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Nearing the End of Life

Learning that you have advanced cancer – cancer that’s growing and might not be responding to treatment – can make you feel lost and afraid. At this point, you may realize the cancer is likely not going away. But being prepared to deal with what can happen toward the end of life can enable you to get the support and care you need so you can have the very best quality of life possible.

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 the last stage of life. Understanding what to expect both physically and emotionally might help you live more fully.

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Communication with Others as You Near the End of Life

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. You can use this information to help get answers to your questions and concerns about this very

sensitive and difficult time.

Who do you need to talk to?

You and your health care team

Communication between you and your cancer care team about decision-making during the final stage of life is very important. Ask questions, take more control, and begin to actively plan the remaining part of your life. It's normal to want to be prepared for the future.

Honest discussions about your options and your decisions is helpful for everyone involved in your care. Your cancer care team needs to know about any preferences you might have, such as where you want to receive care. It's also important to let them know about any cultural, religious, or spiritual beliefs or values. 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

Cancer takes up a lot of time and energy. Cancer and end-of-life care often puts a huge physical and emotional burden on those closest to you. Some people might thrive as caregivers, while others withdraw under these circumstances. They could grow closer to you, or pull away just when you feel you need them more than ever. Remember that your partner is dealing with their own emotions and probably feels a lot of pressure to be strong and to meet your needs.

It can be troubling to know what your partner may be 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. Relationships can become strained and conversations can be uncomfortable.

The loss 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, talk with your partner about what each of you is feeling. You may 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 personal space and private time for yourself and your partner. 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. Make the most of each day, be grateful, and know each day is 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 and whether you feel you are able to have sex. . It's OK to feel like you want to just touch, hug, or hold hands.

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 they are managing it. Your partner might 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 themselves. Ask a friend or another family member to help out if you think there's too much for one person to do. If you decide to ask others to help, 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 cancer, any news you've been given from your doctor, and any other needs you may have. Explore their

thoughts and feelings with them. Tell your family...

- That you're open to discussion and that you're willing to talk about anything.
- That there may be times you don't feel like talking and you'll let them know when that is.
- 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.
- That you'll be as honest with them as you can be and would like the same from them in return.
- 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.
- About plans you've made or need to make and get their input.

If you have adult children, they might 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 physically be there for much longer. But professionals who work with families strongly encourage you to avoid trying to protect them. 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 Illness¹](#).

Your friends

Some friends respond as you would expect them to – they're warm, supportive, and available. Other friends might seem to be more awkward around you. They might 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 and spirituality 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 their 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:

- Be sure your doctor and cancer care team are aware of any beliefs that might affect your care decisions.
- 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

The goal of any cancer care is to give you the best possible quality of life. At this time, you may want to feel as well as you can without any more cancer treatments and side effects. 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. Keep in mind that decisions do not have to be forever. In some cases, you can change your mind about treatment. Or, you can change your mind about some other part of your care. Still, it's your choice and it's important that you are comfortable with your decisions.

You may find that some people question 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 best for you. If someone questions you, explaining that you have fully explored all options together with your doctor should be enough to help them understand. 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 can help things go more smoothly. It might not be possible to completely relieve all symptoms that you have, but they can be treated. **Treatment of symptoms, like discomfort and pain, is different from treatment aimed at the cancer itself.**

Advance directives

It might not be enough to just tell your family about your medical care wishes. You can choose the kind of treatment you get and refuse any treatment that you don't want, but only if you plan ahead. If you haven't already made a decision about your care at the end of your life, now is the time to do it. Advance directives put your decisions about your future health care in writing. Advance directives are legal documents.

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.

See [Advance Directives²](#) for more details on the types of documents available, how to create one that meets your needs, and what it means if you have one.

An important note: If someone calls 911 or Emergency Medical Services (EMS), even after an expected death, the law often requires that EMS try to revive the patient or take them to a hospital. Be sure your family and friends are ready and know exactly what you want, so that they don't dial 911 in confusion or panic.

Choosing hospice care

It's usually not the act of dying, but the quality of dying that's one of the biggest concerns at the end of life. People who come to accept dying as a natural and normal part of life may not want to prolong the process. But thinking about whether to stay at home or go elsewhere for care is one decision many want to make. Some are in the hospital and want all treatment available to keep them alive as long as possible, no matter what their condition might be. Some choose to receive hospice care at home. Others choose to go to an assisted living center, a nursing home, or an inpatient hospice program. Again, **you should make the choices that you feel are best** for you, your family, and your situation.

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.

Hospice care puts you and your loved ones in the care of experts on 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.

Learn more in [Hospice Care](#)³.

Organ and tissue donation

Some people are interested in donating organs. Some people with cancer may not qualify to be organ donors. Others may have the options of donating certain organs or tissues or your entire body for medical research. If you would like your body to benefit someone or some cause after your death, you should 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.

For more information on this see [Can I Donate My Organs If I've Had Cancer?](#)⁴

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've 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're willing to follow your requests and see if they have any questions about your wishes.

Keep all of these documents in a safe place in your home. You can put them in a safe deposit box if you want, but give copies 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. 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.

Hyperlinks

1. www.cancer.org/treatment/children-and-cancer/when-a-family-member-has-cancer/dealing-with-parents-terminal-illness.html
2. www.cancer.org/treatment/treatments-and-side-effects/planning-managing/advance-directives.html
3. www.cancer.org/treatment/end-of-life-care/hospice-care.html
4. [/content/cancer/en/treatment/survivorship-during-and-after-treatment/be-healthy-after-treatment/can-i-donate-my-organs.html](http://content.cancer/en/treatment/survivorship-during-and-after-treatment/be-healthy-after-treatment/can-i-donate-my-organs.html)

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Emotions and Coping as You Near the End of Life

This is written for the person with advanced cancer, but it can be helpful to the people who care for, love, and support this person, too.

Knowing that death is not far away takes an emotional toll on the person with cancer and their loved ones. Some people might feel shock or fear. They might feel guilty about being a burden or worry about how their death will affect loved ones left behind. 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 sometimes it can help to pinpoint what part of death they're afraid of. Are they afraid of where they might die? 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 for how people may fear death.

Trying to figure out what you fear can help you face it and manage it. It will also help others be able to 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 talk with you about the 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. 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 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 stage of life, a person might regret or feel guilty about things they have done or not done, or maybe about things they have said. 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 expectations or think we haven't met someone else's. But worrying endlessly about things won't make you feel better about them. Worrying won't improve relationships or ease burdens.

Sometimes the best thing to do is to decide to “let yourself off the hook” and not feel guilty about things that are out of your control. You can't change the past, but there are things you might be able to do today. Maybe you'll consider apologizing for the things you regret. Maybe you can ask for forgiveness or forgive others and yourself. It may be best to try to let go of the things that can't be changed.

This is a good time to [talk with your children](#)¹ 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. Spend your time focusing on your children's future, not feeling guilty about the past. Strengthen your relationships with loved ones. 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. 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 stage of your life. You're grieving the loss

of the life you planned and expected. You might feel well and not have many symptoms, so you're having trouble grasping that much loss is going to happen. Or, you may have lost things already, such as the strength to get around like you used to, or the interest in doing the things you enjoy, or maybe the ability to get together with friends. You may feel distanced from those who are not coping well with the fact that you are in your last stage of life. 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 physically 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 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 can help you feel that a burden has been lifted. It can help you move on to care for 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 unpleasant and make you worry.

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 may be able to help. Counseling may be especially helpful in helping you 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](#)² well can make a big difference in how much joy or pleasure you can find in your last stage of life.

Feeling alone

When someone knows they've reached their last stage of life, there can be a loneliness that's different from any other. It's a loneliness that happens even when you have people around you. There may be 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 people that you can connect with can ease your sense of loneliness. Your health care team may end up being one of your greatest resources in this area.

Seeking meaning

It's normal to want to feel like there's a purpose in life and that there is a reason for being on earth and for what has happened in life. 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 trying to find out what your purpose in life has been. Maybe you're wondering what your special contribution to the world has been. Or, what you have done to make the world a better place. Maybe you would like the world or your children, family, and friends to remember you in a certain way. Think about what things have been really important and that you 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.

Hyperlinks

1. www.cancer.org/treatment/children-and-cancer/when-a-family-member-has-cancer.html
2. www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/emotional-mood-changes.html

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Physical Changes as You Near the End 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.

These are some things a person may experience during the last stage of life, usually as death gets closer. It's important to know that each person's experience is different. It's not always normal to feel bad, and there are often things that can be done to help you feel better. We also give some tips on how to manage these symptoms.

Communication with the people who are helping to care for you is key. Be sure to check in and tell your health care team how you are doing. If it's difficult or tiring for you to communicate, be sure your loved one or caregiver can help you to pass on information your health care team needs to know.

Fatigue

Fatigue is the feeling of being tired and not being able to do things at your usual pace.

This tiredness can affect you 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?

The first step in helping to manage fatigue is recognizing and controlling any symptoms that make it worse, like pain, nausea, neuropathy, or constipation. Another step is to try to prevent more fatigue by carefully balancing rest and activity. If you feel tired, stop and rest. 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. They may be needed, but you may want to talk with your health care team to find out if switching to new ones or taking them at different times may help. You might even be able to stop taking certain medicines 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. If you're shaky, don't use sharp utensils or other things that might cause injury. If you're able to drive, be careful to not drive when you are feeling fatigue.

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, so they don't waste energy traveling to and from the bathroom. Plan rest periods when you are out of bed so that you can sit to regain energy. Take short rests during activity. Keep chairs close by so you can sit down right away without using extra energy.

Fatigue can also make you sleep more. This can be troubling for some people who might be afraid they won't wake up again. Needing more sleep is often normal in the last stage of life. It's also common to withdraw from people, turn inward, focus on yourself, and talk. Although some people want to surround themselves with friends and family, others may want a quiet, peaceful environment. Listen to your body, be sure to tell people what you need, and try to 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.

You can learn more in [Cancer-related Fatigue](#)¹.

Pain

People with cancer often have pain, and often fear it will get worse. Cancer pain is considered to be chronic pain because it usually lasts longer than pain caused by other problems.

Pain can make you feel irritable, sleep poorly, decrease your appetite, and decrease your concentration, among many other things. While pain can't always be completely relieved, **pain can be controlled and managed**. Pain does not have to be a part of dying. If you have pain, it's very important to track it, report it, and ask for help in controlling it.

You and your health care team must work together to reduce any suffering due to pain and enhance your quality of life. You should talk to them about your pain and develop a pain control plan together. Then, they'll need you to tell them how well your pain control plan is working. Talk to them at every visit, and call in between visits if something is not working or your pain gets worse. Don't be discouraged if your medicines must be tweaked a few times to get the best pain control with the fewest side effects. Your health care team understands that pain is different for everyone, and your pain is whatever you say it is. You should expect that your pain can and will be controlled. If it isn't being controlled successfully, you may want to ask your team to refer you to a pain specialist.

When you report your pain, it's best to describe it 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 record of all of this in a [pain diary](#)² 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.

Types, doses, and forms 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 types, forms, and doses of pain medicines available.

The types of pain medicines range from acetaminophen (Tylenol[®]) to non-steroidal anti-inflammatories (NSAIDs) to stronger drugs called narcotics, such as opioids (morphine-like drugs). 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.

There are also different doses of each medicine. Some people need less, and some need more to keep pain controlled. Some may find they need to increase their dose over time. Needing larger doses of drugs has nothing to do with being unable to withstand pain, nor does it mean that you are a complainer. The body can become tolerant to a drug, and you may need to increase the dose because of that tolerance.

There are also many forms of pain medicine, such as long-acting and short or fast-acting drugs. For example, there are time-released forms of opioids that are long-acting and taken at certain times 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. Short or fast-acting rescue drugs can be used to quickly control "breakthrough pain" that may happen in between the doses of long-acting medicines. It's very common for a person with cancer to take more than one drug to manage chronic and breakthrough pain.

Pain medicines also can be given in many different ways. Pills are the most common type. Injections or IV pain medications may be used, and sometimes a pump can be used to constantly give certain pain medicines. There are also patches that stick to the skin, lozenges that don't have to be swallowed, drops that go under the tongue, and even rectal suppositories that can be used when needed. Not every drug comes in every form, and not every form may be helpful to every person. Work together with your health care team to find out which will work best for your pain control plan.

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. Sometimes physical therapy may help. 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.

Signs that a person is in pain

If you are a caregiver and your loved one is not able to talk about the pain they may be having, there are things you can watch for that show pain or discomfort. Signs of pain 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 will help you keep your loved one as comfortable as possible.

You can learn more in [Cancer Pain](#)³.

Appetite changes

As time goes on your body may seem to be slowing down. Maybe you find yourself eating less and losing weight. This is often experienced by people with advanced cancer, and other who are in the last stage of life.

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. You might feel less hungry because you're probably moving less, have less energy, and your digestive system is slowed. It's normal in the last stage of life for

parts of your body to start slowing down. Maybe you feel full more quickly or are interested in fewer types of foods. When you eat less, the cancer cells may compete with the normal cells in your body for the nutrients that you do manage to take in and digest. This can all lead to weight loss.

What can you do about appetite changes?

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. For example:

- Some causes of poor appetite can be managed with medical treatment. There are medicines that can help stimulate your appetite, decrease nausea, and help food move through your stomach more quickly.
- A nutritionist might be able to offer tips on how to get the most out of each bite you take.
- Supplemental drinks or shakes can sometimes help you get needed nutrition more easily.
- You might find that you're able to eat more when others are at the table.
- You might find it easier to eat 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. At later stages, these efforts can even make the person feel worse. (See [What to Expect When a Person With Cancer Is Nearing Death.](#))

Avoid family food battles

It can be very upsetting to family if you start eating less. Some of them may think your interest in food represents your interest in life. By refusing food or not eating much, it may seem to your family that you're choosing to shorten your life or that you will starve.

It's important that you and your loved ones talk about issues around eating. The last stage of your life doesn't have to be filled with arguments about food. Again, loss of appetite and being unable to eat happens to many people with advanced cancer. When you feel like eating less, it's not a sign that you want to leave life or your family. It's often a normal part of the processes that can happen in the last stage of life. If you're getting into arguments with your loved ones, try to let them know that you appreciate their concern and understand their attempts are acts of love. You can let them know you're not rejecting their love, but your body is limiting what it needs at this time.

You can learn more in [Eating Problems](#)⁴.

Problems breathing

Just thinking about breathing problems can be scary. Trouble breathing and/or shortness of breath is common in people with advanced cancer, some more than others. It might not go away completely, but there are ways it can be managed.

Sometimes breathing problems make you feel short of breath, like you need to take breaths more often, or that you are breathing faster and harder than normal. You might feel like you have fluid or congestion in your throat or 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 that may help make it easier for you to breathe:

- Try sitting up, propping yourself up on pillows, or 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](#)⁵ 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 breathing will get worse as the disease progresses. Remember that every person's situation is different, and it's very hard to know exactly what will happen.

Also remember there are steps to help manage each change in your condition. Talking to your health care team and reporting what you're feeling will let them know how they can help.

See [Shortness of Breath](#)⁶ to learn more.

Hyperlinks

1. www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/fatigue.html
2. [/content/dam/cancer-org/cancer-control/en/worksheets/pain-diary.pdf](http://content.dam.cancer.org/cancer-control/en/worksheets/pain-diary.pdf)
3. www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/pain.html
4. www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/eating-problems.html
5. www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/pain/opioid-pain-medicines-for-cancer-pain.html
6. www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/shortness-of-breath.html

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Saying Goodbye

This information has been written for the caregiver and patient. It gives some hints on ways a caregiver and patient can express what they're feeling to each other in the final stage of life, especially as death gets closer.

Saying goodbye is not easy, and often does not come naturally. It also may be hard to do because of the patient's health or because of the place where they are receiving care. Remember that every person's situation is different. No one can really predict what may happen at the end of life, how long the final stage of life will last, or when death will actually happen.

If able and if time allows, people often use this time to gather family to say goodbye. But, sometimes death happens quickly or a loved one is out of town or traveling. This can limit the time to say goodbye.

If they can be together, family may take turns with the patient, holding hands, sharing good memories, or just sitting quietly. Some caregivers and family members may feel the need to stay busy by making meals or doing chores and other activities around the house. This can also be a time to perform any religious or cultural rituals and other activities desired before death. It's a chance for many families and friends to express their love and appreciation for each other. The key is to be reassuring and honest, and to speak from the heart.

Here are some hints that may help you in this difficult time.

- Try to plan ahead, but remember it's not really possible to predict when the last minutes or hours of life may happen.

- Understand and respect that each person has different needs and ways to express what they're feeling.
- Be open about knowing the end of life is approaching.
- Try to avoid topics and unpleasant memories that may cause hurt, stress, or pain.
- You don't have to be formal with goodbyes when taking a break from being together, or if a caregiver is leaving the room for any reason - just expressing your love is often recommended by hospice experts.
- Consider other types of communication for people who may be out of town or traveling, such as phone calls, video apps such as FaceTime or Skype, or other technology.
- For caregivers, know that many experts believe those who are unconscious or unresponsive may still be able to know you are present and can hear what you're saying.
- If you're having trouble managing your emotions, consider asking your clergy or health care provider for help or for a referral to a counselor or mental health specialist.

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What to Expect When a Person With Cancer is Nearing Death

This information has been written for the caregiver, but many patients want this same information for themselves. It gives some signs that death may be close and gives the caregivers some ideas about ways they may be able to help.

The signs of death being near can be different for each person. No one can really predict what may happen at the end of life, how long the final stage of life will last, or when death will actually happen. Sometimes death comes quickly due to an unexpected event or problem. Other times the dying process moves slowly and the patient seems to linger.

If possible, it's important to have a plan for what to do just following a death, so that the caregivers and other people who are 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 so that you will know exactly what to do at the time of death.

Just like the timing of the dying process cannot be predicted, it's also hard to predict what exactly will happen in the final stage of life and especially near death. The following symptoms are examples of what may happen in some people with cancer who are dying. While not all may happen, it may help you to know about them.

Possible changes in body function

- Profound weakness – usually the patient can't 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
- Lips may appear to droop
- 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. It's best to time any position changes to be about 30 minutes after pain medicine is given.
- 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 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 force fluids. Near the end of life, some dehydration is normal.
- Apply cool, moist washcloths 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 they are mentally clear before going back into semi-consciousness

What caregivers can do

- Plan your times with the patient when they are most alert or during the night when your presence may be comforting.
- When talking with the patient, remind them 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 nurse if needed.
- 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 their medicines, such as vitamins, replacement hormones, blood pressure medicines, and diuretics, unless they help make the patient more comfortable

What caregivers can do

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

Possible changes in secretions

- Mucus may collect in the back of the throat. This may cause a rattling sound with breathing that’s very distressing to hear, but it isn’t usually uncomfortable for the patient.
- Secretions may thicken and build up due to less fluid intake and because the patient can’t 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 and mouth with water and a soft toothbrush or foam mouth swabs.
- Certain medicines may help. Ask your doctor or 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
- Pupils may not change size
- May have trouble closing eyelids
- 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
- Patient may grunt while breathing
- Neck muscles may look tight to help breathe
- 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
- 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.
- Bathe the patient as they can tolerate it - this could be a sponge bath or simply washing certain parts of the body.

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 want to sit with the person 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've 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.

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