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 you probably have limited time to live. Your doctor may have even told you that no treatment can really help stop your cancer and you have only a short time left. Patients and family members often have questions about what they should expect during these last months of life. The information shared here has been written to help answer some of those questions.

Thinking about death can be scary and painful, but it’s a time to focus on physical, spiritual, emotional, and family concerns. Sharing your goals, hopes, expectations, and concerns with your family, loved ones, 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 so you can have the very best quality of life possible.

Learning that your cancer is advanced and that treatment is not helping may make you feel lost and afraid. This is natural. People have many questions, such as:

- What’s going to happen to me?
- Have I done everything I should have done?
- What are my other options?
- How much longer do I have?
- 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 my doctor wants to continue 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 live fully and get the most out of this last phase of your life.

This is written for the person with cancer, but it can be helpful to the people who care for, 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.

There are also professional cancer information specialists who are ready to talk with you about these issues 24 hours a day, 7 days a week at our National Cancer Information Center. You can speak to one of them by calling 1-800-227-2345.

Your emotions as you near the end of life

*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’s feeling the shock of how final death is and the guilt of being a burden on her family. She is also concerned about her 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’s hard to talk about it; still, these issues must be addressed. Knowing these feelings are normal and expected may help you cope with what’s happening. Some of the emotions you can expect to have include:

**Fear**

People may feel 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.

Your fears may be either concrete, like pain, or abstract, like your life’s purpose. Either way they’re very real.

Trying to figure out what you fear can help you face it and manage it. It will also help others support and care for you better. For example, if you’re afraid of being alone, share this with your family and loved ones so they can plan to have someone with you. Sharing with loved ones and your health care team gives them a chance to help you find ways to cope with and ease some of your fears. It gives them a chance to correct any wrong ideas you may have, too. 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 it won’t work. Very few people actually feel ready to die. It’s perfectly normal to feel angry about your life being cut short – it’s unfair and you
have a right to be mad! 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. But it may help to try to direct your anger 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 that she feels guilty about being a burden on her family. She also feels guilty that she will be leaving her children without a mother.

In their last few months of life, a person might regret or feel guilty about many things. We feel regret when we think that we should have done something differently. Or maybe there’s 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 how does it help anyone if you 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’re 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 can’t change the past, but there are things you might be able to do today. 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 can’t 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 your kids who they can talk with when you’re 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 the best you can, and use your time for what’s most important to you.

Grief

It’s 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 you are going to die soon. This is another loss that can 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’re all going through. Being able to rise above the grief and connect spiritually to something greater than one’s self might 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 so that they no longer weigh you down. It may take many tries, but once you have done this you will feel a burden has been lifted and you can move on to the other physical and emotional tasks that make up the end of life. There are many important tasks at the end of life, but coming to terms with the losses is one of the most painful.

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.

Some anxiety is expected, but if it’s severe it can be treated through counseling or with medicine – the goal is to make you more comfortable and help you 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 and not worry about tomorrow. Breaking problems into smaller, easier-to-manage pieces 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 when life is ending. Depression can sometimes be helped with anti-depressants, counseling, or a combination of both. Managing anxiety and depression well can make a big difference in how much joy or pleasure you can find in your last few months of life.

Feeling alone

Very few people know what it feels like to know for sure they are facing their last months of life. There can be a loneliness that’s different from any other. It’s 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 their life had purpose – that there was some reason for their being on earth. Some people find meaning in their work. Others find that raising a family has brought them the greatest sense of joy and accomplishment. It’s 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 doesn’t 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 that can be uncovered using personal reflection. Sharing your thoughts, experiences, and wisdom is a gift that your friends and family can cherish for years to come.
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...”

With your health care team

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

Once the health care team says, “There are no more treatments that might cure your cancer,” the patient often thinks, “The ball is back in my court.” This 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 need complete and honest information. Telling your doctor exactly what you want to know and getting the information you need are empowering steps. (In the section called “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 treatment decisions when facing the end of life

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

If you choose to have more treatment in spite of a doctor’s recommendations, explain your decision to those involved in your care. Even if they don’t understand or agree, you still must follow your own sense of what’s 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.

On the other hand, you may prefer to spend your time focusing on the quality of your life. You may want to feel as well as you can without any more cancer treatments and side effects. Know that any symptoms you have can always be treated. Treatment of discomfort and pain is known as palliative or supportive care, and it’s different from treatment aimed at the cancer itself. When you decide you don’t want more cancer treatment, some family members may find it upsetting. Again, they will probably feel more supportive if they know that you’ve looked into all your options. You may want to share the reasons for your decision so they can better understand.

With your network of support

You may be someone who has never needed a large support network. Maybe it’s not easy for you to reach out to others, especially when you may feel you don’t 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 Survivors 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’s 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.

**With 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 a big disappointment as a 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 try to meet your every need. Some people just can’t handle that kind of pressure and may withdraw under these circumstances. They could 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 partner 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’ll probably find that you are both going through the same kinds of emotions. Try to accept what each person says without judgment, argument, or defending yourself. 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 having cancer 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 petty arguments go. Focus on the good times, happy memories, and the times you have been there for each other.

**Alone time**

It’s 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 a few 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 don’t 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.

Help take care of your partner

You may need to talk to your partner if you’re worried about being a burden to them because they are 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 there’s too much for one person to do. Be sure to tell your partner you are going to do that. In this way, you can help take care of your partner, too.

With your 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 idea of losing you. They need your love and understanding. Though it might 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 signs of the dying process, and how to manage them should they occur. Explain to your family that you’re open to discussion and that you’re willing to talk about anything. Explore their thoughts and feelings with them. Tell them that you are open to talking, but there may be times you don’t feel like it and you will let them know when that is. Tell them that you’d rather not try to put on an act and have to pretend you’re 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 tired or a little down.

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’ll be prepared. Tell them about plans you’ve made or need to make and get their input. Adult children may be juggling their own children, jobs, and caring for you. It’s a stressful time. Sometimes they might not be able to meet your expectations. Open, honest communication will help you support each other through this time.

Children and teens

It’s natural to want to protect children from the harsh reality that you won’t be there in a few months. But professionals who work with families would strongly encourage you not to try that. Even the youngest 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 might even believe that something they’ve done caused the cancer to grow. It’s up to you to assure them that they had nothing to do with your cancer, its growth, or with the fact that you will not win your battle against it. Let them know that you’ll 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 what plans will be in place when you’re no longer there. Explain in some detail what will happen when you’re 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’s 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 anything they want.

Sometimes it helps to tell your kids about people and places they can go to when they’re 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 time. Encourage your child to help you with some physical tasks, such as getting things for you or reading books to you. This way they don’t feel so helpless or in the way. It’s easy for busy adults to ignore or push kids 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. For more on talking with children and teens, see Helping Children When a Family Member Has Cancer: Dealing With a Parent’s Terminal Illness.

With your 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’re the same person and you’d like to spend some of your remaining time with them, if they are willing to do that. Try to understand that what you’re 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 think about, some people may avoid spending time with you.

With 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 with 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 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 they may 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 come to 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’s usually not the act of dying, but the quality of dying that’s 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 people want to stay at home and have hospice care there. Others choose to go to an assisted living center, a nursing home, or an inpatient hospice program. Some are in the hospital and want any treatment available to keep them alive as long as possible, no matter what their condition might be. 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’s 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 try to think about and prepare for how you’re going to die.

**Advance directives**

It might 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, but only if you plan ahead. If you have not already made a decision about your care at the end of your life, now is the time to do it.

An advance directive puts your decisions about your future health care in writing. Advance directives are legal documents. One type of directive clearly states your wishes about who you want to make your medical decisions. Another type can give specific details about how you would like to die. Your doctors will generally follow instructions in your advance directive if you become unable to express your desires as your illness progresses, but only if they know about those wishes and have copies of your directive. Having an advanced directive helps take the burden off your
family members and healthcare team. It also helps to ensure that you will get what you want up until the very end of your life. The main types of advance directives are briefly described below:

**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 it, you name someone who will make medical decisions for you if you become too ill to make decisions yourself. This person will talk to the doctors and health care team on your behalf and make decisions for you if you become unable to do so. In a DPOA for health care, you can also 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 need to let that person know what you have in mind, and what you do and don’t want. Make sure that the person you choose understands your wishes, and that you feel certain that they can carry them out. Also be sure that your family members know who you have appointed as your decision-maker.

**Living will**

The other main type of advance directive is a living will. A living will gives you power to state your wishes if you can’t 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 want 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 healthcare team ahead of time, but it’s even better to have it written down, too. Having these issues clearly resolved to your satisfaction can give you and your family peace of mind.

**Do Not Resuscitate and Do Not Attempt Resuscitation orders**

If you are in the hospital, you can ask your doctor to add a *Do Not Resuscitate (DNR)* or an *Allow Natural Death (AND)* order to your medical record to keep staff from trying to revive you if you stop breathing. But an in-patient DNR or AND order is only good while you are in the hospital, and some hospitals may require a new form be signed each time you are admitted – even to the same hospital. There are other special orders that can be used in hospitals, such as “Do Not Intubate” (so that CPR would be tried but you wouldn’t be put on a breathing machine). Talk with your doctor about your options while you are in the hospital, and make sure your wishes are noted in writing.

Some states have a special *Do Not Attempt Resuscitation (DNAR)* order for use outside the hospital. The non-hospital DNR is intended for emergency medical service (EMS) teams, who answer 911 calls. In most cases, EMS must do everything they can to try and keep you alive. 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 is a way for patients to refuse full resuscitation efforts even if the EMS is called. It must be signed by both the patient and the doctor.
Making sure your plans are followed

Once you’ve decided on your plan, it’s important that you share it with others who might be involved in your care. Your partner, adult children, and even your parents will need to know. Often older people assume that their adult children know what they want, but when asked, their children really don’t feel at all certain. This kind of misunderstanding leads to conflict, fear of making the wrong decision, or even avoiding making decisions when the time comes to do so.

Keep in mind that, without a written advance directive in hand, your doctor may ask your closest family members – spouse, parents, adult children – to make decisions when you can’t. In some states, there’s a legal sequence of who makes decisions when a family member can’t. States have very different laws, for example, requiring doctors to confer with next of kin, or calling for court-appointed guardians. A written advance directive helps to ensure things are handled the way you want them to be, but only if your doctor has a copy and your family knows about it. Even then, family members can sometimes challenge your directive if you can’t speak for yourself.

When called upon to make decisions about your health care, your family must feel sure about what you want in order to feel comfortable enough to voice these decisions. Even if you have it in writing, it helps prevent anxiety and conflict among your immediate family if they’re all very clear on what you want. It makes a difference when they hear it from you – it often means much more than hearing it from another family member or even seeing it in writing.

If your family is estranged, or if they are likely to feel uncomfortable and disagree over difficult emotional decisions, it’s even more important to have these things in writing and be sure everyone close to you knows about it.

More information on advance directives

- 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 all of your health care providers. Talk to your family about your wishes so they know what you want. Be sure your closest family members can quickly and easily 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 read on our website.

Organ and tissue donation

Some people are interested in donating organs. Even though you have cancer, you still may have the 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. Many states also have organ donor cards or add notations to your driver’s license. Be sure that your family and
those close to you know your wishes about this too. See our document, *Can I Donate My Organs If I’ve Had Cancer?* to learn more.

**Letter of instructions**

Although this is not a legal document, it can be very helpful. This letter 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 look after or take in 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 phone numbers of those who should be contacted right after your death. This could include relatives, your lawyer, your financial adviser, the human resources manager at your former job, your insurance agent, or whomever else might need or want to be involved at this time.

You should list the location of important papers and bank and investment accounts. Note also the person who should contact these organizations. You may also want to 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, and/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 follow your requests 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 originals in a safe deposit box if you want, but copies should be given to close family members, members of your health care team, and your lawyer. It’s important to make sure more than one person knows where these documents are and can get to them quickly if you aren’t there to let them into your home. It’s also important to tell your health care team what the documents say when and if the need arises. If your wishes have changed since you last set up such a document, be sure that old copies are destroyed and that your loved ones know where your new documents are.

**Life insurance**

If you have life insurance through your job and you 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 don’t 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. If it does, this could save you money and keep your policy in effect.

You may also want to double-check the beneficiary or beneficiaries you’ve named on your life insurance policy. Be sure the money is going to those you want to get it.
Health care coverage

COBRA: A way to keep your health insurance after leaving your job

Employer-based health insurance is usually a type of group insurance, which can be to your advantage. If you left work because of your health, you are entitled to keep your job-based 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). You pay the premium for your insurance plus up to 2% to cover costs. Your employer might help with the costs of your insurance premiums, but is not required to do so.

Before you sign up, you’ll want to compare your COBRA costs with a similar marketplace plan. (See below, “Getting coverage through the health care marketplace.”) Be sure to include any employer contributions to COBRA or financial help with marketplace plans as you work through this comparison. Consider also coverage, co-pays, and co-insurance on services and medicines you’re likely to use.

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 called What is COBRA?

Getting coverage through the health insurance marketplace

Since the Affordable Care Act became law, each state has a health insurance marketplace offering private, individual health plans. These plans are not allowed to reject you due to your pre-existing condition. The marketplace plans set premium costs based on your age, location, and tobacco use. If your income is low you might also qualify for financial help to buy a plan.

The health care marketplace has open enrollment each year, in which you can make changes or enroll in a plan without penalty or explanation. For 2014, open enrollment extends through March 31, and will re-open in November. But if you’ve lost or quit your job, or if you’ve had a change in life circumstances such as marriage or divorce, you qualify for a special enrollment period in the marketplace. This special enrollment lasts only 60 days. You can enroll in a marketplace plan by:

- Finding your state’s marketplace website: visit www.healthcare.gov/, click “enroll”, and choose the state where you live
- Calling the marketplace helpline at 1-800-318-2596
- Enrolling by mail. You can download an application form from the healthcare.gov website or call the 800 number above to find out how to get one mailed to you

If you are having trouble getting coverage, you can get more detailed information by calling the American Cancer Society and asking for our Health Insurance Assistance Service at 1-800-227-2345. You can also ask for our document called Health Insurance and Financial Assistance for the Cancer Patient or read it online.
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’ve been covered for 24 months, you’ll be eligible for Medicare. Some healthcare providers and hospices accept Medicare. This will give you some choices in your healthcare. You can learn more about 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.

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 might help if you don’t have coverage. But to qualify for many of these programs, your income must be very low.

Medicaid

Medicaid is another government program that covers the cost of medical care, but not all healthcare providers accept Medicaid. To get Medicaid, your income must be very low, below a certain level. (These levels vary from state to state.) Since the new health law went into effect, some states have allowed people with higher incomes to sign up for Medicaid. If your income is low, you should think about re-applying for Medicaid, even if you’ve been rejected before.

If you are 55 or over and qualify for Medicaid, state programs must try to recover the cost of certain benefits they paid on your behalf. This means that after your death, most or all of the money that comes from the sale of your assets (your estate) could be going to the state Medicaid program. States may not recover the money from your estate if your spouse is still alive, if you have a child under age 21 or if you have a blind or disabled child of any age. Each state sets up its Medicaid recover program in its own way, so you’ll need to check with your state Medicaid office for details.

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’s 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’s 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 to see if you meet the criteria. A human resources expert at your work-
place can discuss this with you and/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. In this case, the rules are different. Once you’ve 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 either case, you might qualify for disability benefits. But you must meet Social Security’s definition of disability, which is quite strict. If you’re turned down, it’s 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 won’t 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 www.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.

**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 you with symptoms and teach about medicines, central venous lines, and wound care, to name just a few 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. You can read more about this in our document called *Home Care Agencies*. 
Choosing hospice care

Hospice care puts you and your loved ones in the care of experts on the end of life. Hospice care focuses on quality of life rather than length of life. The hospice philosophy accepts death as the final stage of life: it affirms life and neither hastens nor postpones death.

Hospice care treats the person rather than the disease, working to manage symptoms so that a person’s last days may be spent with dignity, surrounded by their loved ones. It’s also family-centered – it includes the patient and the family in making decisions.

You, your family, and your doctor decide together when hospice care should begin. If home hospice care is chosen, a caregiver must be in the home with the patient 24 hours a day.

To learn much more about this option, please see our document called Hospice Care, or call us for a free copy.

What makes me eligible for hospice care?

Even though a person must be expected to have 6 months or less to live to enter hospice, other standards are also 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 the spread of cancer cells to distant parts of your 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. Home hospice care is covered by most health plans, Medicare, and even Medicaid in some states. (See the section, “Who pays for hospice care?”)

What does hospice care provide?

Hospice care is used when your disease can’t be cured, and you are expected to live about 6 months or less if the illness runs its usual course. Hospice gives you supportive or palliative care, which is treatment to help relieve symptoms, but doesn’t cure the disease. Its main purpose is to improve your quality of life so that you can be as alert and pain-free as possible. Here are some of the services you can get through hospice:

- Pain and symptom control
- Home care and/or inpatient care (if needed)
- Spiritual care that’s designed for your needs
- Regular family conferences
- Coordinated care – the team of people involved in your care work together to meet your and your family’s needs
- Respite care, to allow friends and family some time away from caregiving
- Bereavement care for surviving loved ones to help them through the grieving process
How do I find hospice care?

Since most communities have more than one hospice provider, you and your family will need to decide which agency you’ll use for hospice services. Finding the hospice program that best meets your needs may take some research, but it will be time well spent.

You and your family should do this early in your care while you have the strength and ability to take part in the decision. Quality of care, availability of needed services, the types of services covered, staff training and expertise, and insurance coverage all need to be considered. Here are some things to think about as you 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, or the Visiting Nurse Association.

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 a hospice able to get funding from Medicare and, in some states, Medicaid. Check the blue pages of your phone book for other resources in your area or search online for your state hospice organization.

National resources

National organizations that deal with hospice care accreditation, treatment, and patient advocacy are listed in the “To learn more” 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 in most states, 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

To get payment from Medicare, the agency must be approved by Medicare to provide hospice services. The patient must be seen by their own doctor and the hospice medical director (a doctor)
to be certified for the first 180 days of hospice care. After the first 180 days, the patient must be seen again to be re-certified every 60 days for as long as the patient is getting hospice care.

If you’re not sure how hospice might work for you, Medicare offers a one-time only hospice consultation. You can meet with a hospice medical director or hospice doctor to discuss your care options and treatment needs. You don’t have to choose hospice care if you use this consultation service.

**Medicaid**

In 1986, laws were passed to allow states to develop coverage for hospice programs. Most states have a Medicaid hospice benefit, which is patterned after the Medicare hospice benefit. See more information on Medicaid in the section “Health Care Coverage.”

**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 it doesn’t cover all the costs, the patient and 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’s 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 tell your healthcare team 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’s gone. I have used up my supply for that day. I get tired of being tired. It’s 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’s 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. Then you can help prevent more fatigue by carefully balancing rest and activity.

Some of the symptoms that make fatigue worse include:

- Pain
- Nausea and/or vomiting
- Diarrhea
- Constipation
- Sleep problems
- Poor nutrition
- Shortness of breath or trouble breathing
- Dehydration (not having enough fluid in your body)

Fatigue can often be reduced by getting relief from these symptoms.

Fatigue is also made worse by anemia (a low red blood cell count) or by imbalances in blood chemistry, and both of these things can be treated. Fatigue tends to be worse if you are anxious, worried, sad, depressed, bored, or under-stimulated. Your healthcare team and your caregivers can help you find ways to manage the things that can make you feel more fatigued. Tell them how you feel, and try different things to see if they help you feel less tired.

For instance, severe anemia (a drop in the red blood cell count) can be treated with blood transfusions or with drugs that cause the body to make more red blood cells. These treatments can’t cure the cancer, but they can make you feel better in the last months of life.

Some medicines can make you feel tired, too. You may need to talk with your healthcare team about switching to new ones or taking them at different times. You might even be able to stop taking drugs that aren’t helping or aren’t needed any more. Make a list of medicines you take, along with the doses and the times you take them, and check with your doctor or cancer team. Or take all your medicines with you to your next appointment.

Sometimes simple changes in where and when you sleep can make you feel less fatigued. 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, help you keep moving, and let you stay strong and flexible as long as possible.

Keep safe when you’re active. If you’re unsteady on your feet, make sure you have help when walking. You may feel safer if you have a walker or wheelchair. Your doctor or hospice team can help you get the equipment you need to be comfortable and safe.

Plan activities around the times you feel the best and have the most energy. 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 may help ease fatigue.
Some people find a bedside commode or toilet chair helps – 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. Take short rests during activity – keep chairs close by.

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. Having chronic pain can make you feel irritable, sleep poorly, decrease your appetite, and decrease your concentration, among many other things. But pain can be well controlled and managed in expert hands. It’s 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.

Your health care team should check in with you often to find out how much pain you are having. It’s important to keep them up to date on all changes in your pain and other symptoms. They’ll need you to tell them how well each pain control plan work is working. Don’t be discouraged if your medicines must be tweaked a few times to get the best pain control with the fewest side effects. You may want to ask your cancer team to refer you to a pain specialist if your doctor can’t control your pain.

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, 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 using 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. You can find a Daily Pain Diary and a lot more information on pain control online or call us for free copies.

If you’d like to learn more about dealing with cancer pain, see our document Guide to Controlling Cancer Pain. You can call us at 1-800-227-2345 to get a free copy sent to you or you can read it online.

Types of pain

Acute pain starts suddenly, is severe, and lasts a short time. It’s often a signal that body tissue is being injured in some way. Acute pain often goes away 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 that has spread to the bone. Another type of chronic pain is caused by a tumor pressing on organs or nerves.

When people have chronic pain that’s being treated with pain medicines, they might describe the pain they have as persistent (continuous or chronic) 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 happens even when a person is taking pain medicine regularly for persistent pain. Breakthrough pain typically comes on quickly. It usually lasts only a short time but it can interfere with your activities, reduce your energy level, and cause fatigue and other problems. It may be unpredictable, but sometimes it’s brought on by certain activities. It might come back several times a day.

Chronic or persistent 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, “rescue” 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 have. For mild pain (usually 1 to 3 on the scale of 0 to 10), pain medicines like acetaminophen (Tylenol®) or non-steroidal anti-inflammatory drugs (NSAIDs, such as aspirin, ibuprofen or naproxen) may be used.

For moderate pain, or pain that’s a 4 to 6 on the scale, opioids (morphine-like drugs) may be used. NSAIDs may also be used with the opioids. The dose of opioid will start low, be given around the clock, and then is increased as needed to control your pain.

If your pain is severe (a 7 to 10 on the 0 to 10 pain scale), opioids are usually started right away. Long-acting, time-released forms of opioids work very well if used around the clock. These long-acting drugs work by keeping your blood levels of the drug steady, which helps keep your pain under control for long periods of time. Fast-acting, rescue drugs can be used to control breakthrough pain.

Opioid pain medicines come in many forms that can be given in many different ways. Patches that stick to the skin, lozenges or “suckers” that don’t have to be swallowed, drops that go under the tongue, and even rectal suppositories can be used when needed.

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.

It’s very common for a person with cancer to take more than one drug to manage chronic and breakthrough pain. And some people need much higher doses of opioids than others. Don’t 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 the body can become tolerant to a drug, so it has less effect. Needing to increase your pain medicine does not mean that you are going to die soon. In fact, evidence has shown that poor pain relief hastens death.
Sometimes other drugs may be used. For instance, certain anti-depressants or anti-convulsants (seizure control drugs) often work well to help with nerve pain. Steroids may be used to help with certain types of pain, such as that caused by swelling or inflammation. These medicines are often given along with the opioid drugs.

**Side effects of opioids**

Some side effects of opioids can be quite troublesome, but many of them 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 during the day to help the patient stay awake.

Dry mouth is another annoying side effect. 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’s first started or if 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 help 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.

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 rarely an issue. Even so, pain must be treated. 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 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.

**Other ways to help cancer pain**

With certain types of pain, doctors can do special procedures such as nerve blocks, targeted radiation treatments, or even surgical procedures to control pain. If your pain isn’t well controlled,
your doctor might also refer you to an expert in pain management. The pain specialist might have some different options to help you.

Medicines and medical procedures are not the only ways to help lessen your pain. There are other things you can do. Some people find distractions like music, movies, conversation, or games help. Using heat, cold, or massage on a painful area can help. Relaxation exercises and meditation can help lessen the pain and lower anxiety for some people. Keep in mind that for most people with cancer pain these measures alone are not enough to control pain. But, they may help improve comfort when used along with pain medicines.

**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 eating less and losing weight. This is a normal part of the last months of life, but it may be the start 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 may compete with the normal cells in your body for the 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’s important that you and your loved ones talk about 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’s 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’s not a sign that you want to leave life or your family. It’s 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’re 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, dry mouth, 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 tips 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’re able to eat more 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 full meals 3 times a day. These
measures may work for some, but they won’t help most people who are very close to the end of life. (See the section, “When death is near.”) At later stages, these efforts can even make the person feel worse.

It’s important to recognize changes in appetite so that you can get help when it’s needed. Talk to your medical team about how much you’ve been eating and whether 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 be scary. *Dyspnea* (disp-nee-uh) is the term used to describe trouble breathing or shortness of breath. It’s very common in people with advanced cancer, but it can be addressed and well-managed at the end of life.

You may feel short of breath or like you need to breathe faster and harder than normal. You might feel like you have liquid in your lungs and it makes you want to cough. Often these symptoms come and go. Tell your healthcare team about any breathing problems you have so you can get help with them.

A number of things 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 there’s fluid in your lungs, medicines can be given to slow the fluid build-up. Sometimes opening a window, a cooler room temperature, or having a fan blowing on your face will help you feel less hungry for air. You can be taught breathing and relaxation techniques to use when breathing is hard. Medicines to reduce anxiety may help you worry less 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 be able to get help with your breathing problems. Talk to your healthcare or hospice team about your symptoms so they can 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 manage any discomfort quickly. Ask your healthcare team 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 caregivers some ideas about what they may do to help.

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

It’s important to have a plan for what to do after death, so that people with the patient 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 the doctor about it so that you will know exactly 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
- 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, and may be hard to rouse or wake
- Short attention span, may not be able to focus on what’s happening
- Confusion about time, place, or people
- Limited ability to cooperate with caregivers
- Sudden movement of any muscle, jerking of hands, arms, legs, or face

**What caregivers can do**

- Help the patient turn and change positions every 1 to 2 hours.
- Speak in a calm, quiet voice and avoid sudden noises or movements to reduce the chances of startling the patient.
• If the patient has trouble swallowing pain pills, ask the doctor or hospice nurse about getting liquid pain medicines or a pain patch.

• If the patient is having trouble swallowing, do not give them solid foods. Try ice chips or sips of liquid.

• Do not push fluids. Near the end of life, some dehydration is normal. It’s 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, might 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 your times 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 the patient is very restless, try to find out if they are having pain. If it appears they are, give breakthrough pain medicines as prescribed, or check with the doctor or hospice nurse if needed (see the section on pain in “Physical symptoms in the last 2 to 3 months of life”).

• When talking with a confused person, use calm, confident, gentle tones to reduce chances of startling or frightening the patient.

• Gentle touching, caressing, holding, and rocking are usually helpful and comforting.

Possible changes in metabolism

• The patient may have less interest in food. (The patient has less need for food and drink.)

• Mouth may dry out (see “Possible changes in secretions” below)
• May no longer need some of his or her medicines, such as vitamins, chemo, replacement hormones, blood pressure medicines, and diuretics, unless they help make the patient more comfortable.

**What caregivers can do**

• Apply lubricant or petroleum jelly (Vaseline®) to 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 cause a rattling sound that’s very distressing to hear, but it isn’t usually uncomfortable for 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 to the side may help secretions drain from the mouth. Continue to clean the teeth with a soft toothbrush or 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 and look blue or mottled (blotchy).

• Other areas of the body may become either darker or paler.

• Skin may feel cold and either dry or damp.

• Heart rate may become fast, faint, or irregular.

• Blood pressure may get lower and become hard to hear.

**What caregivers can do**

• Keep the patient warm with blankets or light bed coverings.
• Don’t use electric blankets, heating pads, etc.

Possible changes in senses and perception

• Vision may become blurry or dim.

• Hearing may decrease, but most patients can 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 to collect urine, 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 may be lost as the muscles relax

What caregivers can do

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

If you have a hospice or home care agency involved, call them first. If you have completed funeral arrangements, calling the funeral director and doctor are usually all that you have to do.

If the patient dies at home and is not under hospice care, caregivers are responsible for calling the right 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.

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 might be the hardest thing you and your family have faced so far. Now you’re looking at your own death, which is even tougher. Your family members recognize this, too. The next few months may be hard, but while you might not have been given the gift of time, you have the chance to focus on the quality of time and special sharing with your loved ones.

Through the information shared here, we have tried to help you prepare 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.

**To learn more**

**More information from your American Cancer Society**

Here is more information you might find helpful. You also can order free copies of our documents from our toll-free number, 1-800-227-2345, or read them on our website, www.cancer.org.

**Dealing with advanced cancer**

- Hospice Care (also in Spanish)
- Guide to Controlling Cancer Pain (also in Spanish)
- Advance Directives
- Distress in People With Cancer
- Talking With Friends and Relatives About Your Cancer (also in Spanish)
- Talking With Your Doctor (also in Spanish)
- Advanced Cancer (also in Spanish)
- Bone Metastasis (also in Spanish)

**For caregivers and loved ones**

- Listen With Your Heart (also in Spanish)
- What it Takes to Be a Caregiver
- What You Need to Know as a Cancer Caregiver
- Caring for the Patient With Cancer at Home: A Guide for Patients and Families (also in Spanish)
- Family and Medical Leave Act (FMLA) (also in Spanish)
- Home Care Agencies (also in Spanish)
- Coping With the Loss of a Loved One (also in Spanish)

**Helping children cope**

- 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
- Helping Children When a Family Member Has Cancer: When a Child Has Lost A Parent
Insurance and financial issues

Advanced Illness: Financial Guidance for Cancer Survivors and Their Families
Coping Financially With the Loss of a Loved One: Financial Guidance for Families
Health Insurance and Financial Assistance for the Cancer Patient (also in Spanish)

Books

Your American Cancer Society also has books that you might find helpful. Call us at 1-800-227-2345 or visit our bookstore online at www.cancer.org/bookstore to find out about costs or to place an order.

National organizations and websites*

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

Compassion and Choices
Toll-free number: 1-800-247-7421
Website: www.compassionandchoices.org

For local referrals to pain specialists, hospice programs, and other resources; offers patients assistance in completing living wills and advance directives, and in talking to families, friends, and health care providers about health care wishes

CancerCare
Toll-free number: 1-800-813-4673
Website: www.cancercare.org

Provides free professional support groups and individual counseling services by phone and online to people with cancer, caregivers, loved ones, and the bereaved.

Family and Medical Leave Act (US Department of Labor)
Toll-free number: 1-866-487-9243
TTY: 1-877-889-5627
Website: www.dol.gov/whd/fmla/index.htm

Has information on the Family and Medical Leave Act of 1993 (FMLA), which helps people keep jobs and health insurance while taking time off to care for themselves or loved ones

Family Caregiver Alliance
Toll-free number: 1-800-445-8106
Website: www.caregiver.org

Provides information and resources on long-term caregiving; searchable resource feature on their website provides information on publicly funded and private caregiver support programs in each of the 50 states and the District of Columbia

National Family Caregivers Association (NFCA)
Toll-free number: 1-800-896-3650
Website: www.thefamilycaregiver.org
Website and quarterly newsletter offer can-do advice, helpful resources and stories about family caregivers, and a bereavement kit for when members are no longer caregivers, to help them deal with their loss and move on with their lives.

**National Hospice and Palliative Care Organization (NHPCO)**
Toll-free number: 1-800-658-8898; in Spanish 1-877-658-8896
Website: www.nhpco.org

Provides information about hospice programs in your area; also publishes information for consumers and has frequently asked questions on their website.

**Hospice Education Institute**
Toll-free number: 1-800-331-1620
Website: www.hospiceworld.org

Offers information about caring for the dying and the bereaved; maintains a directory of hospice and palliative care programs in the United States; and provides general information about good hospice care.

**Hospice Foundation of America (HFA)**
Toll-free number: 1-800-854-3402
Website: www.hospicefoundation.org

Acts as an advocate for hospice care by conducting public education and information; lists hospices by geographical area, which is available at www.hospicedirectory.org.

**Hospice Net**
Website: www.hospicenet.org

Provides information and support to patients facing life-threatening illnesses and to their families and friends; also can help find a local hospice.

**Centers for Medicare and Medicaid Services (CMS) -- HHS**
Toll-free number: 1-800-633-4227
TTY: 1-877-486-2048
Website: www.cms.hhs.gov (or for just Medicare info: www.medicare.gov)

Answers questions about how to apply for Medicare, Medicaid, disability, or survivor benefits, and also answers questions about coverage for all Medicare recipients.

**Medicare Rights Center (MRC)**
Toll-free number: 1-800-333-4114
Website: www.medicarerights.org

Fact sheets and basic information and explanations of Medicare rights and benefits.

**Social Security Administration (SSA)**
Toll-free number: 1-800-772-1213
TTY: 1-800-325-0778
Website: www.socialsecurity.gov

Has general information, qualification criteria, and information about how to apply for program benefits (such as Social Security Disability Income and Supplemental Security Income if you cannot work); makes referrals to local SSA and Medicare/Medicaid offices.
National Association of Area Agencies on Aging (n4a)
Toll-free number: 1-800-677-1116
Website: www.n4a.org

To find agencies with local support services for older people with cancer, see their online Eldercare Locator

American Council of Life Insurers (ACLI)
Telephone number: 202-624-2000
Website: www.acli.com

Offers information on financial security, with links to state government life insurance departments. Also online, “Living Benefits from Life Insurance,” describes how policy owners with a terminal illness can accelerate their life insurance benefits.

*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 www.cancer.org.

References


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


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