“She was breathing fine when the nurse visited, so a breathing problem wasn't discussed.”

Carrying Out and Adjusting Your Plan

Managing shortness of breath requires help from professionals, who must be kept informed of any breathing problems and how the interventions are working
Topics with an arrow in front of them are actions you can take or symptoms you can look for.

The information in this guide fits most situations, but yours may be different. If the doctor or nurse tells you to do something other than what is recommended here, follow what they say.

Understanding the Problem

Shortness of breath, which is sometimes called *dyspnea*, can be a significant problem for people with advanced cancer. The person who experiences shortness of breath feels as if he or she cannot get enough air. A person normally breathes at a rate of 16 to 20 times per minute; a person with shortness of breath will breathe at a much higher rate.

Studies show that people with many kinds of advanced cancer experience shortness of breath or have trouble catching their breath. People with lung cancer in particular are likely to complain about this problem, and most experience shortness of breath even during the early stages of their cancer.

Shortness of breath can be caused by inability of the lungs to get enough oxygen and of the heart to send out that oxygen through the body. Feeling short of breath can make a person anxious which, in turn, can make the problem worse. Relieving that anxiety may help to reduce shortness of breath.

Managing shortness of breath requires help from professionals. This is not a problem that you can cope with at home alone.

Your goals

Call for professional help when needed.

Help the person being cared for to be as comfortable as possible.

Ask the physician or nurse if oxygen or medicine will help.

When To Get Professional Help

Call the doctor or nurse if any of the following conditions exist:

⇒ **The person with advanced cancer complains about “not getting enough air” or that he or she “can’t breathe” or is “short of air.”**

People who cannot speak may use gestures, such as waving a hand or pointing to their nose or mouth. A person with breathing problems may look normal; therefore, you should always accept what the patient says about trouble breathing.

Before you call for help, be sure the person is sitting up, either in bed or in a chair. This will help get as much oxygen as possible into the lungs.

⇒ **The person with advanced cancer is breathing quickly when moving, but breathing does not slow within 1 or 2 minutes after the activity has stopped.**

The number of breaths taken each minute goes up naturally after any activity—even simple ones such as being turned or washed in bed. After the activity stops, however, the person’s breathing should slow.

If the person you are caring for is resting but still complains about feeling short of breath, is gasping for air, or breathes with increasing frequency, call the home health or hospice staff for help.

Have the answers to the following questions ready when you call the doctor or nurse:

1. What medicine, if any, is the patient taking?
2. Are any of these medicines narcotics or pain killers?
3. When was the last time that pain medicines were given? How much was given?
4. Is the patient taking oxygen? If so, how many liters (a number such as 2 or 6) are running?
5. If the patient is taking oxygen, is it being delivered through a thin line into the nose (a nasal cannula) or through a mask that covers the nose and mouth? If a mask is not being used, is there one in the house?

Here is an example of what someone might say when calling for professional help:

“I’m Jim Magasaki. My brother Pat feels more and more short of breath, like he can’t get enough air. I opened the windows, but that didn’t help. He’s on oxygen at a setting of two. What’s next?”

What You Can Do To Help

There are two steps you can take to deal with breathing problems:

Help the person being cared for be as comfortable as possible.

Ask the physician or nurse if oxygen or medicine will help.

Help the person being cared for be as comfortable as possible

⇒ **Encourage relaxation.**

Tense muscles add to the feeling of breathlessness, and they make the act of breathing harder. Pleasant, involving activities as well as relaxation exercises can reduce the general level of tension.

⇒ **Prop the person in a sitting position.**

Sitting up makes breathing easier. Put several pillows behind the patient's back, or use a large foam wedge, which can be purchased at medical supply stores. A hospital bed that can be raised at one end also can be used to elevate a person's head.

⇒ **Use a reclining chair for naps or sleeping.**

A reclining chair can allow a person to sleep in a partially upright position, which gives the lungs more room to breathe. These chairs sometimes can be borrowed from the American Cancer Society.

⇒ **If activities cause shortness of breath, plan for rest periods between them.**

Rest periods between activities will give the person with breathing problems a chance to catch his or her breath. Resting before and after visitors or meals also can be helpful if they cause shortness of breath, as sometimes occurs.

⇒ **If talking causes shortness of breath, shorten the time for visiting or talking.**

Talking can increase the number of breaths a person needs. If this happens, wait

quietly until his or her breathing slows.

⇒ **Open a window or use a fan to get air moving in the room.**

Air moving through a room helps a person to feel less short of breath.

⇒ **In the winter, use a humidifier or place pans of water near radiators.**

People often breathe through their mouths when they are short of breath. This causes dryness in the mouth, but moistening the air being breathed can help. Humidifiers or pans of water placed near radiators help to loosen mucus and moisten the dry throat and nasal passages. If a cough brings up thick phlegm from the lungs, a humidifier can help to loosen that phlegm as well.

⇒ **Offer throat lozenges or hard candy to help with dry throats.**

Sucking lozenges or candy often helps a dry throat, because it increases the production of saliva, which moistens the throat when swallowed.

Ask the physician or nurse if oxygen or medicine will help

⇒ **Ask about giving oxygen.**

If shortness of breath is a problem, using small amounts of oxygen around the clock can help. Oxygen can be ordered by a doctor and delivered to the home by a medical equipment company. Visiting or hospice nurses also can talk with the physician about the problem and arrange for oxygen. The people who deliver oxygen as well as the visiting nurses will be able to teach you how to use it.

The person with advanced cancer who is having trouble breathing generally starts by using a “nasal cannula.” This is a small tube that goes from the oxygen source to the person’s nose, dispensing oxygen into the nose and, therefore, into the lungs. This usually eases shortness of breath. If the problem is severe, a mask can be used to administer the oxygen.

⇒ **Ask the physician if medicine will help.**

Narcotics (pain medicines) can help to ease shortness of breath. If the person with advanced cancer is *not* taking narcotics for pain, then a very small dose of

morphine can help. If the patient already is taking a narcotic for pain, the amount may need to be increased to help with the shortness of breath.

Shortness of breath causes anxiety, and reducing anxiety will help to relax muscles and make the act of breathing easier. There, use of anti-anxiety medications can help the patient as well.

Possible Obstacles

Here are some common obstacles that other caregivers have faced:

1. “It makes me very upset when he can’t breathe properly, so I get confused about what to do.”

Response: It is very upsetting to see someone you care for struggling to breathe, so your reaction is understandable. To be sure that you do the right things, you should work out your plan in advance, before the problem occurs, and practice what the doctor or nurse suggests.

2. “She was breathing fine when the nurse visited, so a breathing problem wasn’t discussed.”

Response: The best way to ensure that all of your problems are dealt with is to make a list and keep notes when talking with health professionals. If breathing was a problem earlier that week, be sure to mention it.

Think of other obstacles that could interfere with carrying out your plan

What additional roadblocks could get in the way of the recommendations in this guide? For example, will the person with advanced cancer cooperate? Will other people help? How will you explain your need for help to other people? Do you have the time and energy to carry out the plan?

You need to develop plans for getting around these roadblocks. Use the COPE ideas (creativity, optimism, planning, and expert information) in developing your plans, and see Solving Problems Using This Guide for a discussion of how to use the COPE ideas in overcoming your obstacles.

Carrying Out and Adjusting your Plan

Carrying out your plan

Managing shortness of breath requires help from professionals. Keep them informed about the seriousness of the problem and how your actions are working. Usually, it takes a number of steps to relieve shortness of breath as well as to ease breathing and anxiety. Do not give up. Hospice or home health care staff will work closely with you to keep the person being cared for both comfortable and calm. Sometimes, something you have tried may have helped a little but not as much as you had hoped, so combine those steps that helped a little.

If your plan does not work

Health professionals may want to hospitalize the person you are helping until the problem is solved. Keep asking if something else can be tried; make sure that all possible strategies have been considered.

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Problems with Communication, Mental Confusion, and Seizures

Overview

Understanding the Problem

Communication problems and mental confusion may be caused by age, the illness, or medicine

When To Get Professional Help

Symptoms that indicate professional help is needed
Information to have ready when you call for help
What to say when you call

What You Can Do To Help

Make it as easy as possible for the person being cared for to understand both you and others
Help the patient to avoid becoming confused
Know what to do if a seizure occurs

Possible Obstacles or who I am.”

“Why talk about the past? She can’t even remember where she is now.”

“I feel so sad that he doesn’t know who I am.”

“Why bother to explain anything? He doesn’t know where he is

Carrying Out and Adjusting Your Plan

Keep track of what seems to improve communication
Report continued problems to the hospice staff

Topics with an arrow in front of them are actions you can take or symptoms you can look for.

The information in this home care plan fits most situations, but yours may be different. If the doctor or nurse tells you to do something other than what is recommended here, follow what they say. If you think there may be a medical emergency, see When To Get Professional Help.

Understanding the Problem

Problems with communication and confusion can cause both caregivers and the person with advanced cancer to become angry and frustrated. Sometimes, this even leads the patient to stop trying to communicate. Family caregivers may be tempted to give up as well, but they should understand that steps can be taken to cope with these problems.

Older patients are more likely to have trouble understanding what is happening and what they hear. They often are weaker than younger patients, are worn down by their illness, and may have problems with their vision or hearing. At 65 years of age, about one in 20 people suffers from some problem in their ability to understand and to speak. As adults grow older, this problem becomes more likely to occur; by age 90, one in three adults suffers from significant communication problems.

Serious communication problems and mental confusion also can be caused by medication, changes in body chemistry, or the presence of cancer in the brain. In addition, lack of sleep or rest can add to a person's disorientation (not knowing where one is or who other people are), as can new and unfamiliar surroundings.

Although very rare, seizures are another problem with normal brain functioning in the person with advanced cancer. When a seizure does occur, both caregivers and patients can become very frightened, so preparing in advance is wise, especially if the medical staff warns you that a seizure may happen.

Your goals

- Call for professional help if needed.

- Help the patient to avoid becoming confused.

- Make it as easy as possible for the patient to understand both you and others.

- Know what to do if a seizure occurs.

When To Get Professional Help

Call the doctor or nurse if any of the following conditions exists:

⇒ **A sudden change in ability to speak after a new medication is started.**

This should be reported to a physician or hospice nurse. The medication may be

the cause of the problem, and the doctor may need to the dose or the medicine itself.

⇒ **Mental confusion that is new or increased.**

Sometimes, people with advanced cancer become especially confused and restless before they die. Any change such as clouded thinking or not knowing where they are should be reported.

⇒ **A sudden, dramatic change in personality.**

If someone is outgoing one week but very quiet the next, or vice versa, the cause may be a physical change in the brain, such as depression, a medicine being taken, a stroke, or the natural journey toward dying. Talk with a health professional if this is a worry to you or the person with cancer.

⇒ **Sudden changes in physical functioning or ability to care for themselves.**

If the patient suddenly needs help to manage routine tasks such as dressing or washing, which used to be managed alone, call the physician's office or hospice and ask that a nurse or hospice worker be sent.

⇒ **Danger of falling because of confusion.**

Mental confusion increases the likelihood that someone will not know where they are or what they can do alone. Climbing out of bed or getting up and walking can cause a fall. Ask a hospice nurse to come to the house and help you to make the rooms safer. If the patient does fall, make the person comfortable on the floor using pillows and blankets and then call for help. For example, the staff at a local fire company can come out and gently lift the person back into bed; they have the strength and know how to move people safely.

⇒ **A sudden change in ability to talk, such as long pauses or slurred words while speaking.**

Sudden changes in the ability to speak can happen right away or within a short period of time, such as several days. Problems with speaking can result from a stroke, in which parts of the brain do not get enough blood or oxygen. Recognizing changes in speaking may be difficult with persons who have advanced cancer, because these patients may be sleeping more and talking less anyway. Even so, watch for changes such as a person who uses complete sentences suddenly speaking in short words, using sentences that make no sense, or babbling. Other symptoms of a stroke are numbness on one side of the face or

body; inability to move one side of the face when smiling, frowning, or speaking; and inability to move a hand, arm, or leg.

Have the answers to the following questions ready when you call the doctor or nurse:

1. When did the confusion or word slurring start?
2. Were any new medications started? If so, which ones and when?
3. Has the person you are helping changed where they are living?
4. Have other changes occurred in patient's setting? If so, what are they?

Here is an example of what someone might say when calling for professional help:

"I'm Melissa Watson, Shelva Mahoney's daughter. My mother is Dr. Lindquist's patient. This morning my mother suddenly started slurring her words and wasn't sure where she was."

What You Can Do To Help

Here are three ways to deal with communication problems or confusion:

Make it as easy as possible for the person being cared for to understand both you and others.

Help the patient to avoid becoming confused.

Know what to do if a seizure occurs.

Make it as easy as possible for the person being cared for to understand both you and others

⇒ **Avoid whispering.**

⇒ **Use simple words and short sentences.**

Shorter words and sentences are easier to understand. Also, ask questions one at a time, and wait for an answer. Try not to give complex choices, either. Do not ask questions such as "Do you want to lie down now or have Fred visit?" Instead, just

ask “Do you want Fred to visit now?” Avoid treating the adult like a child or using baby-talk, however.

⇒ **Use a picture or the “real thing” to get your message across.**

If the person with cancer does not seem to understand a simple question, show something to help get the message across. For example, if you want to know if he or she would like something to drink, show a glass of liquid.

⇒ **Keep other noise down in the room.**

If others are talking and a TV or radio is blaring, it will be hard for anyone to hear a conversation or a question. Keep this in mind if the patient is having difficulty understanding someone else’s speech.

⇒ **Explain to visitors or other caregivers how they can help the patient to hear and understand better.**

You can leave written instructions for new visitors or respite workers who come to sit with the person being cared for; however, example is the best teacher. Remind the visitor that hearing or talking is a problem, and show what you do to cope with any confusion and to improve communication.

⇒ **Explain what is happening before you turn, move, or help the person with cancer.**

It helps a confused person to know what is going to happen before a change such as getting out of bed or drinking occurs. Try not to treat the patient like a child, however. Just use simple words and explain what is going to happen.

⇒ **Try not to argue.**

It is easy to lose patience with someone who is not mentally clear or keeps forgetting what you tell them. Arguing can increase the person’s anxiety, however, and actually make it harder to understand what you are saying.

Help the patient to avoid becoming confused

⇒ Try to keep the person awake during the day and asleep during the night.

Many people who are very sick get night and day mixed up, and this can add to their confusion. Try to keep the person more awake during the day so that he or she can sleep during the night. This way, certain routines, such as mealtime or bath time, will not seem so disorienting.

⇒ Use a night light in the room, and help the patient to see and remember where he or she is.

A person who is a little confused sometimes can wake up and not remember where he or she is. A night light gives just enough illumination to help the person see and get oriented.

⇒ Keep the patient's surroundings as familiar as possible.

Getting confused can result from unfamiliar surroundings or people. Even if the patient goes to a nursing home or a special hospital unit, take pictures, photographs, favorite pillows, or covers into the new setting to retain some familiarity.

⇒ Keep a clock and a calendar within sight.

It is easy to lose track of the time of day and the day of the week. Clocks and calendars help to remind all of us about the time.

⇒ Continue giving medication on a regular schedule.

Some medicines may be prescribed because they help to keep the person with cancer mentally clear. One example is steroids, such as prednisone, which decrease swelling or inflammation in the brain. If confusion or problems with talking are caused by a cancer in the brain, it is important to keep giving medications that keep any swelling from quickly getting worse.

⇒ Ask if medication doses (except for pain medicines) need to be lowered because of weight loss.

Some medicines can add to a patient's confusion. Perhaps the doses of these drugs can be lowered without losing their desired effects.

Know what to do if a seizure occurs

⇒ Place a soft washcloth in the person's mouth.

In hospitals, nurses use a tongue blade wrapped with white gauze, but a soft washcloth folded lengthwise will do the same thing at home. The purpose of placing something in the mouth is to prevent the patient from biting his or her tongue or lips while the seizure lasts.

⇒ Avoid putting your hands in the person's mouth.

Do not try holding the person's tongue or mouth with your hands. Most likely, you will get bitten. Instead, place the soft washcloth inside the person's mouth when it opens.

⇒ Put pillows on both sides of the body.

Pillows will help to keep the person both in place and from falling out of bed.

⇒ Pad any side rails on the bed with soft blankets.

Metal side rails on hospital beds can hurt and bruise a person when he or she bumps into them. Padding the side rails is a good idea if you expect a problem with seizures.

⇒ Turn lights down to soft lighting.

Soft illumination is calming, and people with cancer in the brain usually rest better when they are not squinting into bright lights.

⇒ Tell others how to handle seizures.

Keep a list near the patient's bed of what to do if a seizure occurs. If volunteers or others who are not the usual caregivers stay with the patient, they can read this list and know what to do.

Possible Obstacles

Here are some common obstacles that other caregivers have faced:

1. “Why bother to explain anything? He doesn’t know where he is or who I am.”

Response: Confusion can come and go, so you will not always know if the person is confused at that particular moment. Explain things, and talk with him as an adult.

2. “Why talk about the past? She can’t even remember where she is now.”

Response: Remembering the past might be easier for her than remembering what happened yesterday. In general, this is true for many older adults (those over 85 years or so). Talking about the past can be pleasant and comforting as well, and it can bring tears as well as laughter. If other friends or family are present, they also will enjoy the stories and learn more about the person with cancer.

3. “I feel so sad that he doesn’t know who I am.”

Response: It is sad to lose the sense that he knew you before and now he does not. This can make you feel like you have lost someone. Maybe there were things you wanted to say or do together, and you now wonder if it is worth it. Say those things anyway, and hope that your words are understood as coming from you (because you cannot always be sure that he does not know who you are).

Think of other obstacles that could interfere with carrying out your plan

What additional roadblocks could get in the way of the recommendations in this plan? For example, will the person with advanced cancer cooperate? Will other people help? How will you explain your need for help to other people? Do you have the time and energy to carry out the plan?

You need to develop plans for getting around these roadblocks. Use the COPE ideas (creativity, optimism, planning, and expert information) in developing your plans, and see Solving Problems Using This Guide for a discussion of how to use these ideas in overcoming your obstacles.

Carrying Out and Adjusting Your Plan

Carrying out your plan

Be patient and creative. It will take time to discover the best ways to communicate with someone whose mental abilities are limited. Also, be realistic in your expectations.

Checking on results

Look for signs that the patient recognizes you and understands what you have said. Keep track of what causes any such improvement.

If your plan does not work

If communication and confusion remain problems after following these strategies in this plan, ask hospice and other health professionals for further suggestions and guidance. They are experienced in communicating with people who have advanced cancer and will know what you can realistically hope to achieve.

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Getting “Respite” Care or Extra Help at Home

Overview

Understanding the Problem

What “respite” services are
Why extra help may be needed
Who “respite” helpers are

When To Get Professional Help

Situations indicating that extra help is needed
What to say when you call for help

What You Can Do To Help

Make sure you involve the person being cared for in all decisions
Make sure the extra helpers are both reliable and honest

Possible Obstacles

“We’ve never had anyone else help us before.”
“The person I’m caring for doesn’t want anyone else here.”
“I feel funny having strangers come into my home.”
“It’s too expensive.”

Carrying Out and Adjusting Your Plan

Ask yourself and the person you are caring for how well the plan is working
If your plan does not work, consider temporarily moving the person you are caring for into a nursing home

Topics with an arrow in front of them are actions you can take or symptoms you can look for.

The information in this plan fits most situations, but yours may be different. If the doctor or nurse tells you to do something other than what is recommended here, follow what they say.

Understanding the Problem

The word *respite* (pronounced “res-pit”) is new to many people. It means “rest.” Sometimes, you will see it listed in the telephone book under the ads for local home health care or visiting nurse agencies, which often are called “Respite Care Services.” In this type of care, helpers are sent into the home to stay with the person who has advanced cancer, giving family caregivers and friends a chance to rest.

This type of extra help may be especially needed during the last months or weeks of a patient’s life. Only at this time do many caregivers admit they are not sleeping properly, that they are tired, and that they are worn down by emotional tension and stress. Respite

helpers can assist by coming in at night and talking to the person with cancer, by giving food or drinks to this person, or by helping him or her to move in the bed. Sometimes, respite helpers simply stay with the patient and allow the caregivers time to run errands, visit friends, go to church, and spend some time taking care of themselves. Respite helpers sometimes are trained—families usually want trained helpers to visit rather than having to ask other relatives or friends to help. They want to know that the helpers are skilled in how to give basic nursing care, such as turning someone in bed or giving a weak person a drink.

Most hospice respite workers are women; however, you can ask for a man if that is your preference. For example, an adult man in a wheelchair might want another man to help him with basic needs such as going to the bathroom or washing. It often is best to find this help by asking the hospice social worker or nurse to give you a list of agencies that employ respite workers or the names of reliable self-employed respite workers. It is best not to hire someone out of the newspaper. Instead, ask people who either have used or are using hired respite workers for their recommendations.

Respite workers can be employed by an agency, or they can be self-employed or even volunteers. When they work for an agency, the agency pays them and either bills you or your insurance company, county, or state. Respite workers usually make a bit more than minimum wage. You will have to give the agency more money than this, however, because you must also pay for the time that it takes to supervise and manage their work. The agency bills the county or state if those with cancer or their families are “eligible,”

meaning that household incomes are low enough for the government to pick up the cost of extra help at home. If respite workers are self-employed, they bill you directly. Some volunteer respite workers will offer to spend the night, but these volunteers usually are part of a hospice.

Your goals

Call for help in locating respite workers.

Make sure the person with cancer is involved in all decisions.

Make sure those providing extra help are both reliable and honest.

When To Get Professional Help

The first question you should ask is whether you need help in locating respite care services. As with most problems, you should plan ahead and not wait for a crisis. The following signs usually point to a home care problem that should be referred to a social worker, nurse, or some other agency, such as your area Agency on Aging, for assistance in finding helpers:

Call a social worker, nurse, or an agency such as your area Agency on Aging for assistance in finding helpers if either of the following is true:

⇒ **You feel worn out from the extra responsibilities.**

Your health and well-being are important. If you are feeling worn out, call and talk the situation over with hospice staff or a health professional who knows about getting help in the home. Many times, a person with advanced cancer is eligible to have a visiting nurse come to the house and find out what your needs are. The nurses also can send out a nurse's aide to help with bathing and bedmaking. Aides cannot stay longer than 1 to 2 hours, however, and they usually cannot visit in the evening or at night, which is when you may want to rest. If the person you are caring for is not "sick enough" to have visiting nurses call on him or her but is a senior citizen, you can call the local Agency on Aging. They can send a case or social worker to your home to assess the situation and help you find extra help. Sometimes, money from the county or state is available to help pay for respite care workers; other times, you will be asked to pay. Some towns and areas also have volunteers who are experienced in helping people with cancer

and their families.

⇒ **You worry that you will not be able to take on the extra responsibilities or physical labor of helping a weakened person.**

If you are worried about this, start getting extra help early. This has many benefits. Both you and the person with cancer will have time to get to know and trust the helpers. You can work out household routines with them before you become stressed, and if the helpers do work out, then you know that you can depend on them should home care grow more difficult in the future. This knowledge can reduce some of your stress or worries about handling future problems.

Here is an example of what you might say when calling to get extra help at home”

“I’m Melissa Watson, Shelva Mahoney’s daughter. My mother is Dr. Lindquist’s patient. I’ve heard that respite help might be available to me because she has advanced cancer.”

What You Can Do To Help

There are at least two things you can do at home to find good respite care workers:

Make sure you involve the person being cared for in all decisions.

Make sure those providing the extra help are both reliable and honest.

Make sure you involve the person being cared for in all decisions

Not everyone welcomes extra help right away. Having strangers in the home is a big change. Here are some ideas on how to ease into it:

⇒ **Talk over the reasons you want to get extra help. Be honest about your concerns and what you want.**

The person you are caring for may be more willing to accept this situation if you say that *you* need the extra help to keep giving him or her care at home. This way, the patient realizes that It is very important to you, and that he or she is helping

you by accepting the extra helpers.

⇒ **Set a time limit on how long you will try the extra help to see what it is like.**

For example, suggest that the respite helpers visit twice a week for 2 weeks, then talk over how things are working out and decide whether both of you want to continue having the extra help. Maybe a new helper is needed-if so, set a new trial period.

⇒ **Have the helpers visit for a short time to talk about the tasks they can do and when they can come.**

Meeting someone face to face takes away some of the worry about who a new person is. After the first visit, the patient usually will realize that the “stranger” is there to help and will be more willing to get to know what this “visitor” is like.

Make sure those providing the extra help are both reliable and honest

You want to be sure that extra helpers will not take advantage of the person you are caring for, or of you as a caregiver. Although this problem is rare, it is best to take precautions. Here are some ways to make sure that extra helpers are reliable, honest, and safe:

⇒ **Get the names of potential helpers from hospice social workers, nurses, or your area Agency on Aging.**

Professionals who work with families that are coping with chronic illness are the best people to ask about respite care services. They will explain your options and their costs, and they can recommend workers who they know are “safe” and are good helpers, will show up on time, and will treat everyone in the family with respect. These are people with a good track record. They will not be potential abusers, whether financially, physically, or otherwise.

⇒ **Avoid getting the names of potential helpers from the newspaper or local flyers and bulletins.**

You take an unnecessary risk by hiring someone from of a newspaper or a bulletin board where self-employed people advertise their services. Many times, these people work out just fine. But, you increase the chances of getting a worker

who has bad intentions, such as stealing money or abusing the situation in some way.

⇒ **Ask someone you know who either has used or is using extra helpers who you should call.**

If people you know are satisfied with the extra help in their homes, ask them for advice on how to find reliable helpers. Maybe you can even use the same helpers. Many respite workers can work more than one job at one time, and volunteers may be willing to do this as well.

⇒ **Call the American Cancer Society, and ask if it has a volunteer respite program.**

A few Cancer Societies have volunteer respite programs. Home visitors come and relieve caregivers so they can rest, run errands, and take care of their own needs. Some programs have visitors who will stay longer so that caregivers can go to work, though it might take more than one volunteer to cover an 8- or a 10-hour day.

⇒ **Check at least one reference before using a respite helper who is not employed by an agency or is not a hospice volunteer.**

Possible Obstacles

Here are some obstacles that other caregivers have faced:

1. “We’ve never had anyone else help us before.”

Response: Having helpers in your home takes some getting used to. Even having professionals such as nurses or hospice workers visit is a change. However, you probably will find that you get very close to these people, and that you will look forward to their visits, advice, and conversation. You will grow get close to respite workers and nurse’s aides, too. They will spend the most time with the person who has cancer, and they can share support and love at a difficult period.

2. “The person I’m caring for doesn’t want anyone else here.”

Response: The person with advanced cancer may want to deal with only one or

two special people when it comes to bathing, changing the bed, or other personal care tasks. It may take help from more than one or two people to keep the patient at home, however, especially if caregivers are working or have families of their own to look after as well. When this happens, it is important to ask the person with cancer to try the extra helpers for your sake.

3. “I feel funny having strangers come into my home.”

Response: Getting help at home can feel funny, especially if you have never used it before. You and the person with cancer can try it for 2 weeks or so, then decide whether it is working. You probably will find that you like the people who are helping you, and that their help is very important. In fact, you may wonder later how you ever got along without them. This has been the experience of many families who have cared for a person with a chronic illness at home.

4. “It’s too expensive.”

Response: Lack of money to pay out-of-pocket fees should not stop you. Often, you can get respite help for free from trained volunteers, and in many states, respite help is paid for by the government. Ask a social worker for help. If that fails, ask visiting nurses or hospice workers what kinds of help you can get for free from volunteers or state respite services. Some churches also have respite volunteer programs, and while their volunteers often visit only those families belonging to that church, some do make exceptions and are willing to help. It pays to ask. Of course, if keeping someone at home is just too much, you can choose other options, such as moving the person with cancer to a nursing home or a hospice.

Think of other obstacles that could interfere with carrying out your plan

What additional roadblocks could get in the way of the recommendations in this plan? For example, will the person with advanced cancer cooperate? Will other people help? How will you explain your need for help to other people? Do you have the time and energy to carry out the plan?

You need to develop plans for getting around these roadblocks. Use the four COPE ideas (creativity, optimism, planning, and expert information) in developing your plans, and see Solving Problems Using This Guide for a discussion of how to use the COPE ideas.

Carrying Out and Adjusting Your Plan

Carrying out your plan

Many times, people with cancer enjoy outsiders visiting and like the extra help. If you do not like the helpers, however, then change helpers. Agencies are accustomed to trying several people before the right one is found. You can check on how well this home care plan is working by asking yourself if having the extra help is worth it. You also can ask the person with cancer how he or she feels it is working.

If your plan does not work

If finding extra help is a problem, review the When To Get Professional Help section of this plan.

If the person with cancer refuses to try respite care, you may need to find other ways to get the rest that you need, such as moving the patient to a nursing home for a short time. He or she can return when you are rested or if he or she decides that respite help may be better than staying in the nursing home. Decisions like going to a nursing home do not have to be final.

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*The American College of Physicians Home Care Guide for Advanced Cancer:
When quality of life is the primary goal of care.*

How To Help During the Final Weeks of Life

Overview

Understanding the Problem

- Preparing for the end of life with a chronic illness is different than with a sudden illness
- Signs of dying
- The last days of life are unique for each person
- Goals for the home care plan

When To Get Professional Help

- Recognize situations that require professional help for the patient to reach a natural death

What You Can Do To Help

- Keep the person comfortable
- Give general nursing care
- Welcome visitors
- Cope with changes

Possible Obstacles

- “Different family members disagree about what to do.”

Carrying Out and Adjusting Your Plan

- Keep track of your own energy, and get help if you need it
- Be honest about whether helping at home is too much

Topics with an arrow in front of them are actions you can take or symptoms you can look for.

The information in this home care plan fits most situations, but yours may be different. If the doctor or nurse tells you to do something other than what is recommended here, follow what they say. If you think there may be an emergency, see When To Get Professional Help.

Understanding the Problem

The end of life cannot be predicted for any of us. We do not know when it will happen, who will be with us, how it will occur, or what we will feel. We do know more about the answers to these questions for people living with advanced cancer, however. Cancer is a chronic illness, which means that it takes time for it to grow worse. Dying with a chronic illness is very different from dying because of a sudden illness or event, such as a heart attack or an accident. Certain things about dying (and living) with advanced cancer can be predicted and discussed, including the cause of death, when death will finally occur, and how we know when a person is living the very last days of his or her life.

Many misconceptions exist about what can happen during the final days and weeks of a person's life. One stubborn myth about dying from cancer is that the person will finally die from only one cause. Someone might say, "It'll be the heart that goes last." When people have a chronic illness such as late-stage cancer, however, they usually do not die from one major event or for only one reason. Instead, they die because of many different factors that combine to slow down the body's important systems, such as the heart and lungs. In a sense, the physical body slowly "gives up."

We cannot say exactly how long someone will live with a chronic illness. Many times, family members and friends want to know this information. They want to prepare themselves, make plans, or understand what will happen in the next few weeks or months. Doctors and nurses can give predictions of how long the person has to live, but these are only estimates or best guesses. Sometimes, the guesses are accurate; sometimes, the guesses are not. For example, some people have lived much longer than their "predicted" 3 or 4 months. In fact, some of these people have gotten better, returned to work, taken up their hobbies again, and enjoyed life for much longer than expected. It was not until months later that they finally slowed down, became weaker, and died.

Certain physical signs warn us that the end of life is growing close. Most people with an advanced, chronic illness such as cancer spend more time in bed or on a couch or chair. People with any type of advanced cancer eat much less food, and they drink fewer liquids. They also sleep more, lose weight, and become much weaker.

Not every warning sign is physical, however. People may talk about "leaving" or "having to go." Their dreams make them feel as if they want to "get going" or "go home." Although this is not common in every situation, this language and the emotion behind it are ways of talking about dying. The patient also may ask to see special friends or relatives, and some haziness or confusion can occur as one day blends into another.

Keeping track of the day of the week becomes less important, as do other details.

The last days of life are unique for each person as well. They are very personal, and they are very private. People usually are less interested in the outside world, and they want the closeness of only a few people-or maybe just one other person-to comfort them. Exceptions do occur, of course. Some want many friends and family members around them, but this is rare.

So, this is the general picture of a patient in the final weeks of life: very weak; drowsy, with much sleeping; unable to eat any food and difficulty swallowing fluids; less able to talk and to concentrate; bodily comfort (as long as medicines are continued); and peace with dying.

Your goals

Know when to recognize situations that require professional help for the patient to reach a natural death.

Keep the person comfortable.

Give general nursing care.

Welcome visitors and children.

Tell others how they can help.

When To Get Professional Help

Health professionals can play an important role during the final days of life, but their advice and treatments (if any) will not be geared toward person. At this point, it is hard to change the underlying physical problems, but the discomfort that results from those problems can be eased.

Call the doctor or nurse if any of the following situations exist:

⇒ **The person you are caring for has difficulty becoming comfortable.**

You will know when people with advanced cancer are uncomfortable. They may tell you, or they may be tossing or moaning. If they are not conscious or awake, they may be frowning. Call the hospice or home care staff for help. If home care

nurses or hospice staff are not available, call the doctor's office and ask that a visiting nurse or hospice nurse come to your home because the person is uncomfortable and, at this point, you do not know what to do.

⇒ **The person you are caring for is confused or seeing things that are not there.**

Occasionally, being confused about the time of day, day of the week, or the date is normal, but severe confusion can upset people with cancer as well as you. Severe confusion might mean that they do not know where they are or who they are with. This can be a real problem if they are unhappy about where they think they are or afraid of what they see or hear. They may even see things that are not there. Sometimes, these visions are of people who have already died, such as a mother or a child. These are called *hallucinations*. If these visions comfort the person, they are not a problem. If they scare or upset the person however, or if the hallucinations are affecting or upsetting the family, they are a problem. Call about severe confusion or upsetting hallucinations.

⇒ **The person you are caring for is suffering from severe fear or anxiety.**

Try to understand what is frightening the person, but do not make assumptions. You could be wrong, and that would hinder your ability to help. It is okay to ask the person what worries them most. This allows you to focus on the real issue rather than guessing about what the person is afraid of. For example, you may assume the person is afraid of dying when, in reality, he or she is afraid of being left alone or running out of money.

Sometimes, anxiety is caused by medicine. If so, the medicine can be changed, and anti-anxiety medicines can be used. Visiting nurses can talk with the doctor and ask to have these medicines ordered.

⇒ **You feel tired and overwhelmed.**

Needing help from other people is not a failure on your part. Your health is important if you are going to provide the best care for the patient. Eating and resting are crucial. Sometimes, it is hard to ask for help when you are caring for someone through the final days of their life-but you should! Call for help from a visiting nurse agency or a hospice. These groups will send out nurse's aides to give baths, do light laundry, change the bed, and give you both help and support. Registered nurses and other professionals will help you to manage medical problems that arise. Family and friends are important now as well. Ask them to

help, and give them specific tasks that will help you as well as make them feel useful.

⇒ **You do not think that you can handle keeping the person at home.**

Some caregivers are comfortable helping someone during the final days of life. Perhaps they have done this before; perhaps they have watched others do it. Giving nursing care and dealing with problems are not so upsetting to them.

Other caregivers have more difficulty. If they work outside the home, they may be overwhelmed by the strain of “two jobs.” They also may have children. The task of caregiving may be new for them as well. They may have never been with someone during the final days of life or have helped with a natural death. They may have too much going on in their own lives to be able to handle the added demands of caring for a person with advanced cancer.

If you are not sure that you can handle caregiving near the end of a person’s life, talk about your worries with someone. Social workers at the hospital or hospice are very helpful. Even if the person with cancer does not go to that hospital anymore or just goes to an outpatient clinic, call the hospital and ask for their department of social work. If you have visiting nurses, ask them to send a social worker to your home. They can help you to sort out which parts of caring for someone at home are most difficult, then you can discuss if you should move the person somewhere else, such as to a nursing home, or if someone else can take over some of your responsibilities at home. That decision, of course, is always up to you and the person being cared for. Include the patient in all of these decisions and discussions as much as possible.

⇒ **The person with cancer is having trouble breathing.**

Report problems with breathing, especially if the person finds it hard to draw air into the lungs or release air. Labored or difficult breathing is very upsetting, but professional staff can help. They might order oxygen or other medicines to relieve anxiety. Sometimes, the patient is worried about running out of oxygen. If this is true, tell the supply company to bring you more than one tank, and set it up where the person with cancer can see it and feel reassured that a back-up tank is handy. Use a fan to keep air in the room moving, which can make breathing seem easier. Run the fan near their face, or open windows.

Another way to ease breathing is giving anti-anxiety medicines and narcotics. Ask

the nurses to arrange this with the physician. These medicines are available in several forms; pills, liquids, and suppositories are most frequently used.

Shortness of breath can and should be relieved even up to the time of death. See Shortness of Breath for a discussion of what can be done for this problem.

What You Can Do To Help

Here are four ways that you can help during the final weeks of life:

Keep the person comfortable.

Give general nursing care.

Welcome visitors.

Cope with changes.

Keep the person comfortable

⇒ **Use an eggshell mattress and foam cushions.**

Many people with cancer lose weight; therefore, they may be less comfortable lying on their former mattress or sitting in chairs that used to suit them. Eggshell mattresses are made of foam and are softer than conventional types. Some people also cut up foam rubber to put on chairs or couches. The foam softens the seat and makes it more comfortable. Eggshell cushions and mattresses can be bought at large department stores or medical supply stores. Sometimes, visiting nurses will order a special mattress to prevent bedsores.

⇒ **Use lip balm or salve to prevent chapped lips.**

Dry lips and mouth can be a serious problem when a person is not drinking much. Some of this discomfort can be prevented by using lip balms. Avoid using Vaseline if the person is on oxygen, however, as it can clog the line.

⇒ **Use the end of a straw to give small sips of liquids.**

Some people have trouble drinking from a glass because of weakness. If so, give fluids by dipping the straw into the glass and then holding your finger over the end of the straw. This holds liquid in the straw. Drip the liquid into the person's

mouth by loosening the finger for short periods of time.

⇒ **Use a special spoon to give liquid medicine.**

Pharmacies carry special spoons that help to avoid spilling liquid medicine. The spoon handle is enclosed and looks like a tube. You can pour the medicine into the scoop part, and it will flow down into the tube and into the person's mouth. It is much easier to take medicine such as Maalox with this type of spoon, but you also can use a syringe. Have the nurse show you how to use it. If the person is having trouble swallowing, a few drops under the tongue will still be absorbed.

⇒ **Easing discomfort caused by fever.**

Sometimes, fevers develop because not enough liquid is taken. If so, encourage the person you are caring for to drink more. Cool cloths applied to the brow can help as well, but do not give icy or cold baths. In some cases, the doctor may order antibiotics to fight the infection if, for example, the infection is causing pain or discomfort.

⇒ **Manage and prevent problems with bleeding.**

Minor skin bleeding sometimes occurs because of bumping the arms or wrists on furniture. This is because the skin is not as tough as it once was. Medicines also can cause changes in the skin so that it is easily scraped open. Small gauze pads can be placed over any open spots and wrapped with 1- or 2-inch gauze to stay in place. Avoid using tape, however, as it might tear open the skin when removed.

If a nosebleed occurs, tilt the head back, but do not have the person lie flat. This could make the person choke on blood dripping from the nose into the throat. Put ice wrapped in a washcloth on the nose for short periods, such as 2 minutes.

Pressure on the skin and nose stops most bleeding. Bleeding inside the body or in the urine and stool, however, cannot be stopped in this way, because you cannot put pressure on these areas. If bleeding from the nose or other places continues, call the visiting nurse. The physician might order medication to slow down the bleeding as well.

⇒ **Consider using an electric hospital bed.**

Electric beds are easy to operate. The person with cancer can control the positions, and so can you. Hospital beds also can be non-electric, using a crank at the bottom to raise it up or bring it down and to elevate the head or feet. Cranking takes more work and bending, however. Many families set the bed in a living room or den on the first floor so that they will be near and visitors will have more room to visit.

⇒ **Let the patient plan the day.**

Letting the patient plan the day will show respect and support his or her dignity. Let the person plan what to do, what to eat or drink, when to sleep, and when to visit with others. Some people find watching television helpful.

⇒ **Touch, and talk.**

Even if the person is sleeping much of the time or slips into a coma, touching and talking remain important. Touch can include back rubs or holdings hands. Visitors can read scriptures or stories or review old times. Some people read poems, and background music can help. All of these decrease a person's sense of being alone and can be very comforting.

⇒ **Invite ministers and church members to visit.**

Prayers and conversations with ministers and fellow church members can be very comforting for some people. Priests or deacons may want to bring sacraments, such as last rites or communion. Many home health agencies and hospice groups have a chaplain on staff who can visit as well. These visits should not be forced, however. It is up to the person with cancer to decide who would be comforting.

⇒ **Understand that what you do is not wrong.**

Some caregivers worry they are not doing enough to keep the person comfortable or are not doing the right things. A few may even feel responsible for bringing on an early death. Nothing you can do (or not do) will change what is happening or lead to an early death. There really are no "mistakes" made at the end of life. The important point to remember now is that the goal is comfort.

Give general nursing care

⇒ Use a pan for bathing.

If the person you are helping does not want to get in the tub or shower anymore, he or she can sit on top of the toilet seat or on a chair in front of the sink and bathe. If the person does not feel like getting out of bed, you can help with a bath in bed. Think back on how this was done in the hospital or the way you bathed small children. You need to set a pan of warm to hot water on a table or sturdy chair, then wring the washcloth well, soap it, and help the person to bathe. Be sure to keep him or her covered with a soft sheet or blanket to avoid a chill; this is important for privacy, too. It is wise to start with the face and then do the arms and legs, the chest and back, and finish with the private area. A nurse or nurse's aide can help you with bathing.

⇒ Soak the feet in warm water.

Many people enjoy the feeling of warm water and miss bathing in a shower or tub. You can make up for this by helping the person to soak his or her feet in a pan of warm water. Do one foot at a time, and leave it soaking for about 10 minutes. This will avoid a spill.

⇒ Change the sheets at least twice a week.

If the person is spending a lot of time in bed, the sheets will get soiled more quickly. Fresh sheets usually are enjoyed. If the person is resting on couches or sleeping in a reclining chair, a fresh sheet cover is nice in these locations as well.

⇒ Help with mouth care twice a day.

Keep up the same routines for dental and mouth care, including denture care if needed. A fresh mouth makes the person feel better.

⇒ Use lotions that do not contain alcohol.

Skin dryness can become a problem as a person drinks less. Read the label on any lotion you are using, and avoid lotions containing alcohol. Gently rub lotion on the elbows, heels, back, and spine. These places are very dry and can break down.

⇒ **Prevent bedsores.**

When a person is in bed for a long time, some spots on the body can develop sores because of constant pressure. At first, they are pink, but then they turn red, the skin opens, and the size of the sore quickly increases. Bedsores start under the skin, and you may not even know they are there until they become severe. Bedsores often hurt, and the most likely places for them are where bones are sticking out, such as at the ankle bones, heels, end of the spinal column, hips, and elbows. Visiting nurses and hospice staff can help you to prevent bedsores. Call for their help if you notice very red areas or open sores.

⇒ **Do not force food.**

Forcing food will distress the person with advanced cancer as well as the family. It is natural for a dying person to want less food. This is the body's natural way of approaching death-by shutting down.

It is hard to give up trying to feed someone you care about. Using intravenous (IV) fluids or special tube feedings for nutrition are *not* part of dying naturally, but if the person with cancer wants these treatments, that is his or her right. Talk this over with the home care nurses, hospice staff, and physician. You can still offer sips of water. Cut a straw into a shorter length so that he or she can sip liquids. If the patient is too tired to sip, drop water into his or her mouth just to freshen it and give comfort. This will be very much appreciated.

Welcome visitors

Not everyone is comfortable visiting a person in the final weeks of life. Some people want to stay away. Others want to come and help. The person who is sick should have control over who will visit. Here are some ideas to help manage visitors:

⇒ **Set time aside for bathing and rest.**

Stay in control of the schedule; otherwise, visitors may come and go all day. Let people know if a visit is better in the afternoon or evening so that both you and the patient have time for rest and personal care.

⇒ **Tell visitors if they are staying too long.**

At this point, it is okay to be honest. Visitors want to know what both of you

want. If you or the person with cancer are tired, ask for shorter visits or telephone calls.

⇒ **Ask the person with cancer who he or she would like to see, and invite those people.**

The person with cancer has a right to control the social scene. He or she may not want to see certain people or, if it is a bad day, anyone.

Cope with changes

Helping someone who is very ill brings on many challenges. You may have to take on new responsibilities. You also may face new physical, emotional, or mental strains. Here are some ways to help deal with these challenges:

⇒ **Locate bills, checks, accounts, and important papers such as insurance policies.**

The person with cancer may have shared decision-making about finances with you previously. If not, it is time to locate important papers like these and talk about what they mean and what needs to be done.

⇒ **Learn new household chores.**

If the person with cancer has done certain household chores in the past, such as shopping, preparing meals, or cleaning clothes, you will have to do them yourself now or ask someone else to do what needs to be done. Nurse's aides and home helpers can do some shopping and run errands, but they may not visit daily and do not always have the time for these chores. It often is better to depend on friends, neighbors, or relatives for these things (unless you want to do them yourself).

⇒ **Ask the bank ahead of time how accounts are handled after someone dies.**

The bank will probably tell you that two names are needed on an account to be able to withdraw funds after someone has died. If you do not have two names on the account, put them on weeks *before* the person with cancer dies.

⇒ **Talk with a friend about your feelings.**

Being with a close friend or someone you can talk to is an excellent way of sorting out your feelings. Knowing that others care and are there to listen gives many people support, strength, and confidence during this difficult experience.

⇒ **Plan something nice for yourself once a day.**

Many caregivers do not take any time for themselves, and they sometimes feel guilty if they do. Going to lunch with someone or taking a nap are two examples of short activities that can help you to keep anxiety or stress from building to the breaking point.

⇒ **Seek professional help for your emotional problems.**

Many people are reluctant to ask for help from counselors; they think that it means they are “crazy” or not strong enough. Professionals such as counselors, ministers, psychologists, psychiatrists, social workers, or nurses are experienced in listening and can help you deal with your stress. These people are there to help you with emotional, mental, or psychological problems.

Physicians can evaluate if certain medicines will help you. For example, antidepressants may help. If your doctor does prescribe an antidepressant, he or she will follow you closely and watch for side effects such as blurred vision, feeling “out of it,” or extreme fatigue. If any of these side effects happen, the doctor will change either the drug or its dose. Anti-anxiety drugs also can help, especially if you are having trouble sleeping.

Possible Obstacles

Here is an obstacle that other caregivers have faced:

1. “Different family members disagree about what to do.”

Response: Tensions sometimes run high during the final days of life. People may have different opinions about a lot of issues, and it is not easy to resolve these, especially when people are upset. If a decision does not need to be made now, try to postpone any discussions of controversial issues. If a decision is needed immediately, imagine that you are looking back on it a year from now-and make the decision you think that people will feel best about at that time. Some decisions will not please everyone. Just make the best decision you can-and live with the consequences. *Always be sure that the patient’s comfort comes first.* want, but if this cannot happen, accept your own limitations. For example, if he or she wanted

to die at home but this is not possible, realize that you did all you could at home and that dying in the hospital or nursing home was the only way to ensure the person's comfort.

Think of other obstacles that could interfere with carrying out your plan

What additional roadblocks could get in the way of the recommendations in this plan? For example, will the person with advanced cancer cooperate? How will you explain what is needed to other people? Do you have the time and energy to carry out the plan?

You need to develop plans for getting around these roadblocks. Use the COPE ideas (creativity, optimism, planning, and expert information) in developing your plans, and see *Solving Problems Using This Guide* for a discussion of using these ideas to overcome your obstacles.

Carrying Out and Adjusting Your Plan

Checking on results

Keep track of your own energy, and see *Getting "Respite" Care or Extra Help at Home* for ideas. Remember, you do not have to help the person at home alone, and you can say no to the responsibility for this task if you want. If you are worried about doing a good job or unsure that you want to be doing any of these things at all, ask for help. Doctors, nurses, and social workers can help you.

Continue watching for signs that immediate professional help is needed.

If your plan does not work

1. See [When To Get Professional Help](#). If you answer yes to any of the questions there, call the doctor and find out how to get a visiting nurse or hospice professional to visit quickly.
2. Keeping someone who is very sick at home can be tiring and stressful. Be open to changing your plans about how to do this, and be honest about whether you want to do this at all. If you move the person to a nursing home,

you can always move him or her back home, or to someone else's home, when you have more energy or help.

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What To Do Before and After the Moment of Death

Overview

Understanding the Problem

- Follow the person's wishes
- “Care” compared with “cure”
- Signs of dying
- Signs that death has occurred

When To Get Professional Help

- Situations indicating that professional help is needed

What You Can Do To Help

- Help with comfort and rest
- Prepare for physical problems
- Prepare the funeral home ahead of time
- Avoid calling 911 or an emergency team
- Prepare a list of people to call near the time of death
- Feel free to say goodbye at the place of death

Possible Obstacles

- “Some family members feel we should do everything possible to let him live longer.”
- “If I prepare in advance, people will think that I want her to die.”
- “I don't want my children to remember their grandmother like this.”

Carrying Out and Adjusting Your Plan

- Ask the person if his or her wishes are being followed
- Be honest if helping at home is too much

Topics with an arrow in front of them are actions you can take or symptoms you can look for.

The information in this home care plan fits most situations, but yours may be different. If the doctor or nurse tells you to do something other than what is recommended here, follow what they say. If you think there may be a medical emergency, see When To Get Professional Help.

Understanding the Problem

The most important goal when death is near is to do what the person with advanced cancer would choose. Ideally, he or she knows what is happening and has participated in decisions about how to live and die. If not, you should strive to do what this person would want.

Most people in a hospice want a natural death. Therefore, in the last stage of the illness, physical problems are not treated with a “cure” in mind. Any chemotherapy or radiation is given to ease distressing symptoms, such as pain in a hip bone caused by a growing tumor. Treatment also can be given to prevent unfortunate results from tumor growth, such as paralysis of the lower half of the body, being unable to move one’s legs, or losing bladder control. In these cases, a few doses of radiation or drugs help patients to regain comfort. Ideally, what happens during the final days and moments of life is guided by the goal of maintaining comfort and reaching a natural death.

Following the wishes of the person with cancer may mean decisions that are different from what you would choose for yourself and that are against the advice of physicians and nurses. For example, nurses might suggest getting a hospital bed, which could make bathing and drinking liquids easier for the caregiver and the family. The person with cancer may refuse, however, because he or she wants to stay in a familiar bed. In other words, practical choices may not be the patient’s choices. If the family cannot provide care without the help of a hospital bed, they should talk this over with the patient. The family should be open about what it needs while remaining sensitive to what the person who is dying wants.

When a person has advanced cancer, dying often occurs slowly (over several days or a week or so), but it also can happen quickly (in a few hours). You should be prepared for either situation.

Each day, the person grows weaker and usually sleeps more, especially if his or her pain has been eased. Many families do not know when dying is taking place, and they are not always sure when death itself has happened. Over the past 100 years, more people have died in hospitals and nursing homes. Death has become less of a natural event in family life, and fewer see the process from beginning to end. People with illnesses once died at home, and families were accustomed to watching for signs that the end of life was near. Today, many families are choosing to be like their grandparents and to help someone

they love through the final weeks and days of life at home.

Near the very end of life, you can expect the person's breathing to become slower-sometimes with very long pauses in between breaths. Some pauses may last longer than a minute or two. This type of breathing frequently occurs if the person is in a coma; you will know a person is in a coma because he or she cannot be awakened. In rare cases, however, the person may open his or her eyes. This may surprise you. He or she usually does not talk but is awake for a short time. In other words, some people come out of, and go back into, comas. The skin will be cool, especially around the feet and hands, and it also will be a different color at these places-usually blue, gray, or some combination of both. If the person's skin is naturally dark, such as for an African-American, it will become dusky. Finally, the patient also may become incontinent of urine or stool. Usually, however, the person has had so little to drink that this does not amount to much.

At the end of dying is death itself. You will know this has happened because the chest will not rise and you will feel no breath from the nose. The eyes may be glassy (if they are open). You will not feel any pulse in the places where you felt it before. When you realize someone has just died, it is a very "still" and quiet moment.

Your goals

- Help with comfort and rest.
- Prepare for physical problems.
- Prepare the funeral home ahead of time.
- Avoid calling 911 or an emergency team.
- Prepare a list of people to call near the time of death.
- Feel free to say goodbye at the place of death.

When To Get Professional Help

Some families have never cared for a very sick person at home. Nurses, social workers, or ministers who have helped other people near death can give you advice and assistance. They can explain what is happening and what can make the person with cancer more comfortable. They also can help you to decide if keeping the patient at home is really the best decision.

Call for professional help if any of the following problems occur:

⇒ **The person is uncomfortable.**

Dying should not be physically painful. Many medicines are available to give comfort during the final days of living with cancer, and health care professionals can order these for you and show you how to give them. See Cancer Pain for information about pain medications.

⇒ **The person is having trouble breathing and seems upset, even if he or she is asleep or in a coma.**

Medicines are available that can relax persons with cancer and help them to breathe. Oxygen also helps. Breathing problems can upset both you and the person being cared for.

⇒ **The person has problems passing water or with bowel movements.**

Even during the final days of life, people need to pass water and stool. Usually, the urine is dark and comes in much smaller amounts. It does not matter that the person is not eating or drinking. The body still makes problems with urination and constipation, so call them for help.

⇒ **The person has fallen.**

Falls happen, especially when a person is weak or confused. After the fall, it may be difficult getting the patient back into a bed or a chair-especially if he or she is heavy or in pain. If you have difficulty moving the person, call for help while making him or her comfortable on the floor with a pillow under the head (and with a sheet or a blanket if necessary). If hospice or home care staff cannot come, local fire companies can be called for help or instructions about how to lift people properly. Hospice nurses also may show you how to gently help the person. If you have helpers, place a sheet or a blanket underneath the person and lift by using the sheet or blanket rather than by pulling on the person. This is a much easier and safer way to help someone back into bed or a chair.

⇒ **You are having trouble giving medication.**

Some people have difficulty swallowing and cannot take the pills that are needed for comfort. If a person is unconscious or in a coma, he or she cannot swallow and should take nothing by mouth (not even liquids). Most medicines can be given in other ways, such as by suppositories or injections. Ask the hospice staff to teach you the best way to give medicine.

⇒ **You feel that you cannot go on caring for the person at home.**

Keeping someone who is very sick at home can be tiring and stressful. You should be honest with yourself about whether you can, or even want, to care for such a person at home. If you move the person to a nursing home or a special hospital unit, you can always move him or her back home, or to another person's home, when you have more energy or help. Home care or hospice nurses and social workers can explain your options and help you to decide what is best for both you and the person with advanced cancer.

⇒ **You are upset thinking about being without the person who is dying.**

Sometimes, grief hits you before the death occurs, and you feel afraid or overwhelmed. When this happens, share these feelings with an understanding person. Hospice staff and clergy are experienced and skilled in helping you with such feelings. Friends and relatives also can help if they are understanding and supportive.

⇒ **You or the person with cancer feel that you are being punished, or you feel guilty or worried about something in the past.**

Feelings that you are being punished sometimes are mixed with guilt, regret, or sadness, as well as with feelings of being unable to forgive, get angry, or express love. Talking with hospice staff or clergy often can help to sort out your feelings and understand why you feel as you do. Understanding friends or relatives also may be helpful.

What You Can Do To Help

Here are six ways to help both the person being cared for and yourself during the final days of life:

- Help with comfort and rest.
- Prepare for physical problems.
- Prepare the funeral home ahead of time.
- Avoid calling 911 or an emergency team.
- Prepare a list of people to call near the time of death.
- Feel free to say goodbye at the place of death.

Help with comfort and rest

Rest and sleep are important even during the final days or hours before death. Some believe that death comes very gently if the person is relaxed and rested. Help with comfort and rest in these ways:

⇒ Continue giving medicine for pain on a regular schedule.

A person can feel pain even in a coma, when dozing, or when not even conscious or awake at all. Keep giving medication at the same interval as before, such as every 4 hours. If you give less medicine, or give it less often, you may notice signs of pain. Watch for clenched fists, frowns, restlessness, moaning, or attempts to turn. Should any of these occur, check that you are following the correct schedule. If you are, ask the doctor about increasing the amount of the medicine.

⇒ Play soft music if it seems to be relaxing.

Music can be very soothing, even when a person is not conscious.

- ⇒ **Have two people gently turn the person every few hours, or rearrange his or her position with pillows.**

Turning the person does not have to be hard to do if you use two people. One stands on each side of the bed. Move the person from lying on his or her back so that he or she is tilting toward one side for a few hours. Then, a few hours later, turn the person completely on that side. As time goes on, repeat this in the other direction, returning the person back to lying on his or her back for a few hours and then to lying completely on the other side. Pillows and cushions can be used to prop knees or arms off the bed to avoid bed sores, and rolling a pillow and tucking it behind the back will keep the person lying on his or her side.

- ⇒ **Use a folded sheet under the heavy part of the body to help with turning or lifting the person to the top of the bed.**

Take any single- or double-sized sheet and fold it into a square that is a little larger than the bed underneath the person. Then, roll up half of this square, turn the person to one side, and slide the square under the patient. When you turn the person onto his or her back, you can pull and smooth out the rolled up half so that the person is now lying on top of the square. If you need to pull the person up in bed, have two people take hold of the square, on each side of the bed, and lift the square so that the person is lifted slightly off the bed and gently slide him or her to the top of the bed. This works because the heaviest weight of the person is off the bed and two people are lifting with equal pull on both sides.

The square sheet also can be used to help with turning a person from side to side. Ask a visiting nurse or nurse's aide to show you how to do this, and practice with them until both you and those helping you know how to turn and move the patient.

- ⇒ **Give back rubs, and maintain skin moisture with lotion.**

Gently rubbing the patient's back, arms, legs, or hands with lotion relieves any muscle soreness and aches, and it helps the person to feel cared for and not alone. Avoid lotions with alcohol in them, however. The skin usually is dry at this point, and alcohol-based lotions will only make it drier.

⇒ **Roll up washcloths or small towels, and place them inside the patient's hand after shaping it into a loose fist.**

Sometimes, a weak person's hands can grow stiff and almost freeze in position unless they are massaged and moved. Gently roll the wrist back and forth, massage the palms, and then massage and move the fingers. Afterward, place a rolled washcloth inside the palm and shape the fingers around it.

⇒ **Avoid using bright lights.**

Soft lighting is easier on the eyes and promotes an atmosphere of rest. People with brain tumors often are bothered by bright lights or daylight; they prefer darker rooms. Explain to visitors why the bedroom or other setting is dark.

⇒ **Moisten the patient's eyes, or use a warm, damp cloth over them several times a day.**

Toward the end of a person's life, the skin dries out, and so can the eyes. If the eyes are left open and are very dry, they also can develop sores that are uncomfortable. You can avoid this by moistening a cloth and gently placing it over the person's closed eyes.

⇒ **Moisten the person's lips, and use lip salve or balm to prevent dryness.**

The lips and mouth also can get very dry, so use whatever balm or ointment has worked in the past to keep the person's lips moist. A few drops of water into the mouth every few hours can help to prevent severe drying. Some over-the-counter balms, such as Herpecin-L, also prevent mouth sores and ulcers, which can appear at the corners of the lips and cause discomfort.

Prepare for physical problems

Preparing for a close friend or family member to die means thinking about some basic questions ahead of time. This will make it easier to deal with problems when they occur. Hospice and home care staff know which problems are likely to happen and how to prepare for them.

- ⇒ **Keep the phone numbers of home health nurses, hospice staff, and physicians nearby.**

These numbers may be hard to find when you are under stress or feeling as if you are in a crisis situation. Make a list, and keep it on the refrigerator or by the phone. Everyone helping with home care needs to know where these numbers are as well, so make sure to point them out.

- ⇒ **Have pain, anxiety, or sleeping medicine at home in liquid or suppository form, or check that a local pharmacy has them.**

You may need to change from pills to liquid medicines or suppositories as the condition of the person with cancer changes. Hospice staff can talk you through a new way to give medicine, either during home visits or by phone. Most pharmacies have the necessary drugs in the forms that you will need. Hospital pharmacies can help as well, and the hospice or home care nurse can assist you in locating such medicines if you live in a small town or rural area. It is very important to plan ahead for how you will change from pills to liquids or suppositories.

Some doctors recommend atropine to dry up throat secretions that cause a gurgling sound or make it harder for the person to breathe. This drug can be very helpful. It dries respiratory wetness, so the person with cancer does not need to cough up secretions, which can be very distressing.

- ⇒ **Fold a sheet to use as a lift sheet, and save newspapers or plastic bags to protect the mattress from any liquid or urine spills.**

During the final weeks of life, the person with cancer will likely be staying in bed. It is important to keep the bed clean and dry for sanitary reasons as well as to promote a feeling of well-being.

- ⇒ **Select a pan that can hold water for any bathing that is done when the nurses are not visiting.**

Warm water baths, even in bed, are relaxing and make a person feel fresh. If the person with cancer allows family members or friends to do this, be prepared with a pan, washcloths, and a light blanket to keep him or her covered during baths.

⇒ **Obtain extra sheets to fit the person’s bed, even if you need to borrow them.**

Some families find they need extra sheets because they do not have the time or extra help to do laundry. Extra sheets also can be helpful when lifting or turning the person in bed.

⇒ **Keep candles, flashlights, and blankets ready if severe weather cuts off power.**

Power failures do occur. Have a few back-up lights ready by stocking candles, matches, and flashlights, and prepare to keep the patient warm with extra blankets.

⇒ **Write information and instructions about home care and people to call in a single notebook.**

Tell people who are helping you where the notebook is, and ask them to read it and be sure they understand your instructions. This will ensure good care for the person with advanced cancer when you are away.

Prepare the funeral home ahead of time

⇒ **Inform the funeral home that you expect a natural death in the near future.**

Preparing the funeral home staff will help them as well as you. They will recognize your name and be prepared when the death occurs, and they can check with the primary physician to be sure that the death is expected and “natural.” Most hospices will make this call to the doctor or the funeral home for you, which reduces the chances of a misunderstanding or unnecessary questions when they come to take the body. Although rare, some funeral staff may wonder if any “foul play” has occurred (and if they should call the police). Such questioning happens more often in cities rather than rural areas, but no matter where you are, the hours just after death is not a time when you want to deal with suspicious people.

The funeral home staff also can tell you about the costs and different kinds of services so that you can be thinking about what you want and can afford. Some families prefer to make these arrangements early so that the person with advanced cancer can help in the planning. Others make these arrangements just before death occurs.

⇒ **Do not feel that you must call the funeral home immediately after the person dies.**

Once the person with cancer dies, some people want to “get on with it” and have the body picked up quickly. Others prefer to sit with the body, cry, and talk. Sometimes, friends and family who were not present at death want to see the body before it is moved from that last place where the person was alive. If so, wait for the others to arrive and express their grief. Time is no longer an issue. The body can stay in the home for quite some time before the funeral home staff needs to pick it up. If the person died in a chair, it is best to lay the body down on a couch or bed after death and the first goodbyes are said. Even if the person had lost a lot of weight, lifting the body will be difficult and probably take at least two adults.

Avoid calling 911 or an emergency team

⇒ **Understand what calling 911 means.**

When you or someone else calls 911 or the emergency number in your area, you need to remember that the crew will arrive expecting to *save* a life or give “aggressive treatment”- even, in most states, if the person has a “living will” containing his or her wishes to the contrary. Ambulance crews are bound by law to do this. Aggressive treatment means inserting tubes, trying to start the heart if it has stopped, and attempting to move air into and out of the body. These attempts to restore life rarely work for people who have died from advanced cancer, and they do not help with the person’s comfort.

It may take time to persuade the crew that you want help controlling a symptom, such as trouble with breathing or pain, and that you do not necessarily want them to save a life. Any emergency team will want to know who the primary doctor is, and they may want to call his or her office after the situation is “under control” and the distressing symptom has been relieved. Should the person with cancer die while they are there, expect the emergency team to do what they know best: life-saving action. They also probably will move the patient from the home and to the hospital, and even admit them to an intensive care unit.

Once the person is in a hospital, whatever is in a living will may be ignored until the physicians agree that the he or she can be allowed to die a natural death. In many states, a living will that is valid at home is not valid at a hospital until a

doctor puts it in the

hospital chart. Sometimes, living wills that were put in the chart earlier are lost, and you will need a new one. Do not assume that a living will accepted at one hospital will automatically be accepted at others.

Some small towns, rural areas, and certain states allow communication between home health agencies and hospices and local 911 or emergency response teams to prevent this problem. If the patient and family agree, hospice staff can inform local emergency teams in advance about who has a terminal illness and what the goals should be if the family calls for “emergency” help. Unfortunately, many areas of the nation do not permit this type of practical information exchange, and they do not let 911 teams follow the wishes of a living will. Check to see what is allowed in your area by asking your hospice team.

- ⇒ **Ask someone you trust to tell others that calling an emergency team is not the best idea when the goals are comfort and care, not cure and life-saving.**

Be sure to tell people who sit with the patient or provide nursing care that calling 911 is not what you and what the person with cancer want (if that is truly the case). Post this information on the refrigerator or near the phone if you are not home while others are providing care.

- ⇒ **Call the hospice or home health staff if the patient has fallen.**

If the hospice or home health staff cannot visit, ask if you should call 911 or your local emergency response number. They can help you decide what the next step should be, and they are available 24 hours a day.

Prepare a list of people to call near the time of death

- ⇒ **Decide who would want to visit the home near the time of death to say a final goodbye.**

One way to know this is by listening to people’s requests. Some will ask to be called when the time is near. As a caregiver, however, you cannot be all things to all people. Ask someone else to make a note of who wants to be called. Not everyone will be home or available by phone that day, so ask your designated

caller or someone else to take responsibility for calling those who could not be reached.

⇒ **Make a list of people who want to know when the person dies or to hear near the time of death.**

After you and any family and friends decide who wants to be called near the time of death, make a list of their names and phone numbers. Otherwise, make a list of how to get in touch with these people so that they are told about what has happened.

⇒ **Decide who would be most helpful to you near the time of death.**

You likely will feel tired and stressed near the time of the person's death, and this is when you need, and should get, help. You will give better care and be under less stress if you get this help from others. If possible, tell them in advance that you may need help; otherwise, just call and say, "Could you do this for me?"

⇒ **Ask selected adults to be "on call" to help with any younger children near the time of the person's death.**

Some adults have a way with children, and children also like and trust certain adults. If you know such adults, ask them to play with and help any children who are present.

⇒ **Decide if clergy or a counselor should be called before or at the time of death.**

People with advanced cancer may want to talk to a minister, priest, rabbi, or counselor when they are very ill or dying. Prayers, rituals, and silences with these people can be very comforting to the person letting go of this life as well as to those people involved in his or her care. If the person with advanced cancer wants this, call ahead of time and ask the minister or counselor to visit before the time of death.

Possible Obstacles

Think about ideas or attitudes that could stop you from following the wishes of the person with cancer and preparing for his or her death. Here are some examples of obstacles that other caregivers have faced:

1. “Some family members feel we should do everything possible to let him live longer.”

Response: Usually, when people say “we must do all we can,” they are really saying “I’m not ready to see this person die.” They are saving the person’s life to avoid facing the death and the loss. “Heroic” measures should be pursued only if the person with cancer wants them. Doctors and nurses should talk with the person about these decisions before a crisis occurs, and they can ask the person to fill out a living will that states his or her wishes about the end of life.

2. “If I prepare in advance, people will think that I want her to die.”

Response: People will always have opinions no matter what you do. Preparing for a death, such as calling the funeral director ahead of time, will help to make the time after a person’s death easier and resolve some of the unknowns. No one has the right to make judgments about how you have handled the death. Every family is different, and you know what is right for you and your loved one.

3. “I don’t want my children to remember their grandmother like this.”

Response: Seeing a very sick person can be upsetting for children, especially if the patient is connected to tubes or machines. As long as children are prepared for what they will see, however, the benefits of such a visit usually will outweigh the negatives. Think about what the children can learn by seeing someone who is very sick. In a sense, it prepares them for the future, because sickness is one of life’s realities, as is death. Why hide this part of life from them? Letting children visit also tells them they are an important part of the family, and it teaches them that death is something people can cope with. See *Helping Younger People Cope With Death And Funerals* for more ideas about how to make visits with sick relatives or friends easier on them.

Think of other obstacles that could interfere with carrying out your plan

What additional roadblocks could get in the way of the recommendations in this guide? For example, will the person with advanced cancer cooperate? How will you explain what is needed to other people? Do you have the time and energy to carry out the plan?

You need to develop plans for getting around these roadblocks. Use the COPE ideas (creativity, optimism, planning, and expert information), and see Solving Problems Using This Guide for a discussion of how to use these ideas in overcoming your obstacles.

Carrying Out and Adjusting Your Plan

Carrying out your plan

The moments around the time of death are charged with emotion for many reasons, and you probably will need help from a home health or a hospice nurse and staff at this point.

Checking on results

Ask yourself if the person you are caring for is comfortable and if his or her wishes are being followed. Also, ask if you have the physical and emotional strength to give the care that is needed. If not, other settings, such as nursing homes or a hospice or palliative care unit in a hospital, are available.

If your plan does not work

Helping someone to die at home is hard work, and you may need to take the person you are caring for somewhere else to live out the final days of his or her life. This is not a failure on your part. Family members and friends can visit and not feel so responsible for nursing care or for keeping the patient comfortable. You can still help to give basic care in a nursing home or a hospice as well and be sure that the person is comfortable.

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*The American College of Physicians Home Care Guide for Advanced Cancer:
When quality of life is the primary goal of care.*

Helping Younger People Cope with Death and Funerals

Overview

Understanding the Problem

Adults have different opinions about including children
Young people have a right to be included in decisions that affect them

When To Get Professional Help

Situations indicating that professional help is needed

What You Can Do To Help

Invite young people to visit the person with advanced cancer
Answer concerns about dying and death
Share decisions about who goes to funerals or memorial services
Deal with the possible disapproval of other adults
Help young people at the funeral or memorial service
Expect struggles with grief both now and in the future

Possible Obstacles

“Aunt Mary may never speak to us again, that’s how strongly she feels about the children coming to the funeral.”
“Children are too young to know what’s going on.”

Carrying Out and Adjusting Your Plan

Watch for early signs of emotional problems
Seek professional help if problems persist

Topics with an arrow in front of them are actions you can take or symptoms you can look for.

The information in this home care plan fits most situations, but yours may be different. If the doctor or nurse tells you to do something other than what is recommended here, follow what they say. If you think there may be an emergency, see When To Get Professional Help.

Understanding the Problem

People have different ideas about whether to include children-no matter what their age-at the bedside during someone's final days of life, at the time of death itself, and at the funeral. Opinions about this differ depending on the family's manner of handling such matters and also on the type of death involved. For example, was the death sudden, or did the illness last a long time? Some adults do not want children seeing someone they know growing weaker or hooked to tubing. Opinions also depend on what the child's relationship is with the person who has cancer. Is it a parent? A brother? A sister? A close relative or friend? If it is someone the child does not know very well, maybe it is less important for the young person to visit. Also, consider whether other helpful adults or older children can pay attention to the child and help with any questions and feelings.

Along with these practical questions, people's ideas about whether children should be involved also are shaped by what they were told when they were little and someone died. Our opinions are shaped by what we learn from our own families about what is "right."

Finally, your opinions about including children are shaped by how you cope with sadness and death yourself. Everyone copes differently.

Your goals

- Know when to get professional help.
- Plan ahead for any visits by children.
- Answer concerns about dying and death.
- Share decisions about who goes to funerals or memorial services.
- Deal with the possible disapproval of other adults.
- Help young people at the funeral or memorial service.
- Expect struggles with grief both now and in the future.

When To Get Professional Help

Normally, professional help is not needed to make decisions about including children in events. Most questions and concerns can be worked out by family members or friends. A few clues might tell you that children or teenagers are having unusual problems, however, whether it is dealing with watching the person who has cancer grow more ill, with the idea of the funeral, or even with death itself. This is when professional help can

make a difference.

Call on professionals such as teachers, school psychologists, ministers, youth group leaders, social workers, or hospice staff who have helped you if young people are doing any of the following:

- ⇒ **Having trouble sleeping.**
- ⇒ **Showing disruptive behavior at school.**
- ⇒ **Doing poorly in school, if this is a change.**
- ⇒ **Acting differently, such as being quiet and sad when before they were happy and talkative.**
- ⇒ **If you do not know how to handle certain situations and want to talk them over with someone other than family members.**

What You Can Do To Help

Usually, caregivers are busy making decisions near the time of death and before any funeral or memorial service. While you may want to pay more attention to how children or teenagers are feeling and their questions, you may not have time. You also may not have the energy. Do not attempt to take care of everyone else's needs at this point. Instead, think about asking someone special in your circle of family or friends to help with this.

Many questions may come up about involving younger children and teenagers in the final weeks or days of life. This section will help you to:

Invite young people to visit the person with advanced cancer.

Answer concerns about dying and death.]

Share decisions about who should go to funerals or memorial services.

Deal with the possible disapproval of other adults.

Help young people at the funeral or memorial service.

Expect struggles with grief both now and in the future.

Plan ahead for any visits by children

Usually, fewer and fewer people visit during the final days of life, regardless of whether the sick person is at home, in a nursing home, or in a hospital. If visitors or family have children, a common question that arises is whether to bring them. Here are several ways to handle this question:

⇒ Learn what the child knows about what is happening.

If the child knows “Grandma is very sick,” ask the parent or guardian to paint a more complete picture so that the child is prepared. For example, grandchildren may not have seen Grandma recently, but they know what a person looks like in bed. If Grandma has lost weight, say that she shrank a little but is all there, the same height but just smaller. Also, prepare the child by mentioning any other visible differences, such as hair or skin changes. Use simple words. Most important, reassure the child that Grandma knows the child is there even if she is sleeping. If she is awake but not talking, tell the child that Grandma will look but not talk because she is resting.

⇒ Ask the child what he or she thinks is happening, and invite questions.

⇒ Suggest that two people come with young children to visit.

Children have their own ideas and questions about what is happening, and they can be very open about what concerns them. For example, their understanding of dying and death is not the same as ours. It is not formed until 8 or 9 years of age, and even then, children do not fully understand the permanence or finality of death. Teenagers have a much fuller understanding, but their questions may be harder to answer. (“Why is life unfair to good people?”) Different ages have different types of questions. Answer them simply, and if you do not have the answers, be honest and say so.

If young children want to visit with the dying person, remember that their attention span for the visit may be short. After they greet and see the person, they may quickly lose interest in the visit. Other parts of the home or the hospital may become more interesting. Another adult or teenager can take them out and entertain them so that the child is not fidgeting or feeling forced to stay in one place.

⇒ Be prepared for different expressions of feelings from children and from

teenagers.

Even if you think young people are “handling this well,” they may have many new and unspoken feelings. Teenagers need time to think about these. If they are close to the person who is dying, they may feel angry, sad, confused, disappointed, or abandoned. Some teens will talk about this; many will not. Young children can feel the same way, but they are *unable* to talk about it. Therefore, these feelings sometimes come out through sudden changes in behavior, such as acting like a younger child, toddler, or baby. In many cases, this is a safe way for them to let out their feelings.

⇒ **Ask adults you trust to pay attention to young people who visit and listen to their feelings and questions.**

As a caregiver, you have a lot going on, and taking care of children or teenagers can seem overwhelming. This is a task you can share with adults you trust. When you think things are not quite right with younger relatives or children, ask others to check in with them. Friends of the family are good to ask; they can help by paying attention to young children and listening to teenagers.

Answer concerns about dying and death

Children have different questions about death at different ages. They are able to understand death better as they grow older and gain more experience. For example, they may have seen a pet die, or a friend may have lost a parent. They may have read books or watched television and come to know that death is forever.

Young people’s questions about death can be surprising, and they may challenge you at a time when you are tired and trying to make many decisions. The following suggestions may help you to handle questions during the days immediately surrounding the death:

⇒ **Find someone who will listen to the children’s concerns about dying and what happens after death.**

You probably know who your children trust, and if you do not, ask them. Children are honest. For example, if you are a mother with a young child, you might ask, “If you hurt your finger and couldn’t find me, who would you want to help you?” Teenagers might want to know why you want them to find someone to talk with. In this case, say that you have found it helps to talk and sort things out aloud. (Of course, they may or may not take your advice.)

⇒ **Use pictures, dolls, or books with young children.**

Young children may want to draw pictures illustrating how they feel or what they know. This way, questions can come up as you ask them what is in their pictures or why they used certain colors. Another way is for them to play with dolls. Ask them to play, and tell them that today, one doll is Grandma. Watch what they do. This also is a good way to get children ready to see Grandma if she looks different from the way that she looked the last time they saw her. Tell the child that Grandma sleeps a lot now and is in bed all the time. Ask the child to put “Grandma” in bed. Some children may take care of the doll in bed; others may get mad and throw the doll across the room. Young children experience many feelings when there is a sickness in the family. This is normal, however, and you can help them by accepting how they feel.

The hospice may have books to help you reach young children and their feelings. They also may have a list of books available at your local library. Storybooks can help young children to recognize their feelings even when they cannot express them. There are many good ones: picture books for very young children, and books for older children that deal with the serious illness and death of a loved one.

⇒ **Suggest that an older child talk with someone outside the family.**

Older children or teenagers might confide in a school counselor, teacher, school nurse, minister, church leader, Sunday school teacher, youth leader, or neighbor. They may be open with friends about their worries through books or art or music. Then again, they may say nothing at all. Tell them you want to know how they are doing, but add that you know it sometimes helps to talk with someone who is not related or close to the family. Then drop it. Do not push.

⇒ **Be prepared for tough questions about life after death.**

Answers about where people go after death or why people suffer and die vary from family to family, from one religion to the next, and even from one society to another. A Spanish family might believe things about heaven that differ greatly from the beliefs of a Chinese family. Some adults have very set ideas that life after death exists. They can describe heaven very clearly, and they know the way to get there. Believing in life after death-no matter what the religious viewpoint, faith, or path to get there-brings comfort and hope to many people. Other adults may say that the answers to these questions are a mystery. The best answer to say

is what you honestly think in simple, short explanations.

It is important that young people be able to talk with someone who will listen to their concerns. During their lives, they will hear different answers to these types of tough questions: What happens after death? Why do good people suffer? The important thing is that the young person is thinking about these issues, which is a vital part of growing up.

⇒ **Be prepared for tough questions about what happens to the body.**

Teenagers can understand the difference between being buried and being cremated, and children of all ages may be curious about what happens to the body after death. If you or others are uncomfortable talking about this, refer them to people you know and trust. These could be members of the clergy, relatives, or friends. Hospice staff can speak with them as well. Young people should talk about their concerns with someone who will listen. These questions often lead to matters of a more spiritual or religious nature, such as where does the “spirit” go?

⇒ **Answer all questions.**

Answering questions is important, because what children might imagine can be far worse than what actually happens. Young children have simple questions that deserve simple answers. For example, “When they put that tube in Daddy? Is that what killed him?” Without the opportunity to talk about this, a child can grow up being afraid of needles or tubes. Others might say, “I heard Aunt Mary say that Grandma starved to death. Did she?” If children hear this—and with cancer, they often do—and believe it, they can feel guilty that they did not feed Grandma. They also can become angry that others did not feed her.

Young children may ask the same questions many times. This is perfectly normal, however.

⇒ **Remind children that it is no one’s fault when someone dies.**

Children usually will not ask directly if it is their fault that a close relative has died. Guilt is a very common reaction, however, even though it is not reasonable. With young children, say something like, “Just because you got angry at Mommy sometimes, that doesn’t mean it’s your fault that she got sick and died.” It also is helpful to give children permission to be angry, because anger is a normal part of losing someone you love. You can say something like, “Sometimes I get so mad

that Daddy isn't here anymore." Children need to know that these feelings are normal and acceptable.

Share decisions about who should go to funerals or memorial services

Ask for help making decisions about children attending services or for help looking after them, either at services, at home, or at someone else's house.

⇒ Ask young people if they want to go to the service.

Asking young people this question depends, of course, on their age. Very young children cannot help you to make a decision, but older ones can. Making decisions for these children leaves them out. Young children and teenagers should not be protected from the reality of death, nor should they be shut out of the meals or talks after the funeral or memorial service and burial, if there is one. Shutting them out makes them feel alone. It also gives them the idea that death is so horrible that it cannot be coped with.

Funerals can help young people face their grief. Letting them listen to the planning for the funeral and including their ideas makes them feel that they belong to something that will live on. It also gives them a chance to talk about what has happened. Letting them be part of the "rituals" (the things a family normally does when a death occurs) is an important way to learn about this part of living.

Young children (younger than 8 or 9 years) do not understand that death is permanent. They will ask when Mommy or Grandma is coming back. If young children are not included in the funeral ritual, it will be harder for them to understand what has happened. If they have attended the funeral, however, you can say, "Remember when we all went to see Grandma in the casket, and then we went to the cemetery . . . ?" Without this memory, it will be harder for you to help these children understand.

⇒ Ask young people before the service how they are feeling about what is happening.

Even after young people know they are going to a funeral, new feelings can surface. Relatives may be arriving. They may meet people who are unfamiliar to them but who claim to remember when they were little. It can be a confusing time. If you are to help them, you need to be aware of what they are feeling.

Tell children what to expect at the funeral home, what they will see, and what will happen both before and after the service. This helps them to prepare for this new experience.

⇒ **Let them change their minds.**

Young people may decide they want to attend services but then change their minds. Let them decide. They know what they want to do. If it is important for you to have them there, such as with teenagers, ask them to attend for your sake.

⇒ **Remind yourself as well as them that it is the memory of the person's life, not the person's death, that is important.**

It is okay if a young person does not want to go. If a child is very firm that he or she does not want to attend the funeral of a close relative, however, it usually signals that the child is very troubled or confused. Children typically are fascinated by funerals and, most of all, want to be included as part of the family. See if you can get the child to tell you what is worrying him or her about the funeral. Children can have many misconceptions and fears that should be cleared up so that they can feel okay about saying goodbye to the person who has died. Remembering relatives or friends when they were alive is what is important; however, funeral services help to remind us that death really has happened. Children of any age usually will benefit from this (just as adults do).

⇒ **Include them in meals or gatherings after services.**

Children want to feel that they belong, and leaving them out of special gatherings after services sends a message that they are unimportant. Many times, their feelings are hurt. If a child is struggling with sadness or fear, he or she will feel that much sadder and more abandoned.

Deal with the possible disapproval of other adults

⇒ **Expect some adults to disagree with your decision to allow children to attend a memorial or funeral service.**

Some adults cannot bear to see a child suffer because they are so upset themselves about the death. They want to protect the young person from feeling what they are feeling. Some relatives and friends may say it is a bad idea to let young people attend a funeral. They will say things like, "Seeing grown-ups cry will be too

upsetting for her,” or, “Children do not belong at funerals.” If you and other adults decide it is a good idea to include the younger child, some adults may go so far as to say that this is “cruel” or “awful.” Although this is rare, should these adults see the child cry, whether at the funeral or later, you may hear them tell others that you should have followed their advice and hint that you made a bad decision. This can be difficult, but the opposite decision would have been difficult as well. This is a situation in which someone must make a decision, and you know your children best and will be the one dealing with their feelings later on. The job of a parent is to help children deal with life and its sadness. Dealing with death is just one more part of learning about life.

Help young people at the memorial or funeral service

⇒ Assign someone to supervise young children.

Very young children probably will lose interest in the service after a short time. Try to find an adult who can be with them and can leave the service if they are restless.

⇒ Let the child visit the church or place where the service will be held.

Very young children like to know that they can get basic needs met in new places. Visit the church or place where the service will be held ahead of time. Show them where the restroom is, where the water fountain is, and any play areas. This helps them to feel more secure at the service, especially if the person who died was a parent. Remind them that they do not have to stay if they do not want to. They can go outside with an adult and play or take a walk.

⇒ Assign someone to supervise everyday tasks.

Young people need supervision with everyday tasks such as bathing, dressing, eating, and sleeping. They need to keep playing or spending time with friends if they are home. They also need activities if they are traveling and staying somewhere else. If you, as the caregiver, are too busy to think about these things, ask someone who knows the child to make sure that his or her everyday routines are followed.

Expect struggles with grief both now and in the future

⇒ Listen to what others tell children that can either help or confuse them.

Other adults, and even relatives, may tell young people how to feel, such as “Be brave and strong.” They also will have ideas about how they should behave, such as “Don’t cry,” or, “Be extra nice to your mother this week-she just lost her father.” They also might have ideas about what the person who died might want to see the young person doing, such as “Your father wouldn’t want you to cry for him.” Adults who say these things mean well; however, their advice comes from the messages they received from their own parents or relatives when they were young.

Young people and teenagers may be confused when one piece of advice differs greatly from another. One adult may say, “Be strong and don’t cry,” while another may say, “It’s okay to cry,” or, “Crying means we loved your father and will miss him very much.” You should be aware of these conflicting messages so that you can help the child to understand why people feel differently and to be comfortable with how he or she acted.

⇒ Tell them it is okay if they do not know how they feel.

Not everyone knows how he or she feels. If children or teenagers do not know, tell them it is okay. They should not feel guilty about feeling nothing while everyone around them is sad or upset. Their feelings may come months later, so it is important to continue to ask them how they are feeling after the funeral and burial.

⇒ Normal grief reactions.

Many changes follow the death of a close family member or friend. It can help to make a list of everything that went away or changed to understand what the child is experiencing. If young people were close to the person who died, they will feel grief (just as adults do). Tears often come and go in the first weeks after a death. Young people might even feel relieved that the waiting is over and that the death has finally occurred. Children grieve differently than adults-they usually do not cry for long periods of time but are sad briefly and then carry on with their normal activities. This does *not* mean that they fail to understand what has happened. It means that they are not capable of the same prolonged, intense reactions that adults are.

Normal grief reactions include:

Shock and disbelief-At the beginning of grief, death is hard to accept, even if the person had been sick for a long time. This disbelief can give some protection against intense feelings.

Memory-Gradually, memories and pictures of the person become less clear in the mind. Some people may worry this means the person was not that special to them, and they may feel guilty that they cannot always remember what the person looked like.

Dreams-People may have dreams about the person who has died. Some find these dreams very comforting, but others are upset by them and wake up feeling very sad.

Tears-Months later, tears may unexpectedly flow, and this can surprise young people who thought they were “getting over it.” This may be because the child is accepting the heavy feelings that come with realizing that the person has died and will never return.

Fears after a parent dies-Children can be fearful after the death of a parent, and they may wonder what will happen to themselves now. If one parent has died, they may fear losing the other. Familiar household routines can change. The remaining parent might be depressed and grieving, and he or she might have to go to work and leave the younger person with more time alone than before. For whatever reason, young people can feel worried about themselves and what will happen in the future, and it is important to reassure them that you have thought about these things as well. You might say, “It would be very unusual for me to get sick, too. And there will always be other people to take care of you if something should happen to me. That isn’t something you need to worry about.”

Anger and withdrawal-Teenagers may become especially angry after the death of someone close to them. They may feel that the world is unfair, and they may lash out at others or withdraw. Some feel panic about the future and are scared of getting close to others. They may wonder if they are going crazy. They can feel guilty about what they did or said to the person who is gone and be unable to forgive themselves. And just like adults, they also may regret what they did not do.

Sadness-Feelings of sadness may come and go over a long period of time. If young people are allowed to talk with others who are understanding, healing is more likely. How well they knew the person who died and how much they depended on him or her will affect how long these feelings last.

⇒ **Expect special days to be emotional.**

Adults and children often feel grief most strongly when holidays are approaching, around the date of the death itself, and during other special times, such as anniversaries or birthdays. This can happen even when they are not looking at calendars or paying attention to the dates. Children may be upset at these times because they remember the person who died or they are responding to your feelings. Support groups for adults and children can help at these times. Group members can agree it is a harder time than usual, and they can tell similar stories about their reactions to special days that reassure the grieving person.

Consider a group for grieving children if you think the child could use support from other young friends or teenagers. The blue pages in many telephone books list “Support Groups.” You also can check with cancer centers in your area or the American Cancer Society to find them, and they often can recommend reading materials to help you understand how to help children deal with death.

Possible Obstacles

Here are some common problems that adults run into when including young people during the last weeks of life and at funerals or memorial services:

1. “Aunt Mary may never speak to us again, that’s how strongly she feels about the children coming to the funeral.”

Response: Forget Aunt Mary for now. You cannot please everyone, least of all at an emotional, chaotic time like this. Talk the decision over with the children and a trusted friend or other adult, and make the decision that you feel is best. Read this plan for ideas about how to make the event easier for children and other adults.

2. “Children are too young to know what’s going.”

Response: Children know when something is wrong or different. Even young

babies might be more demanding because their schedules have changed or they are getting less attention. If you do not deal with their feelings now, you will have to later-and it will be harder then.

Think of other obstacles that could interfere with carrying out your plan

What additional roadblocks could get in the way of the recommendations in this plan? For example, will the person with advanced cancer cooperate? How will you explain what is needed to other people? Do you have the time and energy to carry out the plan?

You need to develop plans for getting around these roadblocks. Use the COPE ideas (creativity, optimism, planning, and expert information), and see Solving Problems Using This Guide for a discussion of how to use these ideas in overcoming your obstacles.

Carrying Out and Adjusting Your Plan

First, get accurate information about how the child is feeling and reacting to the illness or death. Talk with him or her about what has happened and how he or she feels. Show understanding for what the child is experiencing, and explain how you feel.

Talk with other adults who will be present about the child's feelings, and ask for their help. You probably will have many other problems to deal with during this period, so ask other adults to take over some of your responsibilities with the child.

Checking on results

Be alert for problems the child may have in dealing with the situation, the loss, and the changes in his or her life. Encourage the child to tell you how he or she is feeling by showing that you want to understand. Try to notice problems early, before they become severe. Check with school personnel such as teachers and the school nurse to gauge how the child is doing.

If your plan does not work

Be understanding. This may be a difficult period for the child, especially if he or she must deal with many life changes. Problems usually will decrease over time.

If the child remains very upset for many months or his or her behavior is destructive or very upsetting to others, get professional help. Some clergy are experienced and skilled in dealing with emotional problems related to death. Mental health professionals- especially those experienced with the child's age group-often can help by talking to you and the child about your problems.

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*The American College of Physicians Home Care Guide for Advanced Cancer
when quality of life is the primary goal of care*

Grieving

Overview

Understanding the Problem

Normal feelings to expect after the death of a loved one
Each person's reaction to the loss of a loved one is different, and each person must work through grief in his or her own way
There is no "right" or "wrong" way to feel after someone dies
Most people who are very upset over someone's death take months to get beyond the most severe emotional stress. Grief beyond a year is common but may require help

When To Get Help

Start with your family doctor
Symptoms indicating the need for professional help
Information to have ready when you call for help
What to say when you call

What You Can Do To Help Yourself

Allow yourself to experience the pain of grief
Select a person to share your grief with
Find what works for you in returning to normal routines
Read books or poetry on the subject
Keep a diary or journal
Encourage others to talk about the deceased
Talk out loud to the person who has died
Find out about a bereavement support group

Consider Obstacles

"People say I should be over this."
"People give me advice that I don't want to take."
"Nobody wants to talk about Dad when they're around me."

Carrying Out and Adjusting Your Plan

Checking on results
If your plan does not work

Topics with an arrow in front of them are actions you can take or symptoms you can look for.

The information in this home care plan fits most situations, but yours may be different. If a doctor, nurse, or counselor tells you to do something other than what is recommended here, consider all of the information and apply what is meaningful to your own needs.

Understanding the Problem

People who lose a friend or family member to cancer face the same issues as anyone who experiences the death of a loved one, whether by accident or illness. Your feelings and emotions after someone's death can profoundly affect how you relate to others and get through your daily routine. Depending on your personality, you may find it helpful to confide your feelings to another person-sometimes a friend is best, sometimes a family member, and sometimes a professional such as a nurse, a counselor, or a member of the clergy. You may find consolation through sharing or listening at a group-sharing session involving others who have had a recent loss; such groups usually are led by a counseling professional. On the other hand, if you have never been open about your feelings, it is unlikely that you will suddenly change now. Well-meaning people may insist that you must talk it out, but they may not understand you, your past, or your methods of dealing with life's difficult moments.

Each person must work through grief in his or her own way-and it is work (even if not always of the physical kind). Despite the existence of widely published "stages" of grief, each survivor deals with loss as an individual, and the ways in which people handle their loss vary widely. When you are struggling to deal with your own loss, it is useless to worry about whether you are following somebody else's timetable.

The range of reactions to someone else's death is broad. Some people are devastated when it occurs, and others feel very little emotion. Sometimes, people feel their grief only later, and some people never have strong feelings. Different people also may experience different emotions. They may feel guilt, remorse, sadness, or resentment toward others, such as doctors, nurses, hospice workers, or even God. Some people who lose a family member or close friend feel anger and ask questions such as "Why did this happen to him (the one who died)?" and "Why did this happen to me?" Anger also may reach back to events that occurred during diagnosis and care, and you may ask, "Why didn't the doctors find the cancer soon enough?" or, "Why did mother suffer so?"

You may think that you hear the deceased person's voice calling to you, or you may want to have a conversation with that person. You may experience flashbacks, such as remembering the funeral or even the moment of death itself, for no apparent reason. In addition, you may feel as if you are making progress but then suddenly feel worse, and without knowing what triggered it. Although upsetting, these are normal experiences for people who grieve.

Even if the illness was prolonged and you anticipated the death of your loved one, you

still may encounter both shock and numbness in the same way as if the death had occurred unexpectedly. During this time, which may last from only a few up to 6 weeks, you may experience a sense of “just going through the motions,” as if you were in shock.

When this feeling of numbness and shock begins to subside, you may feel as if you might be overcoming it-thinking “I’m getting back to normal.” Just then, however, you unexpectedly may encounter a deeper sense of grief or sadness as reality sets in. When this occurs, you may experience symptoms of grief like those of acute depression-being unable to sleep soundly, losing your appetite, not wanting to get up in the morning, or not wanting to be around other people.

Whatever happens, understand that there is no “right” or “wrong” way to feel after someone’s death. Most people’s feelings, even if they seem extreme at the time, fall within a range of normal reactions.

Most people who lose someone close to them take months to get over the most severe part of their emotional stress, and for most, it will take at least a year to work through the grieving process. Counselors often consider how a person is doing at the 1-year anniversary of the death as an indicator of how well he or she has adjusted to the loss. Grief that lasts beyond a year is common but may require help.

Remember that life will never again be exactly the way it was before your loved one died. If you are expecting things to “get back to normal” after awhile, you may be disappointed or frustrated to find that the new “normal” is not like the old “normal.” Your life will go on, but-precisely *because* the person was important to you-it will not be the same without him or her.

Your goals

Know when to get professional help with grief.

Understand that people handle loss with a wide range of emotions, none of which is “right” or “wrong.”

Grieve for your loss in your own way rather than feeling that you should be the same as other people you have known or read about.

Understand that most people who grieve return to their daily routines in 2 to 4 months, but healing often takes a year or longer. Each person’s reactions are unique, so be wary of timetables that others may try to force on you.

When to Get Help

The first question you should ask is whether you need help from other people. If you do, an excellent place to start is with your family doctor. He or she may help you directly or aid you in finding the right group session, counselor, or clinic. You should seek help if any of the following is true:

⇒ **Continued difficulty in sleeping.**

If you are losing sleep or feel tired all the time, the first place to go for help is your family doctor. A physician who knows you and your medical history can make an informed decision whether to prescribe medication and, if so, what kind.

⇒ **Substantial weight gain or loss.**

Any substantial change in eating, such as loss of all appetite or a sudden increase in appetite, may be the result of emotional distress. Again, consult your family doctor first, because he or she already knows you and can make an informed judgment about treatment.

⇒ **Prolonged emotional distress.**

If, after 6 months, you do not see a marked improvement of your ability to function in daily life, you should consider seeking help. It is natural to want to withdraw from others after losing a loved one, but if you still cannot enjoy a reasonable quality of life after 6 months, this is a signal that you may need help working through your grief.

⇒ **If you are overcome by suicidal thoughts.**

If suicidal thoughts become central to your thinking and you are encountering them every day, seek help from your family doctor, a counselor, member of the clergy, or a mental health clinic.

Have the answers to the following questions ready when you call your family doctor, counselor, or clinic:

1. How much does grief interfere with my ability to do my job or normal daily activities?

2. Am I having difficulty sleeping?
3. Is my appetite gone, or do I eat significantly more than before the person died?
4. Is suicide an option I would consider?

Here is an example of what someone might say when calling for help:

“I’m David Winters, son of Katherine Winters, who died of cancer 6 months ago. Ever since my mother’s death, I’ve been very upset. I’ve also been having trouble sleeping through the night since about 2 weeks after she died, and I never had trouble before. I think I may need some help.”

What You Can Do To Help Yourself

You can do many things on your own to handle the emotional stress of grief, and you can get help from others as well. You may need one or both forms of help to successfully restore your sense of well-being.

⇒ **Allow yourself to experience the pain of grief.**

What this means is to work through your emotions in the best way you can. If this means crying, screaming, talking to the person who has died, or doing physical activity such as punching a pillow or lifting weights, do that. To heal emotionally, many people need to express their feelings. If you are embarrassed about crying in front of other family members such as your children (whether younger or adult), you may need to tell them: “It may be upsetting to you, but I need to cry and express my feelings. I need to work through this grief.”

⇒ **Select a person to share your grief with.**

Find a good listener who has experienced a similar loss, although it probably is best to choose someone who is not grieving over the same person as you are. Someone outside of your immediate family often is a good choice. You want someone who will let you express yourself, not someone who will try to reason you out of your feelings. Candidates might be a member of the clergy or a sympathetic friend or coworker. Although you may expect family members to be supportive, they most likely are burdened with that very same loss as well. For example, if your spouse dies and you want to share with your adult children, remember that they are grieving the loss of their parent. As a result, they may be

unable to give you the compassion you need. In addition, it often is painful for an adult child to see a parent grieving, and they may want you to “get over it” so that their lives can return to some form of “normal.”

Be aware that some people, even professionals such as clergy, may not be personally prepared to deal with death—perhaps because of their own grief over someone they have lost or feelings about their own mortality. If you are unable to relate to one person, find another. Many hospice programs offer a one-on-one assignment of a bereavement volunteer to aid families after a death, one of many programs typically extended by hospice to help with grief. Others might include newsletters, a library of books about grieving, or information about bereavement support groups.

⇒ **Find what works for you in returning to normal routines.**

If certain activities such as reading or swimming were relaxing for you before, try to pursue them now. See if that will help you to get back to a normal cycle of living. For some people, losing a loved one is so upsetting that they cannot resume these activities until their grief subsides to some extent.

⇒ **Read books or poetry on the subject.**

Many books, including those with first-person accounts, about working through and overcoming grief are available at your local public library. As with other techniques, however, this will not help everyone. Some people will react by saying, “I have enough to worry about without reading someone else’s grief,” while others will find direction, a sense of what is normal to experience, and a feeling of connection with others who have had this experience. Similarly, reading poetry, whether alone or aloud in a group, can help by giving artful expression to feelings that often are hard to express or even identify.

⇒ **Keep a diary or journal.**

Some people find it helpful and therapeutic to write their thoughts and feelings in a diary as they proceed through the process of grieving. The British author, critic, and novelist C.S. Lewis (1898–1963), after losing his wife, kept a journal (*A Grief Observed*) of how he was feeling. A private person for whom neither a support group nor reading a book is helpful may find comfort in keeping such a journal. Some people also find it helpful to write their feelings in a letter to the person who has died, which can help to resolve unfinished business or feelings.

⇒ **Encourage others to talk about the deceased.**

Friends and family frequently avoid discussing the deceased to avoid upsetting the person who is grieving. If you want to talk about the person who has died, you should reassure others that it is okay. All you have to do is say, “I’d like to talk about Dad.” Reassure your visitors that while you may cry or become upset, you would rather do that than awkwardly skirt the subject, because he or she was very important to you. Most people can accept your crying or being upset if you are the one who brought up the subject.

⇒ **Talk out loud to the person who has died.**

In much the same manner as the letter noted earlier, it is not unreasonable to want to resolve issues with a person who has died by holding a one-sided conversation, aloud, with the deceased. Do this if it makes you feel better.

⇒ **Find out about a bereavement support group.**

Bereavement support groups can help to make the process of dealing with loss easier. Signing up for a bereavement support group may be a difficult decision, however, because many people think of their grief as something that is private. You may feel uneasy talking with strangers about your feelings or your loved one. Keep in mind, however, that such groups have helped many people get through their grief and, therefore, may help you.

In a bereavement group, participants learn from each other about normal reactions to grief. Because of their shared experiences, group members often come to care about and to support each other emotionally, and they often share practical ideas for working through their grief as well. In addition, a support group also can help you to get through difficult times like holidays or anniversaries.

Most support groups meet for a limited time, such as six weekly sessions. Others run continuously, and people come in and out as their emotional needs dictate. Most are free; some require a fee. Call a hospice, counseling clinic, member of the clergy, your local Area Agency on Aging, or a hospital to find out about bereavement groups. If that does not work, check your newspaper or the human-services listings of a phone book. It often is good to talk with the leader of a group in advance to learn what is expected and how the group is conducted. Some people attend with a family member or a friend.

If you decide to attend a support group, understand that you may feel worse when you go home after the first session. The reason is that you are dealing with your feelings openly (as well as hearing about everyone else's). In the long run, however, this can be helpful. It also is important to realize that a support group will not restore you to the way you were before the person's death, but it will help you to cope with your new life without the deceased.

Possible Obstacles

Here are some obstacles that other caregivers have faced:

1. "People say I should be over this."

Response: Everyone deals with grief at his or her own pace. You may need to say, "We each go at our own pace. I guess my pace is slower than you expected."

2. "People give me advice that I don't want to take."

Response: Well-meaning advice is not always helpful advice. One example might be if you regularly walked with your deceased spouse and now can no longer bear the thought of walking alone. When people offer advice to take walks, do your best to be gracious and thank them, but then do what *you* feel is best.

3. "People avoid the subject of Dad when they're around me."

Response: Take charge of the conversation, and reassure them: "I want to talk about Dad, and it makes me feel better to talk about him." Your family and friends may not know that you feel this way, so it is important to tell them.

Think of other obstacles that could interfere with carrying out your plan

What additional roadblocks could get in the way of the recommendations in this plan? For example, will other people help? How will you explain your need for help to other people? Do you have the time and energy to carry out the plan?

You need to develop plans for getting around these roadblocks. Use the COPE ideas (creativity, optimism, planning, and expert information), and see Solving Problems Using This Guide for a discussion of how to use these ideas in overcoming your obstacles.

Carrying Out and Adjusting Your Plan

Carrying out your plan

The process of grieving is unique for each person, so you need to find your own, special way of dealing with it. Experiment, and let your feelings tell you which are helping.

Checking on results

The important thing to remember is that people respond to grief in widely varying ways, and that you will have both ups and downs, good days and bad. Healing takes time. You will know that you are successfully working through grief when your stronger emotions begin to dissipate, such as when you no longer feel anger or deep sadness, and when your interest and involvement in outside activities return to their normal level.

If your plan does not work

Grieving is a difficult but natural process. If you cannot resume some of your normal activities or do not seem to feel better after 6 months, you may want to review [When to Get Help](#).

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*The American College of Physicians Home Care Guide for Advanced Cancer
when quality of life is the primary goal of care*

**Adapting chapters from the
Home Care Guide for Cancer
for use in
Advanced Cancer**

The American College of Physicians Home Care Guide for Cancer is a companion volume to this book and is for problems from chemotherapy or radiation therapy when the goal of care is to extend life. It can be purchased at bookstores or ordered from The American College of Physicians (1-800-523-1546, extension 2600) for \$29.95 plus 5.95 shipping and handling. That book has 23 chapters with information for managing physical, emotional, and social problems that can occur as a result of cancer treatments. Even though it was written for when the goal of treatment is cure, the Home Care Guide for Cancer contains a great deal of information that can be helpful in caring for people with advanced cancer when quality of life, rather than extending life, is the primary goal of care. This chapter tells how to adapt chapters in the Home Care Guide for Cancer so that they are appropriate for people with advanced cancer. **With the adjustments recommended in this chapter, the Home Care Guide for Advanced Cancer and the Home Care Guide for Cancer are, together, a comprehensive resource for care during advanced cancer.**

Information about adapting 12 Home Care Guide for Cancer chapters are included in this chapter: fever and infections, tiredness and fatigue, appetite problems, mouth problems, nausea and vomiting, constipation, skin problems, maintaining positive experiences, getting help from community agencies and volunteer groups, moving around the house, coordinating care from one setting to another, and depression.

Chapters in both books have the same organization: understanding the problem, when to call for professional help, what you can do to help, obstacles, and how to carry out and adjust your plan. Adjustments in the Home Care Guide for Cancer are mainly in two sections: “when to call for professional help” and “What you can do to help” sections.

***Note:** Discussion of each chapter begins on a new page so that, when printed, it can be inserted into its matching chapter in the Home Care Guide for Cancer. If printed on 8½” by 11” size paper, trim ½ inch from the edge to avoid having sheets stick out from the book.*

Fever and Infections

Understanding the problem: (Control of fever is different in palliative care and therefore this section should be replaced with the following paragraphs.)

Understanding the Problem

Since childhood, we have all known that fever signaled a problem. In the past, if the fever was caused by an infection, antibiotics were ordered. When the goals of treatment were to cure the cancer, the medical staff kept a close watch on blood counts - especially the white cell count, which protects against infection. Sometimes doctors also ordered special blood counts to pinpoint the cause of infection. During the late stages of cancer, the cause of fever is not always treated and blood tests are seldom ordered. Antibiotics might be ordered but, in some cases, the fever will be allowed to take its natural course and the cause of infection will remain unknown.

Fever has other causes besides infection. Dehydration is one reason for a mild fever. As cancer progresses, the person usually drinks and eats less. The skin and mouth get drier, and less water and liquid circulate through the body. One natural side effect of this situation (called dehydration) is a slight rise in body temperature. When the person with advanced cancer is dehydrated, oral fluids or intravenous (IV) fluids are often ordered to reverse the dehydration and hydrate (or “water”) the body tissues. However, IV fluids are often not ordered for persons with advanced cancer because dehydration is a natural part of dying from an chronic illness. This does not mean that the person with advanced cancer must suffer with a high fever. Fevers can be lowered and should be because they can be very tiring and the chills or sensations that come with them can be exhausting and uncomfortable.

Fever may happen for other reasons. If radiation or chemotherapy is given to reduce the size of a tumor, a fever might follow that treatment and last a short time. This is rare. If the person is taking drugs to build up red blood cells (called erythropoietins) or drugs to build up white blood cells, they may experience flu-like symptoms and a slight fever. Sometimes a person gets warmer when they are close to dying - but the reasons for this are less understood. This can happen if he or she is in a coma (deep sleep). It does not always happen, but if it does, it's important to lower the temperature a little if he or she is uncomfortable. The main goal during late-stage cancer is to keep the person as comfortable as possible.

When to call for professional help:

Add: Pain under the ear or jaw. Pain under the ear or jaw can mean a parotid gland is blocked. This happens when the person stops chewing. Making him or her chew or move the jaw up or down will loosen the gland. Apply warm cloths to the area and give pain medicines.

What you can do to help to reduce fever after reporting it:

Add: Do not bathe in ice water or use rubbing alcohol. This will cool the body too fast and make the person you are caring for uncomfortable.

What you can do to prevent fever and infection:

Drop: Avoid raw fruit and vegetables that aren't washed, raw or undercooked eggs, and food handled by others.

Drop: Offer liquids to prevent urinary infections

These topics can be dropped because chemotherapy and radiation therapy make people especially susceptible to urinary infections and infections from food. Unless the person with advanced cancer is receiving these treatments, these are not likely to be a serious problem.

Chapter adjustments for persons with advanced cancer - When Quality of Life is the Primary Goal of Care.

Tiredness and Fatigue

Understanding the problem: (Dealing with tiredness and fatigue is different in palliative care and therefore this section should be replaced with the following paragraphs.)

Understanding the Problem

People with advanced cancer may feel very worn out and tired. Tiredness may be caused by the disease itself or by medical treatments. It may be caused by anemia, which means there are fewer red blood cells circulating oxygen to the body. Anemia can be caused by cancer, chemotherapy, or nutritional problems and can be prevented or decreased by taking iron pills, vitamin B₁₂ folate, or drugs that stimulate the production of red blood cells. These drugs (human erythropoietin) can improve energy and activity levels and reduce the need for blood transfusions.

Other causes of tiredness are malnutrition (not eating enough) or a temporary increase in waste products as cancer cells are destroyed by radiation therapy or chemotherapy. Some of the systems in the body may no longer work well. By systems, we mean the heart, lungs, stomach, intestines, hormonal, or nervous systems.

Sometimes people feel tired after every course of treatment for their cancer. They complain of not having enough energy or not feeling like they can get going.

Tiredness may happen because normal resting and sleep patterns are disrupted. It may also happen because the person with advanced cancer is feeling depressed or in pain.

You should not “push” the person with advanced cancer to do more than what he or she feels is reasonable. Let him or her decide how much to do. If he or she wants to sleep or rest in bed and not get up, this is fine. What he or she wants is very important now, and it may differ from what medical staff said to do in the past. The goals of care have changed. Now, the person’s goals are first, and they may not be the same as past goals.

If people with advanced cancer want to get dressed and get out of bed, help them to try. If they want to stay in bed, rest, and sleep, let this happen too. In other words, don’t try to conquer tiredness and fatigue - they are natural at this point.

When to call for professional help

Add: Not having enough energy for bathing, moving, or toileting. You may need help from other people in bathing, moving and toileting the person in a bed or on a chair. You can get help from home care nurses, nurses' aides, volunteers, or hospice staff, or you may need to consider moving the person to a nursing home or hospice unit in a hospital if you can't manage at home. See the Home Care Guide chapter on Coordinating Care between Treatment Settings for ideas on making this move to a new place easier.

What you can do to help the person get the most out of the day

Drop: Plan regular exercise to reduce fatigue

Drop: Serve snacks as well as regular meals

These topics can be dropped because the person with advanced cancer may not be capable of regular exercise, because appetite is usually poor, and because eating is often not important to the person with advanced cancer.

Problems with Appetite

When to call for professional help

Add: **If you or the person with cancer is very upset about continued lack of appetite and weight loss.** It's normal to be upset about a lack of appetite in the person with advanced cancer. In part this is because most health care professionals focus on the person's weight during clinic visits. Weight gain is good news and congratulated. Many family caregivers and friends also felt good about the weight gain. This is natural because eating and having a good appetite are signs of health in our culture. The person with advanced cancer has also probably watched his or her weight gain and weight loss very carefully. As a result, his or her lack of appetite and weight loss is seen as bad.

If the person you are caring for is upset about the continued loss of weight, you should talk about this with clinic or office nurses, home health nurses, or hospice staff. You should also talk with staff about your worries as a caregiver. Staff members may suggest ways to counteract a loss of appetite, such as "power packing" foods and liquids. However, they may say that it's time to accept the appetite and weight loss and to talk about important things other than just food and eating.

What you can do to help

Change: Increase Appetite to:

Accept loss of Appetite

Many people with cancer lose their appetite especially in the later stages of the disease when it is a natural part of the end of life. Serve the food requested by the person with advanced cancer, but don't push meals and calories. Instead, try these suggestions:

Drop: Encourage light exercise or walking before meals

Add: **Ask what the person wants to eat or drink.** At this point, there's no reason to push the person to eat or drink more than he or she wants. If a certain food sounds good, serve it in small portions. Try not to be upset that little is eaten. Loss of appetite is common and expected during advanced cancer. Pushing foods or liquids that the person does not want can increase everyone's frustration.

Add: **Use over-the-counter medicines to break up gas.** Many of these medicines contain herbs or drugs that break up gas. One particular ingredient, simethicone, is helpful in attacking gas and breaking up air trapped in the intestines. Check with the hospice or nursing staff before buying these over-the-counter medicines because they shouldn't be used with some other medicines.

Drop section titled: Add more proteins and calories to food

Add section titled: Help with swallowing with the following topics

Add: **Use smaller spoons** If the mouth is dry or sore, normal spoons may be hard to use. Try a smaller spoon or a child's size for mashed foods, such as applesauce or potatoes.

Add: **Put liquid in the end of a straw and drop it into the mouth.** If the person is very weak, drinking from a glass or sipping on a straw can be difficult. If this is the case. Place a straw into a glass of liquid and then place your finger over the top to create a vacuum that will hold the liquid. Lift the straw to the person's mouth, and drop the liquid in by releasing your finger. Even if swallowing is difficult, a small amount of liquid will feel good on the tongue and will be absorbed in the mouth. Don't try this if coughing is a problem or if the person gags when you do this.

Add: **Prop the person up on pillows.** It's much easier to drink or eat when sitting upright. Use pillows. Some people find that a hospital bed works well at home because it can go up and down and the person can sit upright.

Add: **Serve soft foods.** Soft foods are like liquid and go down easily. Try whipping them in a blender or mashing them with milk.

Problems with the Mouth

What you can do to help moisten a dry mouth

Add: Moisten air with a humidifier or pan of water. An electric humidifier puts more moisture into the air. Pans of water placed near radiators also do this. A dry mouth and throat are helped by breathing in this extra moisture.

What you can do to help prevent mouth sores

Add: Moisten the air. Mouth breathing during the day or night causes increased dryness, and a dry mouth is more likely to have problems. A humidifier near a bed or pans of water in the room releases water droplets into the air which make breathing through the mouth more comfortable.

Add: Serve moist foods. Moist foods such as fresh pineapple chunks help to moisten the mouth and make it feel fresh and clean.

Add: Spray a small amount of water into the mouth. A small spray bottle, such as a clear glass atomizer filled with water, gives off a fine mist that moistens and soothes the mouth and helps to control thirst. Even persons with difficulty swallowing or breathing can try this without fear of choking or breathing the water into the lungs.

Nausea and Vomiting

When to call for professional help

Add: If the person hasn't had a bowel movement for more than three days and experiences nausea. Nausea or vomiting can occur if the bowel is full of stool. Report this to the medical staff who can assess what is happening.

Add: If the person suddenly becomes confused when nausea or vomiting occurs. If nausea or vomiting occurs and the person you are caring for gets suddenly confused, call medical staff because some type of chemical imbalance may be occurring.

Add: If you are very worried and want information or advice immediately. If you are following this home care guide and you are still worried, then call. Talking over your concerns and discussing what to do are very important if you are to give the best care.

What you can do to limit nausea and vomiting

Add: Give medicines to make the bowels move at least every two days. Sometimes vomiting or nausea can be caused by feeling too full or being constipated. Laxatives and stool softeners can prevent constipation and its side effects.

What you can do to avoid other problems during vomiting

Add: Move the person onto his or her side so that vomit will not be inhaled (breathed into the lungs). If people vomit while lying on their backs, there is a much greater chance of breathing in the vomited liquids or solids. Keep the person off of the back if nausea is severe. Otherwise, prop him or her up with pillows in a chair or in bed.

Add: Give anti-nausea medicines by rectal suppository or by skin injection. When someone is nauseated or vomiting, it can be too difficult to swallow pills that will reverse the problem. Drugs may have to be given another way, such as through the rectum or by injections through the skin.

Chapter adjustments for persons with advanced cancer - When Quality of Life is the Primary Goal of Care.

Constipation

When to call for professional help

Add: Very hard stools. It can hurt to pass hard stools. They can also tear the skin, increasing discomfort. Stool softeners need to be given along with laxatives. Sometimes oil enemas will soften the stool.

What you can do to help prevent constipation

Add: Keep giving the number of laxatives and stool softeners needed to make the bowels move. Even if constipation is finally relieved, steps to prevent it must be continued. Keep giving laxatives every day, especially if the person with advanced cancer is taking pain medicine on a fairly regular basis or spending most of the time in bed. Give fewer laxatives if the stools are very soft or runny. Give more if they are hard, dry, or hard to pass.

Add: Ask the nurse or nurse's aide to remove stool from the lower bowel by hand. As the end of life approaches, the muscles in the lower colon and the rectum (end of the bowel) lose much of their ability to push the stool out. Nurses know how to remove stool gently by hand. Usually they use a lubricant such as K-Y jelly or Vaseline on their gloved hand and carefully remove any stool sitting at the end of the colon. This procedure, not unusual in the last weeks of life, takes only a few minutes. It can spare the dying person the discomfort of constipation and pressure in the anal area.

Chapter adjustments for persons with advanced cancer - When Quality of Life is the Primary Goal of Care.

Skin Problems

When to call for professional help

Add: Skin on the hips, elbows, heels, or back looks bruised or red. These spots on the body are likely to rub against the bed or chair when a person is very thin and they can break open. Hospice staff can suggest ways to protect these areas.

What you can do to help prevent dryness and itching

Add: Wear soft or old clothing over rashes or dry skin. Use clothing free of sizing, starch, or detergents. Also wear cottons free of dye if skin rashes or dryness are a problem. Older cottons do not contain these products. They “breathe” and let out perspiration, which helps to keep the skin dry.

Add: Use paper tape to secure dressings. Medical tape made of soft paper will not pull the skin when removed. Avoid heavier adhesive tapes on top of dry skin.

Add: What you can do to help prevent pressure sores

There are many different ways to prevent pressure sores. Consult your doctor, nurse, or hospice staff for suggestions, and try some of these ideas.

Add: Use stick-on foam squares with a hole cut out in the middle on areas of red skin to prevent contact with hard surfaces and to let them get more air. Most large department stores and all medical supply stores have different sizes of foam with one side that has a sticky surface. These come in different widths, such as 1 or 2 inch. You can buy a small square and cut it to any size to cover up the skin around a red area that could break open, for example, an ankle bone or heel.

Add: Look at areas that are likely to break open such as heels, elbows or the lower back. Preventing skin breakdowns is important. Look at these areas (ankle bones, heels, elbows, shoulder bones, spine, lower back, and hips) every day to make sure that the skin looks normal and is not turning red. If any place is red, follow the following tips to prevent skin sores.

Add: Use an eggshell foam mattress on the bed, couch, or chair. Hospitals often give these to patients when they are discharged. Otherwise, they can be bought at medical supply stores. Mattress-sized foam fits on top of the mattress and under a sheet. If the person with advanced cancer is short, cut the bottom and use it for cushions on chairs.

Add: **Rub any red areas with lotion each day.** You can help heal red areas by rubbing them. Use a gently circular massage (rub in a circle), which will help blood flow back into the skin. Heel and elbow rubs are now as important as back rubs. Check all bony areas including heels, elbows, hips, knees, ankles, shoulders, and the tail bone and massage if they are red.

Add: **Encourage different sitting or lying positions, if they are comfortable.** Skin sores develop because the blood flow is blocked to that area or the skin gets wet and cannot dry in open air. Lying on one side lets the other side and the back get a break from pressure on a mattress and also increases blood and air flow.

Add: **Use warm heat from a heat lamp or a hair dryer on a very low setting for 10 to 15 minutes on wetter skin 2 or 3 times a day to help skin stay dry.**

Add: **Ask if a pressure mattress filled with water or air should be tried.** Visiting nurses and hospice staff may agree that special mattresses need to be tried. They can order these or loan you one to see if the person you are caring for likes it.

Add: **Cover red areas or open skin spots with a special skin patch such as Tegaderm™ or Duoderm™.** These patches help heal red or open skin areas. They can be bought at a pharmacy. They are very expensive. Again, visiting nurses and hospice staff know how to use them wisely to heal skin problems.

Add: What you can do to help protect the skin from urine or stool

Add: **Try a protective skin covering, such as Desiten™ ointment, if getting to the toilet is a problem.** Adults can suffer from diaper rash just as young children do. Some ointments or creams cover the skin and protect it from urine or stool. If the rash or redness from these causes becomes worse, ask the visiting nurse to make recommendations on how to solve these problems. Rashes from urine or stool can be very uncomfortable and can often be prevented.

Add: **Cleanse areas exposed to urine or stool with warm water and gently pat dry.** Try not to rub these areas when cleaning off any urine or stool. Usually the skin is already very irritated here. Avoid using a lot of soap. Instead, use small amount of soap in warm water and then rinse well with warm water.

Add: Use baby lotion to remove hard stools or stains. Soap will not do as good a job as baby lotion in removing hard stool or stains on the skin. Place this lotion on a washcloth and gently rub it on the soiled are. This will soften the stool and remove it. It may take a few cleanings to remove stains. Be gentle with the skin so as not to break it open.

Add: Keep skin open to the air for a short time after cleansing rather than covering the skin with plastic pads or underwear right away. Air is very healing to skin exposed to urine or stool. Pads and underwear block air flow, so it's a good idea to "air dry" the skin for a little while every day to help it heal and to prevent skin breakdown. Lying under a sheet without underwear will accomplish this while preserving modesty.

Maintaining Positive Experiences

When to call for professional help

Add: **The person with advanced cancer or the caregiver is crying and sad most of the time.** Sadness day after day is another sign of depression. Some antidepressant medicines can take several weeks to be effective, so starting them early is a good idea. Counseling, prayer, and spiritual help may also be comforting as the person with advanced cancer comes to grips with the seriousness of the illness and its later stages.

Add: **The person with advanced cancer is looking for a way to “end it all.”** Suicide or euthanasia (mercy killing) is seldom successful and such attempts often lead to more problems, not fewer. If the person with cancer is discussing plans for a suicide or assisted suicide, it is often because he or she thinks that a cancer death must be painful or humiliating. Professionals who work with cancer patients near the end of life can explain how a natural death can be comfortable and dignified.

Getting Help from Community Agencies and Volunteer Groups

What you can do to help with home nursing services

Add: Ask for volunteer companions. You may need someone to stay with the person with advanced cancer while you run errands or take time out for yourself. Many hospices, churches, or aging services have trained volunteers who can visit and give “respite” care. They can stay for several hours and have been trained in how to be helpful and supportive to people with serious illnesses. Their conversation and listening can be very helpful, and you know that you’ve left the home “in good hands.”

Chapter adjustments for persons with advanced cancer - When Quality of Life is the Primary Goal of Care.

Moving Around the House

What you can do to help to increase safety during walking and moving

Add: Use walkers, canes, or wheelchairs. These can be bought at pharmacies or medical supply stores. They can be borrowed from the American Cancer Society or service clubs that collect such equipment and lend them to community members. Health insurance often covers some of the costs of buying or renting such equipment. Ask medical supply store staff, any health care social worker, or hospice staff member which costs are covered by insurance.

Add: Hire nurses' aides or home helpers who can help with walking, moving, and bathing. If you or the person you are caring for are over 65 years of age, call the local office of the Area Agency on Aging listed in the phone book. Describe your situation. These agencies have many programs that send helpers to the home to assist with safety walking, or bathing. Some programs cost money, but others are free, depending on household income. See the chapter on Respite Care for more information.

Coordinating Care from One Setting to Another

When to call for professional help

- Add:** Sometimes transfer from the home to other health care settings does not go smoothly. If medicines are not being given when they should or if other important routines are not being carried out, ask to talk with a nurse supervisor, or you can ask a physician to write a “medical” order to carry out the routine. Ask for help if any of the following conditions exist.
- Add: Pain medicine is not give often enough.** Some staff members may not understand as much as you do about pain medicine - and how the person you are caring for responds to it. Also, the doses or schedules may be unfamiliar to them. In such situations, staff may wait for the patient to ask for pain pills or shots rather than give them on a regular, around the clock schedule. If this happens, ask the physician to write an order to give the medicine at the times you gave it at home.
- Add: The mouth, lips, or skin get very dry.** As a person approaches the end of life, problems with dryness can occur. The mouth needs to have liquid gently dripped into it - which can be done through a straw. Regular cleaning and swabbing the mouth will also help. The lips need lip balm, ointment, or salve to prevent cracking or sores. The skin needs very gentle cleansing and lotions to prevent dryness and breaking down. If you feel these needs are not being met, ask a supervisor or head nurse to put “water for the mouth” and “lip salve” or “use lotion after bed bath” on a schedule just the way medicines are.
- Add: Rest or sleep are interrupted by unnecessary routines.** Some health care settings have daily routines, such as for meals or bed making, which occur at set times of the day. The person with advanced cancer may not want to be disturbed or asked to eat or to get out of bed for these routines. If you are worried that he or she isn’t being allowed to rest through those interruptions, ask a head nurse for special consideration. The nurse can write on the care plan that certain routines be bypassed if the patient is sleeping.

Coping with Depression

How to get professional help

Add: **Encourage the person with advanced cancer to talk with hospice or medical staff about his or her feelings.** Hospice staff are very experienced with helping with depression and the normal feelings that come with facing terminal illness. Medical staff who are experienced working with people with terminal illnesses can be very helpful as well. You may also benefit from talking with them about your feelings. Along with listening, these health professionals can arrange for medical evaluations and get medicines ordered specifically to ease depression and worry.

What you can do to take care of your own emotional needs when living with a depressed person.

Add: It is normal, when caring for a person with a terminal illness, to feel a strong sense of loss or grief before the death. Don't be alarmed if you find yourself anticipating how it will be when the person you are caring for is no longer there. It is normal to want peace for your loved one and for yourself. People often see or "rehearse" in their minds how it will be afterwards and grieve before the death. This is a normal reaction. Here are some ways to help you deal with these feelings.

Add: **Talk with an understanding person who will listen.** Talking with another person about your feelings of loss and your fears for the future will help you to sort them out, to appreciate that these feelings are normal and reasonable, and to begin planning for the future.

Add: **Spend time with other family members or friends who are close to the person with cancer.** Focus on the many positive memories that you share and support each other.

Add: **Take time out for meditation or prayer.** Quiet prayer or listening to your thoughts helps can help you accept sadness or frustration.

Add: **Let yourself cry.** Crying can be a very good way to express feelings of loss and grief. Most people feel better after crying. They feel they have let out their feelings which helps them to feel calmer and able to face their problems.

Add: **Accept that feelings of loss and grief take time to resolve.** These feelings will not last forever. They will change over time and peaceful feelings will eventually return.

Add: **Limit the number of things you are doing.** You may be expecting yourself to accomplish too much and pushing yourself too hard. You may have to give up doing some things you used to do so that you can focus on what is most important under the present circumstances. After the crisis is over, you will be able to go back to those activities.