



## NEARING THE END OF LIFE

If you are reading this, chances are that you or someone close to you has advanced cancer. This probably means that cancer has spread from where it started to other parts of the body, or it has harmed vital tissues and organs.

At this point, you know that the cancer is not going away and that you probably have limited time to live. In fact, your doctor may have told you that there is no more treatment that can really help stop your cancer and that you have only a short time left. Many patients and family members have questions about what to expect during these last months of life. You may have some of the same questions. The information shared here has been written to help answer some of the questions that patients and family members ask about what to expect during the last 6 months of life.

Learning that you have advanced cancer may make you feel lost and afraid. This is natural. People have many questions of all sorts, such as:

- What is going to happen to me?
- Have I done everything I should have done?
- What are the other options?
- Am I going to die?
- How much control will I have over my life and my death?
- Will my wishes about my care be followed?
- How much pain and suffering will I have?
- What if I feel that I can't take much more treatment?
- What am I going to do about money?
- How long am I going to have to go through this?
- How can I burden my family in this way?
- Will this be too much for my family to bear?
- What happens when I die?

The following may help you understand what to expect both physically and emotionally during these last few months. Hopefully, it will help you to live fully and get the most out of this last phase of your life. It is written for the person with cancer, but it can be useful to the people who love and support someone with advanced cancer, too. Use this information to get answers to your questions and concerns about this very sensitive and difficult time. Please remember that there are also professional cancer information specialists who are ready to talk with you about these issues 24 hours a day, 7 days per week at our National Call Information Center. You can speak to one of them by calling 1-800-227-2345.

## Your emotions or what you may feel

*Sharon, age 42, with advanced cancer: "I still can't believe it's going to happen. I'm tired but I don't feel that bad. I just feel like such a burden on my family. And I'm so worried about my children."*

Sharon is expressing many normal emotions that occur near the end of life. She is feeling the shock of how final death is and the guilt of being a burden on her family. She is also concerned about the children she will leave behind.

Knowing that death is coming soon takes an emotional toll on the person with cancer and their loved ones. This is an emotional time and it is hard to talk about it; still, these issues must be addressed. Knowing that these feelings are normal and expected may help you cope with what is happening. Some of the emotions you can expect to have include the following:

### Fear

People may say that they are afraid to die, but it can help to pinpoint what part of death they are afraid of. Are they afraid of dying alone? Are they afraid of suffering or pain? Are they afraid that they will die and there will be nothing beyond earthly life? Is there a fear that their lives had no purpose or meaning? These are some of the more common reasons that people fear death.

Trying to clearly identify what you fear can help you face it. It will also help others be better able to support and care for you. For example, if you are afraid of being alone, share this with your family and loved ones so they can plan to have someone with you. Your fears may be either concrete or abstract. Either way they are very real. Many people have a natural fear of the unknown. Share these feelings with your loved ones or your health care team. Sharing gives others a chance to correct any wrong ideas you may have and helps you come up with ways to cope with and ease some of your fears. It can also give you a chance to look at and deal with some of your fears in new ways.

## Anger

Anger is sometimes hard to identify, but ignoring anger will not work. It is perfectly normal to feel angry about your life being cut short -- it's unfair and you have a right to be mad! But, unfortunately, anger often gets directed at those closest to us, the ones we love the most. We feel safest with these people and know they will probably accept our anger and forgive us for it. It may help to consider that your anger can be directed at the disease and not your loved ones. Also, you can try to channel your anger as a source of energy to help you take action where it's needed. You can use it as fuel to solve problems, to become assertive, or to get your needs met. You can sing at the top of your lungs, give a speech with vigor, or tell your family some things you really want them to know. Try to re-channel your anger to do meaningful, positive things.

## Guilt and regret

Sharon mentioned (in the section "Your emotions or what you may be feeling") that she feels guilty about being a burden on her family. She also feels guilty that she will be leaving her children behind.

In their last few months of life, a person may regret or feel guilty about many things. We feel regret when we think that we should have done something differently. Or maybe there is something we wish we had not done at all. We may feel guilty when we don't meet our own or someone else's expectations. But why hold onto guilt or regret? Worrying endlessly about these things won't make you feel better about them. It won't improve your relationships with family members. It won't ease the burden they are carrying. It won't make you feel better. It won't make you live longer. It will only make you feel bad.

Sometimes the best thing to do is to decide to "let yourself off the hook" and spend your last days and months not feeling guilty about things that are out of your control. Simply let it go. You cannot change the past, only the present. Apologize for the things you regret and ask for forgiveness. Be willing to forgive others and yourself. Fix what can be fixed and try to let go of the things that cannot be changed.

This is a good time to talk with your children about the important things you want them to know. It's also good to talk to them about how to handle their feelings and the loss they will soon go through. You may want to write letters to the people you love, record messages for them, make videos they can watch -- give them things they can keep to remember their time with you. Tell them who they can talk with when you are gone and encourage them to be open when they are hurting. Spend your time focusing on your children's future, not feeling guilty about the past. Strengthen your relationships with loved ones. Live your life as positively as you can, and use your time for what is most important to you.

## Grief

It is natural to feel intense grief during the last months of your life. You are grieving the loss of the life you have planned and expected. You can no longer look ahead to a seemingly "endless" future. And you may have lost many things already, such as the strength to walk or get around like you used to, or the interest in eating the things you enjoy, or maybe the ability to get together with friends. You may feel distanced from friends who cannot handle the fact that you are going to die soon. This is another loss that may cause sadness and grief. Many physical and emotional losses come before the loss of life itself.

The people you love are grieving too. They know they're about to lose you. How can you and those who love you find meaning in what's happening? Try to talk to your loved ones about the grief and loss of dreams you are all going through. Being able to rise above the grief and connect to God or something greater than one's self will help your loved ones heal after you are gone.

Talking with someone about these feelings -- a partner, a dear friend, a spiritual advisor, someone you trust -- can help you process these feelings and move beyond them. It may take many attempts before you succeed, but once you have done this you will feel a burden lifted and you can move on to the other physical and emotional tasks that make up the end of life. There are some necessary tasks at the end of life, but coming to terms with the losses is one of the most painful ones.

## **Anxiety and depression**

What does anxiety feel like? Anxiety has been described as having a nervous stomach, a shaky feeling all over, being short-tempered, a sense of dread or worry, or a fear of the unknown. It can be quite unpleasant. Anxiety can be treated through counseling or with medicine -- the goal is to make you comfortable and help you to better cope with the changes that are taking place. Anti-anxiety medicines or even anti-depressants can help. Counseling can be especially helpful in changing how you think about things so that you can focus on the present day and not worry about tomorrow. Breaking problems into smaller pieces that are easier to manage can be a good way to handle some kinds of anxiety.

Depression is more than just feeling sad. Depression includes feeling hopeless or helpless, feeling useless, feeling sad for weeks at a time, and having no joy in any activity. These feelings are not normal, not even during the end of life. Depression can sometimes be helped with anti-depressants and counseling, or a combination of both. Managing anxiety and depression well can make a big difference in how much pleasure you can find in your last few months of life.

## **Feeling alone**

Very few people know what it feels like to be facing their last months of life. There can be a loneliness that is different from any other. It is a loneliness of the heart, even when you have people around you. Frankly, there may be very few people who can really talk with you in a way that helps you feel less lonely. Some of them may be experts who are comfortable talking with people at the end of life, such as hospice social workers, nurses, or other end-of-life caregivers. They may have that special gift for silence or listening when you need it. Finding a few people that you can truly connect with is critical to ease this sense of intense loneliness. Your health care team may end up being one of your greatest resources in this area.

## Seeking meaning

Almost everyone wants to feel that there was some purpose to their life -- that there was some reason for their being on earth. Some people find meaning in their work. Others find that raising a family brings them the greatest sense of joy and accomplishment. It is helpful to go through a process of reviewing your life and figuring out for yourself what your purpose in life has been. What was your special contribution to the world? What have you done to make the world a better place? How would you like the world or your children, family, and friends to remember you? What were the things that you thought were really important and want your children to know about for their future? It does not have to be something huge or earth-shaking -- look for those things that have been important to you and those around you. The end of life experience is full of meaning and personal reflection. Sharing your thoughts, experiences, and wisdom is a gift that your friends and family can cherish for years to come.

## The importance of communication

*Bill, age 65, with advanced cancer: "The doctors told me there was nothing else they could do for me except keep me comfortable. I felt like I wanted more say in what was going to happen next. They had offered me all they could; now I felt like I needed a little control. I wanted my family to suffer as little as possible and I wanted it to be as easy as it could be for them. I told the doctor I wanted him to be very honest with me about how long I had left. He told me he thought I had a few months. That was pretty much what I thought and I appreciated his honesty. It wasn't his fault..."*

## Your health care team

Bill did what many cancer patients do at this stage of life take. They choose to take more control and begin to actively plan the remaining part of their life.

Once the health care team says, "We have no more treatment for your cancer," the patient often thinks, "The ball is back in my court." Feeling this way is a healthy approach. Rather than being a passive recipient of care, you may now want to start thinking about how to help others accept and enjoy the time you have left. To do this, you will need complete and honest information. Telling your doctor exactly what you want to know and getting the information you need is an empowering step. (In the section, "Making end-of-life decisions," we will describe some ways for you to be sure that your wishes are followed, even if you become unable to communicate them.)

## **Making decisions**

Some people are not willing to accept "no treatment." You may find that you want to get a second opinion and continue to actively fight the cancer. That's OK! It is your choice and you have to be comfortable with the decisions you make. Making your medical team and your loved ones part of the decision-making process will help things go more smoothly.

If you opt for more treatment in spite of a doctor's recommendations, explain your decision to those involved in your care. Even if they do not understand or agree, you still must pursue your own sense of what is right for you. As long as you have fully explored all options, your friends and family will most likely support you. Keep in mind that no decision is forever. You can change your mind about treatment at any time.

## **Building a support network**

You may be a person who has never needed a large support network. Maybe it is not easy for you to reach out to others, especially when you may feel you do not have a lot to offer in return. Even so, there may be people in your life who want to support you through this time. They may be waiting for you to tell them what to do and how to help. If friends and family are not available, there are often others who are. Online networks of support are also available, such as the American Cancer Society Cancer Survivor Network. Your local health care community may have support groups, and your religious community may have people who simply enjoy serving others. Hospice teams (which we will talk more about later) offer support resources for people with cancer. It is unrealistic, and maybe even unhealthy, to try to get through this time without supportive, loving people in your life. This is the time to reach out and enjoy people and the gifts they have to offer.

## **Your partner**

### **Needs and demands**

Cancer takes up a great deal of time and energy. Cancer and end of life care places a huge physical and emotional burden on those closest to you. Your partner may be either your

greatest ally or your most disappointing source of support. There are obvious reasons for this. Your partner is probably dealing with his or her own emotions and yet feels a lot of pressure to come through for you and meet your every need. Some people just can't handle that kind of pressure and may withdraw under these circumstances. They may pull away at a time when you feel you need them more than ever. This can be very painful.

On the other hand, your partner can be right there for you and that can be painful, too. It can be very troubling to know everything your partner is feeling and thinking and to see the pain they are going through. Sometimes partners try to protect each other from the pain they are both going through, but when this happens, honesty is sacrificed. Walls are built up, topics are avoided, and relationships can become strained and uncomfortable.

The death of a spouse is one of the most stressful events a person can experience. Living with and anticipating this loss every day is even more stressful. If at all possible, try to talk with your partner about what each of you is feeling. You will probably find that you are both going through the same kinds of emotions. Try to accept what each person says without judgment, argument, or defenses. Simply let each person say what they feel. Don't try to fix the feelings. Be aware of them and express your love and care for each other. This is another chance to try to make any past wrongs right and comfort each other. But just because you are sick doesn't mean that you won't get angry and frustrated with each other. Try to focus on the comfort you can give each other and let the petty arguments go. Focus on the good times, happy memories, and the times you have been there for each other.

### **Alone time**

It is also important to allow each other personal space and private time. Reassure each other that you still love each other, but it's OK if you both need some time to be alone. This is a common need as a person faces the end of life. No one can be with someone 24 hours a day. And you cannot squeeze a lifetime into 2 months. Make the most of each day, be grateful for it, and greet the next one as a new chance to enjoy each other.

### **Sex and intimacy**

At this stage of your illness it may be hard to be as sexually close as you have been in the past. You may be tired, in some pain, or simply not interested in sex. But you can still keep physical contact in your relationship and share intimacy. Talk with your partner about your needs. Tell him or her that you want to be close but that you do not feel you are able to have sex. Make sure your partner understands you want physical closeness and affection. At this time simply touching, hugging, and holding hands may feel more intimate than other forms of physical contact.

### **Take care of your partner**

You may need to talk to your partner if you are worried about the burden they are under because of taking care of you. Ask how he or she is managing it. Your partner may show

signs of emotional and physical stress, such as depression, headaches, trouble sleeping, or weight loss or gain. Remind your partner to take care of him or herself. Ask a friend or another family member to help out if you think it is too much for your partner and tell him or her you are going to do that. In this way, you can take care of your partner, too.

## **Family**

Cancer is a family illness. Your loved ones are hurting too. Each member of your family is working through his or her own emotional responses to the fear of losing you. They need your love and understanding. Though it may seem impossible, there are things you can do to help them manage better.

### **Adults**

You can help adult family members by being open about your disease process, the amount of time you've been told you have left, and any other needs you may have. It also helps to share with them the expected symptoms of the dying process, and how to manage them should they occur. Explain to your family that you are open to discussion and that there is nothing that you aren't willing to talk about. Explore, with your family, their thoughts and feelings. Tell them that although you are open to talking, there may be times you do not feel like talking and you will let them know when that is. Tell them that you would rather not try to put on an act and have to act happy if you don't feel happy. Explain to them this doesn't mean you aren't OK. It may just mean you are feeling a little blue or tired.

Tell your family that you will be as honest with them as you can be and would like the same from them in return. Give them information about what you expect to happen in the future so they will be prepared. Tell them about preparations you have made or need to make and get their input. Adult children may be juggling their own children, jobs, and caring for you. It is a stressful time. Sometimes they may not be able to meet your expectations. Open, honest communication will help you all support each other through this time.

### **Children and teenagers**

It is natural to want to protect children from the harsh reality that you will not be here in a few months. Professionals who work with families would strongly encourage you not to do that. Your children, even the youngest ones, need some type of preparation for the future. Honesty is important. Children can usually sense changes or stress in the household and know when something is wrong. Many times what they imagine is far worse than anything you have to tell them.

Children naturally focus mainly on themselves. And they often think they caused the problems they sense in those around them. They may even believe that something they've done caused the cancer to grow. It is up to you to assure them that they had nothing to do with your cancer, with its growth, or with the fact that you will not win your battle against it.



Let them know that you will keep fighting, but the doctors have given you all the treatments they can.

Tell them you want to share some good times with them before the cancer takes over. Children also need to know the plan that will be in place when you are no longer there. Explain in some detail what will happen when you are gone; how they will be cared for and by whom. If the child is mature enough, tell them that you will always be in their heart even if your body is not around. This will be a hard discussion. It is sad for you and for them, but they need to know these things. Tell your child that no topic is off limits. They can talk to you about or ask you any question they want.

Sometimes it helps to suggest people and places they can turn to when they are sad. Encourage your children to talk about their feelings. Make sure they know that you would consider it normal, and even helpful, if they had counseling or were in a support group to help them through this experience. Encourage your child to help you with some physical tasks, such as getting things for you or reading books to you. This way they do not feel so helpless or in the way. It is easy for busy adults to ignore or push children out of the way without meaning to do so. Don't allow your child to feel devalued at such a critical time. These moments with your child are precious. They will become fond memories they can cherish in the future.

## Friends

Some friends respond as you would expect them to -- they are warm, supportive, and available. Other friends may seem to be more awkward around you. They may act as if they don't know what to say or do and seem to have a hard time being "normal." Sometimes you can talk to your friends about their discomfort. Explain that you are the same person and you would like to spend some of your remaining time with them, if they are willing to do that. Try to understand that what you are going through may cause your loved ones to think about the fact that they, too, will die. Because this is not a pleasant thing to do, they may avoid spending time with you.

## Support groups

Taking part in a group can give you sense of belonging. It also gives you a safe place to talk about fears and emotions that you may feel uncomfortable talking about to other people. Group involvement has been shown to ease isolation and reduce stress.

There are many types of support groups, both formal and informal. Some of the formal groups are set up for caregivers, others for people with certain types of cancers, or people of certain ages. There are bereavement groups for adults and even some for children who have lost a loved one to cancer. In a support group, you are with people who are coping with the same problems and issues that you are facing. The encouragement and understanding found

in a group of people sharing a critical life experience can be very valuable. Groups may only last a given number of weeks or months or be open ended.

You may find it hard to go out to meetings in your last weeks of life. Some of the more informal groups, such as a neighborhood group of friends or a church group, may be willing to meet you in your home. Internet support groups may be a good option for people who are homebound and able to use a computer. Often hospice organizations are involved in the last months of life and they offer the help of staff members who can give specific types of support around specific needs. For example, there are staff members who talk about emotional support. There are also those who focus on spiritual concerns. Clergy or other spiritual leaders are often willing to make home visits to people in the last months of life.

You can get information on available support groups from your medical team, your facility or hospice social worker, or from your American Cancer Society.

## Making end-of-life decisions

*Helen, age 72, with advanced cancer: "I'm going to tell my husband that I don't want anyone pounding on my chest or putting tubes down my throat if I stop breathing. I just want to go naturally. I'm going to tell my children too."*

It is usually not the act of dying, but the quality of dying that is the biggest concern at the end of life. Most people who come to accept dying as a natural and normal part of life do not want to prolong the process when it won't really change the outcome. But thinking about a good death is not something most people do. Some patients want to stay at home. Others choose to go to an assisted living center, a nursing home, or an inpatient hospice program. Again, you should make the choices that you feel are best for you, your family, and your situation.

The goal of any cancer care is to give you the best possible quality of life. This is a very personal issue. There are ways you can be sure that your family and your cancer care team know what is important to you and what you want to be able to continue to do.

At this point think not only about how you are going to live the next few months, but also think about and prepare for how you're going to die.

## Advance directives

You need to know that it may not be enough to just tell your family what your wishes are for your medical care. You can choose the kind of treatment you get and refuse any treatment that you do not want. If you have not already made a decision about your health care at the end of your life, now is the time to do so.

An advance directive puts your decisions about future health care in writing. You can also use it to name a surrogate (a substitute, also called a *proxy* or *agent*) to act on your behalf when you cannot act for yourself. Advance directives are legal documents that clearly state your wishes about medical decisions and may even give specific details about how you would like to die. Your doctors will follow your advance directive if you become unable to express your desires as your illness progresses. Having an advanced directive takes the burden of making these decisions off your family members and health care team. It also helps to assure you that you will get what you want up until the very end of your life.

Advance directives can only be used for decisions about medical care. Other people cannot use them to control your property or money. Advance directives take effect only when you are unable to make your own decisions. Make copies of your advance directives and give copies to any of your health caregivers. Talk to your family about your wishes so they clearly understand what you want. Be sure your closest family members know where to find a copy of your advance directive.

You can get more information in our document, *Advance Directives*. It can be ordered from our toll-free number or found on our Web site. Here is a brief description of the most common types of advance directives:

### **Durable power of attorney for health care**

A durable power of attorney for health care (or DPOA) can also be called a medical power of attorney, a health care proxy, or an appointment of a health care agent. A DPOA for health care is a written legal document in which you name someone who will make medical decisions for you if you become too ill to make decisions for yourself. This person will talk to the doctors and health care team on your behalf and make decisions according to your directions if you become unable to do so. In a DPOA for health care, you can note the specific kinds of treatment or procedures you do or do not want. If your wishes are not known, the person you appoint will make those decisions for you based on what they think you would want. So, you will want to let that person know what you have in mind, and what you do and don't want.

### **Living will**

The other main type of advance directive is a living will. This document also gives you the power to make sure your wishes are followed if you become too ill to make decisions for yourself. The living will gives directions about the use of certain medical treatments at the very end of life. For example, you may state that you do not want a feeding tube or intravenous (IV) fluids at the end of your life. You may also decide you do not wish to receive CPR (cardiopulmonary resuscitation) if your heart stops or to be put on a breathing machine (called a ventilator) if you stop breathing on your own. This is something you

should discuss with your family and health care team ahead of time, but it is even better to have it all in writing as well. Having these issues clearly resolved to your satisfaction will give you and your family peace of mind.

### **Do Not Attempt Resuscitation and non-hospital Do Not Resuscitate orders**

Some states have a special advance directive that is called a *Do Not Attempt Resuscitation (DNAR)* or *Do Not Resuscitate (DNR)* order for use outside the hospital. The non-hospital DNR is intended for emergency medical service (EMS) teams, who answer 911 calls and in most cases must give you every possible life-sustaining service. Even though families expecting a death are advised to call other sources for help when the patient gets worse, a moment of uncertainty sometimes results in a 911 call and unwanted measures that prolong death. The non-hospital DNR or DNAR order offers a way for patients to refuse the full resuscitation effort even if the EMS is called. It must be signed by both the patient and the doctor.

If you are in the hospital, you can ask your doctor to add a DNR or DNAR order to your medical record. But an in-patient DNR order is only good while you are in the hospital.

### **Organ and tissue donation**

Some people are interested in donating organs. Even though you have cancer, you still may have some options of donating either your corneas (from your eyes) or your entire body for medical research. If you would like your body to benefit someone or some cause after your death ask your doctor about these options.

Organ and tissue donation instructions can be included in your advance directive document. Many states also have organ donor cards or add notations to your driver's license.

### **Letter of instructions**

Although this is not a legal document, it can be very helpful. This document can be a guide for your family to help them make decisions at the end of your life and after you are gone.

In the instructions, you can name who you want to take in and look after your children or pets. This is useful if the guardian you have named in your will lives out of state. You may also list names and telephone numbers of those who should be contacted right after your death. This could include relatives, your lawyer, financial advisor, the human resources manager at your former job, your insurance agent, or whomever else you consider important in your life.

You should list the location of important papers and bank and investment accounts. Note also the person who should contact these organizations. You can also leave instructions about the kind of funeral or memorial service you would like.

Copies of instructions should be given to the executor of your will, trusted family members, or other loved ones. Be sure to talk with the people who will need to carry out these instructions. Be sure they are willing to do so and see if they have any questions about your wishes.

All of these documents should be kept in a safe place in your home. You can store an original in a safe deposit box if you want, but copies should be given to a close family member, a member of your health care team, and your lawyer. It is important to make sure someone knows where these documents are and can get to them quickly. It's also important to tell your health care team what they say when and if the need arises.

## **Health care coverage**

### **COBRA**

If you left work because of your health, you are entitled to keep your health insurance for the next 18 months. But you must elect to do so within 63 days of when you stopped working. You can do this under the federal law called COBRA (the Consolidated Omnibus Budget Reconciliation Act). Your employer usually requires you to pay the premium for your insurance plus 2% to cover costs. Your employer may help with the costs of your insurance premiums, but is not required to do so. COBRA applies to nearly all businesses that employ 20 or more workers. If you are disabled you can continue your coverage for 29 months. The Social Security Administration decides whether you are considered disabled. For more information please see our document *What is COBRA?*

### **Individual coverage**

If you do not have a COBRA option and need to look into individual coverage, you may find that you are declined coverage by a number of insurance companies and HMOs. If you can find an insurer, the cost of these policies or medical plans will be high. If you are turned down as "uninsurable" and you are without medical coverage, check with your state's insurance commission. Many states offer medical coverage called high-risk pools for those who have been turned down by insurance companies and HMOs. A state-supported plan may cost more than some other plans.

When joining a new medical plan, you may face a "pre-existing condition exclusion period." A pre-existing condition is a health problem that you had before you joined your medical plan, such as your cancer. When this happens, your plan will make you wait before they pay

the costs of that medical problem. Find out if this is the case before joining. The wait is often around a year and it may be too long for the insurance to benefit you.

There are some newer rules that can help you get health insurance coverage through an employer, if you have recently been insured through an employer's group. If you have met the following requirements, then a pre-existing condition exclusion period may not apply to you:

- You have had medical coverage for 18 months (that's why is it very important not to stop your health insurance or let it lapse).
- You have already met a pre-existing condition exclusion period.
- You have not been without health coverage for more than 62 days.

But if you are buying a plan that is not group coverage (including high-risk pools), the pre-existing condition exclusion period is set by the state and can be many years or even unlimited. If you are getting a plan through someone other than an employer, the insurance provider can also impose an "elimination rider" that would keep your cancer treatment from ever being covered by that policy. Remember that even an expensive insurance plan with a high deductible is better than one that won't cover the care you need now. If you are having trouble with this, it may help to talk to an insurance agent.

### **Adding to your Medicare coverage**

If you are on Medicare now, you may be able to add more coverage with a Medigap policy or a Medicare HMO. If you get an add-on policy within 6 months of going on Medicare, you won't have to wait out a pre-existing condition exclusion period. If you get an add-on policy after 6 months of being on Medicare you likely will have to wait before the plan would help pay your medical bills. Find out how long the wait is -- it may be too long to help you.

There are still a few government programs that may help if you don't have coverage. But to qualify for many of these programs, your income and assets must be very low.

### **Medicare**

Are you currently collecting Social Security Disability Insurance (SSDI) income? Keep track of the number of months you've been on SSDI. After you have been covered for 24 months, you will be eligible for Medicare. Many health care providers and hospices accept Medicare. This will give you some choices in your health care. You can get more information on Medicare by calling 1-800-MEDICARE (1-800-633-4227), from your nearest Social Security Administration office (check your local phone book), or by talking with your cancer care team social worker.

## **Medicaid**

Medicaid is another government program that covers the cost of medical care. Not all health providers take Medicaid. To get Medicaid, your income and assets must be below a certain level. These levels vary from state to state. Some people try to qualify for Medicaid by giving away their assets, or selling them for less than they are worth. But anything you give away (or sell for less than its market value) up to 5 years before applying for Medicaid is still counted toward your income. So, giving away assets could delay qualifying for this program. Also, it is a federal crime to help someone get rid of assets in order to qualify for Medicaid. You can talk with your social worker or contact your state Medicaid office about what is required to qualify.

## **Money and income**

### **Disability**

One benefit that may be available to you is long-term disability. You must look at your employer's description of disability and see if you meet the criteria. A human resources expert at your work- place can discuss this with you or your partner and advise you about the best way to qualify for benefits. If your employer pays for your plan, your disability may not be quite as much as the usual 60% to 70% of your wages. Payments are also lower when you also are getting disability income from Social Security or another program.

Some people buy their own disability insurance plans. For these people, the rules are different. Once you have met the plan's definition of disability, you will be paid a specific amount per month from the company.

### **Social Security Disability Insurance**

If you've been working for many years, money has probably been taken out of your paycheck for Social Security. If you're self-employed, the self-employment tax you pay covers your Social Security contribution. In this case, you may qualify for disability benefits. But you must meet Social Security's definition of disability, which is quite strict. If you are turned down, it is best to appeal the decision. Many cases that are turned down at first are approved after an appeal.

Don't count on Social Security Disability Insurance (SSDI) for your immediate needs. Even if your claim is approved, you will not get benefits until the sixth full month of disability. The approval process takes a long time and it may be too long in your case.

To find out how much you could get from SSDI you must fill out Social Security Form 7004. Call the Social Security Administration at 1-800-772-1213 to order this form or print it from [socialsecurity.gov](http://socialsecurity.gov).

## **Supplemental Security Income**

If you did not work much or your income was very low before you became unable to work, you may be eligible for Supplemental Security Income (SSI). To get SSI, your income and assets must fall below a certain level. These levels and the amount you could get from SSI vary from state to state. And the amount usually changes a little each year.

## **Life insurance**

If you have life insurance through your job and leave your job, take your life insurance policy with you. You may be able convert it to an individual permanent policy with no proof of insurability, but you usually must do it within a month of leaving the job. You will have to pay the premiums out of pocket, but some employers have a policy with a feature called a "waiver of premium rider." This means that you keep your group life insurance policy but you do not have to pay the premiums if you are totally disabled. They are paid by the insurance company instead.

If you have your own individual life insurance policy, keep it active by paying the premiums on time. Find out if the policy has a waiver of premium rider. This waiver means the policy's premium is paid by the insurance company if you become totally disabled. This could save you money and keep your policy in effect.

You may also want to double check the beneficiary you have named on your life insurance policy. Be sure the money is going to the person or people you want to get it.

## **Choosing home care**

Your family and friends are considered informal home caregivers. Formal home care is a business that provides care to all types of patients with a wide variety of needs. Home care can provide anything from skilled nursing care to housekeeping services. The focus of home care is on improving health and quality of life. Skilled home care services from a certified agency can do a lot to help with symptom management and instruction about medicines, central lines, and wound care, to name just a few available services.

A doctor's prescription (sometimes called an *order*) is needed for all home care services. In most states you must meet strict criteria for home care. This can include homebound status (the patient only leaves the home to get medical treatments), a need for skilled services, the care is needed part-time only, and the services provided are reasonable and necessary. These



Medicare-mandated guidelines can make it hard for end-of-life care to be managed through a home care agency.

## Choosing hospice care

Hospice care puts you and your loved ones in the care of experts on the end of life. The goal of hospice care is to help patients to live their last days as alert and pain-free as possible. Hospice care aims to manage symptoms so that a person's last days may be spent with dignity and quality, surrounded by their loved ones. Hospice affirms life and neither hastens nor postpones death. Hospice care treats the person rather than the disease; it focuses on quality rather than quantity of life. It provides family-centered care, involving the patient and family in all decisions.

This care is planned to cover 24 hours a day and 7 days a week. Hospice care can be given in the patient's home, a hospital, nursing home, or private hospice facility. Most hospice care in the United States is given in the home, with family members or friends serving as the main caregivers. If a patient wants home hospice care, a caregiver must be in the home with them 24 hours a day.

Hospice care is used when you can no longer be helped by curative treatment, and you are expected to live about 6 months or less. You, your family, and your doctor decide together when hospice services should begin. If you get better or the disease goes into remission, you can be discharged from the hospice program and return to active cancer treatment, if desired. Hospice care may be resumed at a later time if needed.

Making the choice to get hospice care should not be viewed as a last resort. The benefits that you and your family can get from hospice care are very valuable. Through hospice care you will get the help you may need to put your affairs in order, say your good-byes, and spiritually prepare for your death in a way that promotes dignity and comfort. Your family will be fully supported through the dying process and helped through grief and bereavement after your death.

### **What makes me able to get hospice care?**

Even though it is common to hear that you must expect to have 6 months or less to live, many other criteria are used to decide if a person with cancer is eligible for hospice. In most cases, you must have widespread, aggressive, or progressive disease as seen by increasing symptoms, worsening lab values, and/or evidence of metastasis (the spread of cancer cells to distant areas of the body). You must also be unable to work or do certain things for yourself. Finally, you must have either refused life-prolonging therapy or have been getting worse in spite of treatment. You, your family, and your doctor decide together when hospice care should begin.

## **Who gives hospice care and what do they do?**

There are things about hospice care that make it different from other health care. Hospice care focuses on palliative care. Palliative care is treatment to relieve physical and psychological symptoms. It focuses on comfort and increases well-being. Hospice staff members are specially trained to help you and your loved ones through this very difficult time. The knowledge and experience they can share with you can help you to have the very best quality of life right up until the very end.

**A team of professionals:** Hospice care uses a health care team of doctors, nurses, social workers, counselors, home health aides, clergy, therapists, and trained volunteers to care for you and your family. Each team member offers support based on their special areas of expertise. Together, they give you complete palliative care (treatment that relieves symptoms, but is not expected to cure the disease). Their goal is to improve your quality of life by relieving symptoms and giving social, emotional, and spiritual support to you and your loved ones.

**Pain and symptom control:** The goal of pain and symptom control is to help you to be comfortable while allowing you to stay in control of and enjoy your life. This means that side effects are managed to make sure that you are as free of pain and symptoms as possible, but still alert enough to enjoy the people around you and make important decisions.

**Spiritual care:** Hospice care also tends to the spiritual needs you and your family may have. Since people differ in their spiritual needs and religious beliefs, spiritual care is set up to meet your specific needs. It may include helping you to look at what death means to you, helping you say good-bye, or helping with a certain religious ceremony or ritual.

**Home care and inpatient care:** Although hospice care can be centered in the home, you may need to be admitted to a hospital, extended-care facility, or an inpatient hospice facility. The hospice can arrange for inpatient care and will stay involved in your care and with your family. You can go back to in-home care when you and your family are ready.

**Respite care:** While you are in hospice, your family and caregivers may need some time away. Hospice care may offer them a break through respite care, which is often given in up to 5-day periods. During this time you will be cared for either in a hospice facility or in beds that are set aside for this in nursing homes or hospitals. Families can plan a mini-vacation, go to special events, or simply get much-needed rest at home while you are cared for in an inpatient setting.

**Family conferences:** Through regularly scheduled family conferences, often led by the hospice nurse or social worker, family members can stay informed about your condition and what to expect. Family conferences also give you all a chance to share feelings, talk about expectations, and learn about death and the process of dying. Family members often find great support and stress relief through family conferences. Conferences may also be done

informally on a daily basis as the nurse or nursing assistant talks with you and your caregivers during their routine visits.

**Bereavement care:** Bereavement is the time of mourning after a loss. The hospice care team works with surviving loved ones to help them through the grieving process. A trained volunteer, clergy member, or professional counselor provides support to survivors through visits, phone calls, and/or letter contact, as well as through support groups. The hospice team can refer family members and care-giving friends to other medical or professional care if needed. Bereavement services are often provided for about a year after the patient's death.

**Volunteers:** Hospice volunteers play an important role in planning and giving hospice care in the United States. Volunteers may be health professionals or lay people who provide services that range from hands-on care to working in the hospice office or fundraising.

**Staff support:** Hospice care staff members are kind and caring. They communicate well, are good listeners, and are interested in working with families who are coping with a life-threatening illness. They are usually specially trained in the unique issues surrounding death and dying. Yet because the work can be emotionally draining, it is very important that support is available to help the staff with their own grief and stress. Ongoing education about the dying process is also an important part of staff support.

**Coordination of care:** The hospice team coordinates and supervises all care 7 days a week, 24 hours a day. This team is responsible for making sure that all involved services share information. You and your caregivers are encouraged to contact your hospice team if you are having a problem, any time of the day or night. There is always someone on call to help you with whatever may arise. Hospice care assures you and your family that you are not alone and help can be reached at any time.

### **How do I find hospice care?**

Finding the hospice program that meets your needs may take some research, but it will be time well spent. It is important that you and your family do this while you have the strength and ability to do so. Quality of care, availability of needed services, the types of services covered, staff training and expertise, and insurance coverage all need to be considered. Most communities have a more than one hospice provider you can choose from. Ask around about others' experiences with hospices. Other resources are listed at the end of this document but here are some other ways to start your search:

**Local resources:** Your doctor or hospital discharge planner can help you find hospices in your area. Hospice care providers also are listed in the phone book. Your community may have information and referral services available through your local American Cancer Society, an Agency on Aging, a local United Way chapter, the Visiting Nurse Association, or your place of worship.

**State resources:** You may contact your state's hospice organization or its department of health or social services to get a list of licensed agencies. The state health department oversees certification of hospice services. Certification makes them able to get funding from Medicare and, in some states, also from Medicaid. Check the blue pages of your phone book for other state resources in your area.

**National resources:** National organizations addressing hospice care accreditation, treatment, and patient advocacy are listed in the "Additional resources" section at the end of this document. Some of them can also tell you which hospices are near you.

### **Who pays for hospice care?**

Home hospice care usually costs less than care in hospitals, nursing homes, or other institutional settings. This is because less high-cost technology is used and family and friends provide most of the care at home.

Medicare, Medicaid, the Department of Veterans Affairs, most private insurance plans, HMOs, and other managed care organizations may pay for hospice care. Along with this, community contributions, memorial donations, and foundation gifts allow many hospices to give free services to patients who can't afford payment. Some programs charge patients according to their ability to pay.

**Medicare hospice:** To get payment from Medicare, the agency must be approved by Medicare to provide hospice services.

To qualify for the Medicare hospice benefit, a doctor and the hospice medical director must certify that the patient has less than 6 months to live if the disease runs its normal course. The doctor must re-certify the patient at the beginning of each benefit period (2 periods of 90 days each, then an unlimited number of 60-day periods). The patient signs a statement that says he or she understands the nature of the illness and of hospice care, and that he or she wants to be admitted to hospice. By signing the statement, the patient declines Medicare Part A and chooses the Medicare hospice benefit for all care related to his or her cancer. The patient can still receive Medicare benefits for other illnesses. A family member may sign the statement if the patient is unable to do so.

**Medicaid coverage:** In 1986, laws were passed to allow states to develop coverage for hospice programs. Most states do have a Medicaid hospice benefit, which is patterned after the Medicare hospice benefit.

**Private insurance:** Most private insurance companies include hospice care as a benefit. Be sure to ask about your insurance coverage, not only for hospice, but also for home care.

**Private pay:** If insurance coverage is not available or is not enough to cover all costs, the patient and the family can hire hospice providers and pay for services out of pocket. Some

hospices are able to provide services without charge if a patient has limited or no financial resources.

## Physical symptoms in the last 2 to 3 months of life

Here is a list of some of the things a person goes through as death gets closer. We also try to give some tips on what can be done to manage these symptoms. Be sure to talk to your health care team about how you are doing. Don't assume "it's normal" to feel bad. There are often things that can be done to help you feel better.

### Fatigue

*Scott, age 60, with advanced cancer: "I feel like an engine running out of steam. It seems like I have just enough energy to do one or two small things, then it is gone. I have used up my supply for that day. I get tired of being tired. It is so frustrating!"*

Fatigue is the feeling of being tired physically, mentally, and emotionally. Cancer-related fatigue is often defined as an unusual and ongoing sense of extreme tiredness. It tends to be more severe than the tiredness that most of us feel every day, which is short-term and gets better with rest. Many people with cancer feel that fatigue is the most distressing symptom of their disease. It is also a symptom that almost everyone with advanced cancer has.

#### **What can you do about fatigue?**

To manage fatigue, first, control the symptoms that make it worse and then, prevent more fatigue by carefully balancing rest and activity.

Some of the symptoms that make fatigue worse include pain, nausea, vomiting, diarrhea, constipation, sleep problems, poor nutrition, shortness of breath or trouble breathing, and dehydration. You can reduce fatigue by getting relief from these symptoms. Fatigue is made worse by anemia (low red blood cell count) or by imbalances in blood chemistry, and both of these things can be treated. Fatigue is also worse when you feel anxious, worried, sad, depressed, bored, and under-stimulated. Your health care team and your caregivers can help you find ways to manage all of these things that can make you feel more fatigued. Tell them how you feel, and try different techniques to see if they help you feel less tired.

For example, severe anemia (a drop in the red blood cell count) can be treated with drugs that cause the body to make more red blood cells or with blood transfusions. Since this can make you feel better, these treatments can still be used in the last months of life.

If you are hypothyroid (have low thyroid hormone levels), sometimes thyroid medicine can help with this kind of fatigue. And there are some medicines that can make you feel tired,

too. You may need to talk with your health care team about switching to new ones or taking them at different times.

Sometimes simple changes in where and when you sleep can make fatigue better. But getting too much rest can actually make you feel worse and have less energy. Studies have shown that getting exercise at a level you can handle will improve your overall energy and help you stay mobile, strong, and flexible as long as possible.

Plan activities around the times you feel the best. Sit outside, listen to music, go for a ride in the car, spend time watching a meal being prepared -- distractions and stimulation of your senses will ease fatigue.

Be safe. If you are unsteady on your feet, make sure you have help when walking. With severe fatigue, plan any activity during the time you have the most energy. Take short rest periods. Some people find a bedside commode toilet chair helpful so they don't waste energy traveling to and from the bathroom. Plan rest stops when you are out of bed so that you can sit for awhile to regain energy. Keep chairs close by. You may feel safer if you have a walker or wheelchair available.. Your doctor or hospice team can help you get the equipment you need to be comfortable and safe.

Some people may find that they are afraid to go to sleep for fear that they won't wake up again. Again, this is a natural and very real fear. Needing more sleep is normal in the last few months of life. Withdrawing from people, turning inward, focusing on yourself, and talking less are also common at this time. Although some people want to surround themselves with friends and family, others want a quiet, peaceful environment. Listen to your body, tell people what you need, and save your energy for the things or people that are most important to you. Focusing on getting the most from each waking moment is a good way to redirect your worries and fears.

## Pain

*John, age 47: "I need the morphine to do the things I want to do. As long as I lay still in bed, I'm okay -- no pain, but I don't want to spend the rest of my life flat on my back in bed!"*

People with cancer often fear pain more than anything else. But pain can be well controlled and managed in expert hands. It is important to know that pain does not have to be a part of dying. If you have pain, the most important thing you can do is talk to your health care or hospice team about it. They should understand that your pain is whatever you say it is. You should expect that your pain can and will be controlled. You and your team must work together to reduce suffering, relieve pain, and enhance your quality of life.

Describe your pain in as much detail as you can, including where it is, what it feels like, how long it lasts, when it started, and what makes it better, and what makes it worse. Keeping a pain record of all of this may help. Often your health care team will ask you to describe your

pain with a number from 0 to 10, with 10 being the worst pain you can imagine and 0 being no pain at all. Using this pain scale is also a helpful way to describe your response to pain relief measures.

## **Types of pain**

Acute pain is often severe, starts suddenly, and lasts a short time. It is often a signal that body tissue is being injured in some way. Acute pain often disappears when the injury heals.

Chronic pain, which can range from mild to severe, can last for a few weeks or may be ongoing. It can be from the cancer itself or from cancer treatment. The most common type of chronic pain in people with cancer is pain caused by cancer spreading to the bone. Another type of chronic pain is caused by a tumor pressing on organs or nerves. Having chronic pain can make you feel irritable, sleep poorly, decrease your appetite, and decrease your concentration, among many other things. But chronic pain can be well controlled

When people have chronic pain that is being treated with pain medicines, they can describe it: as persistent (continuous) pain and breakthrough (intermittent) pain. Persistent pain stays for long periods of time or almost all the time. Breakthrough pain is a brief and often severe flare of pain that can happen even though a person is taking pain medicine regularly for persistent pain. Breakthrough pain typically comes on quickly, and lasts a short time.

Chronic pain is managed by taking long-acting pain medicines around the clock, whether or not you are having pain at the moment. This keeps your pain under control most of the time. But when pain starts to break through this layer of control, you need to take a dose of fast-acting pain medicine right away.

## **Types of pain medicines**

The nurse or doctor will assess your pain and figure out the average level or degree of pain you are having. For mild pain (usually 1 to 3 on the scale of 0 to 10), pain medicines like acetaminophen (Tylenol<sup>®</sup>) or nonsteroidal anti-inflammatory drugs (NSAIDs, such as aspirin, ibuprofen or naproxen) may be used. NSAIDs are drugs that treat pain as well as inflammation. It is best to use these medicines around the clock to treat the pain without interruption.

For moderate pain, or pain that is a 4 to 6 on the scale, opioids (morphine-like drugs) may be used. Examples of these drugs include hydrocodone (Vicodin<sup>®</sup> or Lortab<sup>®</sup>), oxycodone (Percocet<sup>®</sup>), or fentanyl (Duragesic<sup>®</sup>) patches. NSAIDs may also be used with the opioids. The dose of opioid will start low, be given around the clock, and then increased as needed to control your pain.

If your pain is severe (a 7 to 10 on the 0 to 10 pain scale), other stronger opioids will be started such as morphine or hydromorphone (Dilaudid<sup>®</sup>). Long-acting, time-released forms of opioids like MSContin<sup>®</sup> (a form of morphine) and Oxycontin<sup>®</sup> (a form of oxycodone) work very well if used regularly. These long-acting drugs work by keeping your blood levels of the drug steady, which then keeps your pain leveled out and under control for long periods of time. Morphine sulfate drops (Roxanol<sup>®</sup>) can be given under the tongue to control breakthrough pain even if you have trouble swallowing.

Sometimes, very severe pain may be better controlled with a pain medicine pump which gives the drugs either under the skin (subcutaneously) or into a vein (intravenously, IV). If you need this type of pain control, you can still get it at home. You and your family will be taught how to use the pump, which is called a patient-controlled analgesia (or PCA) pump.

Some people need much higher doses of opioids than others. Do not be concerned if you seem to be taking large amounts of drugs. It has nothing to do with being unable to withstand pain, nor does it mean that you are a complainer. Some people need less, and some need more to keep pain in check.

Over time you may also find that you need higher doses of pain medicines because they aren't working as well as they once did. This is because your body has probably become tolerant to the smaller doses of the same drugs, so the effects of the drug are reduced. Needing to increase your pain medicine dose not mean that you are going to die soon. In fact, evidence has shown that poor pain relief hastens death. Sometimes other drugs such as antidepressants work well to help with nerve pain. Steroids and muscle relaxers may also be used to help with certain types of pain. These medicines are often given along with the opioid drugs.

### **Side effects of opioids**

There are some side effects of opioids that can be quite troublesome. But many of these side effects can be treated or prevented. One of the most common side effects is drowsiness. With a gradual increase in medicine over time, drowsiness will decrease as the person adjusts to the medicine; but it may not go completely away. If the drowsiness is severe, sometimes other medicines are used to help the patient stay awake.

Dry mouth is another side effect that can be annoying. Sips of water, hard candy, ice chips, or anything to moisten the mouth can help. Opioids can cause nausea or vomiting. Anti-nausea pills or suppositories can be given to prevent this. Constipation is a very common side effect of opioids.

Whenever you start to take an opioid, you probably will also be started on some type of bowel regimen which often includes a stool softener and laxative to prevent constipation. Sometimes, a patient can become confused when taking an opioid, especially when it is first started and the dose is high. If this happens, there are ways to lessen that effect, like trying



other medicines, lowering the dose, changing the frequency or trying medicines that improve confusion.

Generalized itching (called *pruritis*) is another common opioid side effect. This, too, can be treated with other drugs and often lessens or goes away over time without any treatment.

Medicines are not the only way to help your pain. There are other things you can do. Some people find distractions like music or using heat or cold helpful. Massaging a painful area can help, as can relaxation exercises. For most people these measures are not enough to control pain, though they may help improve comfort when used along with medicines.

One thing you do not have to worry about while taking medicines for pain is addiction. When pain medicines are used for cancer pain, addiction is not an issue. Taking care of your pain is the most important thing.

If the patient is not able to talk about the pain they may be having, there are things caregivers can watch for that show pain or discomfort. Some signs of pain that they may see include:

- noisy breathing -- labored, harsh, or rapid breaths
- making pained sounds -- including groaning, moaning, or expressing hurt
- facial expressions -- looking sad, tense, or frightened, frowning or crying
- body language -- tension, clenched fists, knees pulled up, inflexibility, restlessness, or looking like they're trying to get away from the hurt area
- body movement -- changing positions to get comfortable but can't

Being able to identify these things and give pain medicine as needed helps the caregiver take good care of the patient and keep him or her as comfortable as possible.

## **Appetite changes**

*Margie, age 34: "I just can't eat, but I know I have to eat to live. It upsets my husband and my kids when I don't...it scares me too sometimes. I try, but I can't do it."*

As time goes on your body may seem to be slowing down. Maybe you're feeling more tired or maybe the pain is getting worse. You may become more withdrawn and find yourself losing weight and eating less. This is a normal part of the last months of life, but it may be the beginning of a battle between you and your loved ones. You are moving less, have less energy, less appetite, and less desire to eat. Food no longer smells good or tastes good. You seem to become full more quickly and are interested in fewer foods. While this is going on, the cancer cells can compete with your body for the essential nutrients that you do manage to digest.

## **Avoid family food battles**

It can be very upsetting to your family to see you eating less. For them, your interest in food may represent your interest in life. By refusing food, it may seem to your family that you are choosing to shorten your life. They may take this personally and think that you want to leave them or are trying to hasten your death -- even unconsciously.

It is important that you and your loved ones talk about the issues around eating. The last few months of your life should not be filled with battles around food. Loss of appetite and being unable to eat (together called *anorexia*) happens to more than 8 out of 10 of cancer patients before death. It is normal in the last months of life for parts of your body to start slowing down and eventually shut down. When you feel like eating less, it is not a sign that you want to leave life or your family. It is just a normal part of the dying process. Explain to your loved ones that you deeply appreciate all their efforts to feed you and that you understand their attempts are acts of love. You are not rejecting their love, but your body is limiting what it needs at this time.

Your body is going through changes that have a direct effect on your appetite. Changes in taste and smell, stomach and bowel changes, shortness of breath, nausea, vomiting, diarrhea, constipation -- these are just a few of the things that make it harder to eat. Drug side effects, stress, and spiritual distress are also possible causes of poor appetite.

Some causes can be managed with medical treatment. For example, nutritional support can be given in the form of suggestions on how to get the most out of each bite you take or through the use of supplemental drinks or shakes. There are also medicines that can stimulate your appetite, decrease nausea, and help food move through your stomach more quickly. You might be surprised to find that you are able to eat when joining others at a table. You may be able to take in small frequent meals or snacks during the day instead of trying to eat regular meals 3 times a day.

Early recognition and intervention is important. Talk to your medical team about how much you've been eating and whether or not you need to do something about it.

## Problems breathing

*Henry, age 78: "I was struggling to breathe. I thought the attack would never end and that was how I was going to die!"*

Even thinking about breathing problems can seem scary. *Dyspnea* is the term used for an unpleasant awareness of breathing. It is a very common symptom in people with advanced cancer. It is another symptom that can be addressed and well-managed at the end of life.

You may feel that you are short of breath or you need to breathe faster and harder than normal. You might feel as if you have liquid in your lungs and it makes you want to cough. Often these symptoms come and go. If they are not recognized, they can't be treated. Tell

your health care team about any breathing problems you have so that you can get early help to manage them.

There are a number of things that can be done to help with breathing problems. Sitting up, propping yourself up on pillows, or leaning over a table may make it easier for you to breathe. Sometimes oxygen coming through a small tube you wear under your nose will relieve most of your symptoms. Opioid pain medicines can work well to decrease shortness of breath and relax your breathing.

If fluid is in your lungs, medicines can be given to slow the build-up of fluid. Sometimes opening a window or having a fan in the room will help you feel less hungry for air. You can be taught breathing and relaxation techniques to use when breathing is hard. Even having medicines to help your anxiety may decrease your worry about shortness of breath. Many people with cancer fear that this problem will get worse as the disease progresses. There are steps to manage each change in your condition and treat each problem. Just like pain, you should not have to feel as if you have no control over your breathing problems. Talk to your health care or hospice team about your symptoms and they will treat your specific problems.

## **Last breaths**

Many people have certain changes in their breathing patterns at the very end of their life. Noisy, moist breathing or severe congestion often happens in the hours before death. This is very distressing for the family because it often looks and sounds like the person is drowning. Most often, this symptom happens while the patient is unconscious and not aware of it. But if the patient is alert, it can be very frightening.

There are many causes of this congestion. Excess mucus, trouble swallowing, decreased cough reflex, weakness, fatigue, and resting flat in bed are just a few reasons for it. Treatment can help to manage this congestion. There are drugs that can be used to help dry up the liquids. Changing position usually helps -- especially sitting up.

Knowing about this possible change in breathing can help you and your family identify, report, and treat it as quickly as possible. Being prepared for this possibility includes good teaching and reassurance from your health care team. Ask them what to expect and tell them what you want them to do about it.

## **When death is near**

This section has been written for the caregiver, but many patients want this same information for themselves. It lists some signs that death may be close and gives the caregiver suggestions for what they may do to help.

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

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

### **Possible changes in body function**

- profound weakness -- usually the patient cannot get out of bed and has trouble moving around in bed
- needs help with nearly everything he or she does. May be unable to change positions without help
- less and less interest in food, often with very little food and fluid intake for days
- trouble swallowing pills and medicines
- more drowsiness--the patient may doze or sleep much of the time if pain is relieved. May be restless and pick or pull at bed linens. May be hard to rouse or wake. Anxiety, fear, restlessness, and loneliness may worsen at night
- cannot concentrate, has short attention span
- confused about time, place, or people
- limited ability to cooperate with caregivers
- involuntary movement of any muscle, jerking of hands, arms, legs, or face

### **What caregivers can do**

- Help the patient turn and change positions every hour or 2.
- Avoid sudden noises or movements to lessen the startle reflex.
- Speak in a calm, quiet voice to reduce the chances of startling the patient.

- If the patient has trouble swallowing pain medicines, ask the doctor or hospice nurse about getting liquid pain medicines or a pain patch.
- If the patient is having trouble swallowing, avoid solid foods. Give ice chips or sips of liquid.
- Do not push fluids. Near the end of life, some dehydration is normal. It is also more comfortable for the patient.
- Apply cool, moist wash cloths to head, face, and body for comfort.

### **Possible changes in consciousness**

- more sleeping during the day
- hard to wake or rouse from sleep
- confusion about time, place, or people
- restless, may pick or pull at bed linen
- may talk about things unrelated to the events or people present
- may have more anxiety, restlessness, fear, and loneliness at night
- after a period of sleepiness and confusion, may have a short time when he or she is mentally clear before going back into semi-consciousness

### **What caregivers can do**

- Plan being with the patient when he or she is most alert or during the night when your presence may be comforting.
- When talking with the patient, remind her or him who you are and what day and time it is.
- Continue pain medicines up to the end of life.
- If patient is very restless, try to find out if they are having pain. If they are, give breakthrough pain medicines as prescribed, or check with the doctor or hospice nurse if needed (see the section on pain).

- When talking with a confused person, use calm, confident, gentle tones to reduce chances of startling or frightening the patient.
- Touching, caressing, holding, and rocking are usually helpful and comforting.

### **Possible changes in metabolism**

- less interest in food -- the patient has less need for food and drink
- mouth may dry out (see the next section on changes in secretions)
- may no longer need some of his or her medicines, such as vitamins, replacement hormones, blood pressure medicines, and diuretics (unless they help make the patient more comfortable)

### **What caregivers can do**

- Put lubricant or petroleum jelly (Vaseline<sup>®</sup>) on the lips to prevent drying.
- Ice chips from a spoon, or sips of water or juice from a straw may be enough for the patient.
- Check with the doctor to see which medicines may be stopped. Medicines for pain, nausea, fever, seizures, or anxiety should be continued to keep the patient comfortable.

### **Possible changes in secretions**

- mucus in the mouth may collect in the back of the throat (This may be a very distressing sound to hear, but doesn't usually cause discomfort to the patient.)
- secretions may thicken due to less fluid intake and build up because the patient cannot cough

### **What caregivers can do**

- If the mouth secretions increase, keep them loose by adding humidity to the room with a cool mist humidifier.

- If the patient can swallow, give ice chips or sips of liquid through a straw. This may help thin secretions.
- Change the patient's position -- turning them onto the side may help secretions drain from the mouth. Continue to clean teeth with a soft toothbrush or soft foam mouth swabs.
- Certain medicines may help. Ask your doctor or hospice nurse about them.

### **Possible changes in circulation and temperature**

- arms and legs may feel cool to the touch as circulation slows down
- skin on arms, legs, hands, and feet may darken in color and look mottled (blotchy dark spots)
- other areas of the body may become either darker or paler
- skin may feel cold and either dry or damp
- heart rate may become fast, faint, or irregular
- blood pressure may get lower and become hard to hear

### **What caregivers can do**

- Keep the patient warm with blankets or light bed coverings.
- Avoid using electric blankets, heating pads, etc.

### **Possible changes in senses and perception**

- vision may become blurry or dim
- hearing may decrease, but most patients are able to hear you even after they can no longer speak

### **What caregivers can do**

- Leave indirect lights on as vision decreases.

- Always assume the patient can hear you.
- Continue to speak with and touch the patient to reassure them of your presence. Your words of affection and support are likely to be understood and appreciated.

### **Possible changes in breathing**

- breathing may speed up and slow down due to less blood circulation and build up of waste products in the body
- mucus in the back of the throat may cause rattling or gurgling with each breath
- the patient may not breathe for periods of up to 10 to 30 seconds

### **What caregivers can do**

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

### **Possible changes in elimination**

- urine may become darker and decrease in amount
- when death is near, the patient may lose control of urine and stool

### **What caregivers can do**

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

### **Signs that death has occurred**



- breathing stops
- blood pressure cannot be heard
- pulse stops
- eyes stop moving and may stay open
- pupils of the eyes stay large, even in bright light
- control of bowels or bladder is lost as the muscles relax

### **What caregivers can do**

After death it is all right if you sit with your loved one for a while. There is no rush to get anything done right away. Many families find this is an important time to pray or talk together and reconfirm their love for each other, as well as for the person who has passed away.

If the patient dies at home, caregivers are responsible for calling the appropriate people. Regulations or laws about who must be notified and how the body should be moved differ from one community to another. Your doctor or nurse can get this information for you. If you have a hospice or home care agency involved, call them. If you have completed funeral arrangements, calling the funeral director and doctor are usually all that you have to do.

-----  
----

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

-----  
----

### **Facing death**

Advanced cancer may very well be the hardest thing you and your family have ever faced. Now you have to face the reality that you will soon die. Your family members recognize this,

too. The next few months may be hard, but while you may have not been given the gift of time, you have the chance to focus on the quality of time and special sharing with your loved ones.

Thinking about death can be scary and painful, but it's a time to focus on physical, spiritual, emotional, and familial concerns. Sharing your goals, hopes, expectations, and concerns with your family and your health care team can help you through this time. Knowing what to expect and being prepared to deal with it can enable you to get the support and care you need in order to have the very best quality of life possible.

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

## **Additional resources**

### **More information from your American Cancer Society**

The following information may also be helpful to you. These materials may be ordered from our toll-free number, 1-800-227-2345.

Advanced Cancer (also available in Spanish)

Advance Directives

American Cancer Society Cancer Survivors' Network (CSN)

Anxiety, Fear, and Depression

Bone Metastasis (also available in Spanish)

Caregiving: How to Care for a Loved One with Cancer -- And Yourself

Caring for the Patient with Cancer at Home: A Guide for Patients and Families (also available in Spanish)

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

Family and Medical Leave Act (FMLA)

Financial Guidance for Cancer Survivors and Their Families: Advanced Illness

Financial Guidance For Families: Coping Financially With The Loss Of A Loved One

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

Helping Children When a Family Member Has Cancer: Bereavement Information for Children and Parents

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

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

Home Care Agencies (also available in Spanish)

Hospice Care (also available in Spanish)

Listen with Your Heart (also available in Spanish)

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

Talking with Friends and Relatives about Your Cancer (also available in Spanish)

Talking with Your Doctor (also available in Spanish)

## **Books**

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

*Cancer in the Family: Helping Children Cope with a Parent's Illness*

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

## **National organizations and Web sites\***

Along with the American Cancer Society, other sources of information and support include:

**American Council of Life Insurers (ACLI)**

Telephone number: 202-624-2000

Web site: [www.acli.com](http://www.acli.com)

**American Pain Foundation**

Toll-free number: 1-888-615-7246

Web site: [www.painfoundation.org](http://www.painfoundation.org)

**CancerCare**

Toll-free number: 1-800-813-4673

Web site: [www.cancercares.org](http://www.cancercares.org)

**Centers for Medicare and Medicaid Services (CMS)**

Toll-free number: 1-877-267-4227

TTY: 1-877-486-2048

Web site: [www.cms.hhs.gov](http://www.cms.hhs.gov)

**City of Hope Pain/Palliative Care Resource Center (COHPPRC)**

Telephone number: 626-256-4673, extension 63829

Web site: [www.prc.coh.org](http://www.prc.coh.org)

**Compassion and Choices**

Toll-free number: 1-800-247-7421

Web site: [www.compassionandchoices.org](http://www.compassionandchoices.org)

**Family and Medical Leave Act**

Toll-free number: 1-866-487-9243

Web site: [www.dol.gov/esa/whd/fmla](http://www.dol.gov/esa/whd/fmla)

**Family Caregiver Alliance**

Toll-free number: 1-800-445-8106

Web site: [www.caregiver.org](http://www.caregiver.org)

**Hospice Education Institute**

Toll-free number: 1-800-331-1620

Web site: [www.hospiceworld.org](http://www.hospiceworld.org)

**Hospice Foundation of America (HFA)**

Toll-free number: 1-800-854-3402

Web site: [www.hospicefoundation.org](http://www.hospicefoundation.org)

Hospice locator service can be accessed at: [hospicedirectory.org](http://hospicedirectory.org)

**Hospice Net**

Web site: [www.hospicenet.org](http://www.hospicenet.org)

**Meals on Wheels Association of American (MOWAA)**

Telephone number: 703-548-5558

Web site: [www.mowaa.org](http://www.mowaa.org)

**Medicare Rights Center (MRC)**

Toll-free number: 1-888-466-9050

Web site: [www.medicarerights.org](http://www.medicarerights.org)

**National Alliance for Caregiving (NAC)**

Web site: [www.caregiving.org](http://www.caregiving.org)

**National Association for Home Care and Hospice (NAHC)**

Telephone: 202-547-7424

Web site: [www.nahc.org](http://www.nahc.org)

**National Family Caregivers Association (NFCA)**

Toll-free number: 1-800-896-3650

Web site: [www.thefamilycaregiver.org](http://www.thefamilycaregiver.org)

**National Hospice and Palliative Care Organization (NHPCO)**

Toll-free number: 1-800-658-8898; in Spanish 1-877-658-8896

Web site: [www.nhpco.org](http://www.nhpco.org)

**Office on Aging**

Phone number: 1-800-677-1116 (to learn how to reach your state's Office on Aging)

Web site: [www.eldercare.gov](http://www.eldercare.gov)

**Social Security Administration (SSA)**

Toll-free number: 1-800-772-1213

TTY: 1-800-325-0778

Web site: [www.socialsecurity.gov](http://www.socialsecurity.gov)

*\*Inclusion on this list does not imply endorsement by the American Cancer Society.*

No matter who you are, we can help. Contact us anytime, day or night, for information and support. Call us at **1-800-227-2345** or visit [cancer.org](http://cancer.org).

## References

Babcock EN. *When Life Becomes Precious: A Guide for Loved Ones and Friends of Cancer Patients*. New York: New York, Bantam Books. 1997.

Coyle N and Ferrell BR. *Textbook of Palliative Nursing*. New York: New York, Oxford University Press. 2001.

Foley KM, Back A, Bruera E, et al. *When the Focus is on Care: Palliative Care and Cancer*. Atlanta, Georgia: American Cancer Society. 2005.

Hwang JP, Smith ML, Flamm AL. Challenges in Outpatient End-of-Life Care: Wishes to Avoid Resuscitation. *J Clin Onc*, 2004; 22(22):4643-4645.

National Comprehensive Cancer Network. *NCCN Clinical Practice Guidelines in Oncology. Palliative Care – Version 1/2009*.

Ryan PY. *Approaching Death: A Phenomenological Study of Five Older Adults With Advanced Cancer*. *Oncology Nursing Forum*. 2005;32:1101-1108.

Seamn-Wrede L. *Symptom Management Algorithms: A Handbook for Palliative Care*. China: Intellicard, Inc. 1999.

VistaCare. Understanding Hospice. Accessed March 23, 2009 at [www.vistacare.com/hospice/default.asp](http://www.vistacare.com/hospice/default.asp)

Last Medical Review: 3/27/2009

Last Revised: 3/27/2009

2009 Copyright American Cancer Society

For additional assistance please contact your American Cancer Society  
1 - 800 - ACS-2345 or [www.cancer.org](http://www.cancer.org)