

Nearing the End of Life

(Abstracted from the American Cancer Society's Website www.cancer.org)

This can be a time to focus on physical, spiritual, emotional, and family concerns. Patients and family members often have questions about what might happen during these last months of life. Understanding what to expect both physically and emotionally during these last few months might help you live fully and get the most out of this last phase of your life. This is written for you who has advanced cancer, but it can be helpful to the family caregivers who is taking care of you and love you, too.

Emotions you may experience

Knowing that death is coming soon takes an emotional toll on you and your loved ones. This is an emotional time, and though it's hard to talk about them, 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 are often afraid to die, but pinpointing what part of death they're afraid of can be helpful. Are they afraid of dying alone? Are they afraid of suffering or pain? Are they afraid they'll 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 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 try to always 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.

A common fear is the fear of dying in a state of pain and suffering. This is why palliative care as well as hospice care is so important and should not be saved for the finale. You deserve being pain free, dying with dignity, and with as much quality of life preserved as possible for you.

Anger

Anger is sometimes hard to identify. Very few people actually feel ready to die. It's perfectly normal to feel angry about your life ending – maybe earlier than you expected. 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'll probably accept our anger and forgive us for it. But it might 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. Try to re-channel your anger to do meaningful, positive things.

Guilt and regret

In the 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 think we don't meet 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, or 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're hurting. Spend your time focusing on your children's future, not feeling guilty about the past. Strengthen your relationships with loved ones. Live the best life 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're grieving the loss of the life you 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've done this you'll feel a burden has been lifted and you can move on to the other physical and emotional tasks that are part of 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 may need to 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

When someone knows for sure they're 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.

Physical symptoms in the last 2 to 3 months of 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. This information may help you find answers to your questions and concerns during this very sensitive and difficult time.

This 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 help manage these symptoms. Be sure to tell your health care 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

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 that doesn't get better with rest. Almost everyone with advanced cancer has this symptom.

What can you do about fatigue?

To manage fatigue, first, control the symptoms that make it worse, like pain or constipation. Then you can help prevent more fatigue by carefully balancing rest and activity. Your health care 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.

Some medicines can make you feel tired, too. You may need to talk with your 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.

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 to regain energy. Take short rests during activity – keep chairs close by.

Some people may find that they're afraid to go to sleep because they're afraid 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

People with cancer often fear pain more than anything else. Pain can make you feel irritable, sleep poorly, decrease your appetite, and decrease your concentration, among many other things. But pain can be 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, it's very important to talk to your health care 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're 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 team to refer you to a pain specialist if your pain isn't being controlled.

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

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.

Types of pain medicines

The nurse or doctor will assess your pain and figure out the average level or degree of pain you have. There are a lot of different pain medicines available ranging from acetaminophen (Tylenol®) to opioids (morphine-like drugs).

There are also many forms of pain medicine, such as long-acting, time-released forms of opioids that are 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 quickly control 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.

Signs that a person is in pain

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

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're 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 arguments

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're 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 arguments over food. Loss of appetite and being unable to eat happens to most 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. As you near end of life, your brain sends messages telling your body that it no longer needs nourishment because it cannot any longer really be sustained. This too is confusing to family members. If you are receiving hospice care, and hopefully you are at this point, the hospice professionals will also discourage your family from trying to force feed you. At later stages, these efforts can even make the person feel worse.

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 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 others are at the table. You may be able to take 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. 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

Even thinking about breathing problems can be scary. Trouble breathing and/or shortness of breath is very common in people with advanced cancer, but it can be 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 health care team if you're having any problems breathing so you can get help with them.

A number of things can be done to make it easier for you to breathe:

Sitting up

Propping yourself up on pillows

Leaning over a table

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, your health care team should be able to help with your breathing problems

The importance of communication when the end is near

This is written for the person with cancer, but it also can be helpful to the people who care for, love, and support someone with advanced cancer. Use this information to get answers to your questions and concerns about this very sensitive and difficult time.

Who do you need to talk to?

Your health care team

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.

Your partner

Focus on the good times and happy memories

Cancer takes up a great deal of time and energy. Cancer and end-of-life care puts 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 might withdraw under these circumstances. They could pull away just 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're going through. Sometimes partners try to protect each other from the pain they're 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're 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 can't 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're 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're going to do that. In this way, you can help take care of your partner, too.

Your family

Cancer is a family illness. Your loved ones are hurting too. Each member of your family is working through the idea of losing you. They need your love and understanding. Though it might seem unlikely, 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.

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 there may be times you don't feel like talking and you'll 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 might just mean you are feeling tired or a little down.

Tell your family that you'll be as honest with them as you can be and would like the same from them in return.

Tell them what you expect to happen in the future so they'll be prepared. It also helps to share with them the expected signs of the dying process, and how to manage them should they occur.

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 tell them.

For more on talking with children and teens, see [Helping Children When a Family Member Has Cancer: Dealing With a Parent's Terminal Illness. www.cancer.org](http://www.cancer.org)

Your friends

Some friends respond as you would expect them to – they're 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're 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.

Religious or spiritual counselor

Religion can be a source of strength for many people. Some find new faith during a cancer experience. Others find cancer strengthens their existing faith or their faith provides newfound strength. On the other hand, those who have never had strong religious beliefs may not feel an urge to turn to religion.

Spiritual questions are common as a person tries to make sense of both the illness and his or her life. This may be true not only for the person with cancer, but for loved ones, too.

Here are some suggestions for people who may find comfort in spiritual support:

A spiritual counselor can often help you find comforting answers to hard questions.

Religious practices, such as forgiveness or confession, may be reassuring and bring you a sense of peace.

A search for the meaning of suffering can lead to spiritual answers that can be comforting.

Strength through spiritual support and a community of people who are there to help can be priceless to the patient and family members.

For those who are interested, a minister, priest, rabbi, other clergy member, or a trained pastoral counselor can help you identify your spiritual needs and find spiritual support.

What do you need to talk about?

Treatment decisions

You may find that some people aren't willing to accept your decision to stop getting cancer treatment. 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. Still, it's your choice and you have to be comfortable with your decisions. You may want to share the reasons for your decision so they can better understand. Making your medical team and your loved ones part of the decision-making process will help things go more smoothly.

At this time, you may prefer to focus 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 symptoms, like discomfort and pain, is called palliative or supportive care, and it's different from treatment aimed at the cancer itself.

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 health care team know what's important to you and what you want to be able to continue to do.

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

Choosing hospice care

Hospice care puts you and your loved ones in the care of experts on the end of life concerns. 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 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. It gives you supportive or palliative care, which is treatment to help ease symptoms, but not 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. You, your family, and your doctor decide when hospice care should begin.