

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.

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 psychological 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 for 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 are no longer under his or her control..

Understand that men and women often communicate in different ways, and make allowances 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. When 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 in.

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 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 his or her life 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 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 levelheaded 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 the 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?

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.

The American College of Physicians gives permission to reproduce and distribute copies of this chapter provided it is not altered and its use is not for profit. For information on translation, subsidiary, and for-profit use, contact David Myers. Phone: 215-351-2642; fax: 215-351-2644; email: dmyers@mail.acponline.org.