

When Life is Nearing its End

When your cancer is getting worse, you will be aware that you are nearing the end of your life. Your health care team will talk with you about this. They will tell you what is happening with your cancer.

A blood test or imaging (such as an MRI or CT scan) may help your health care team determine if your cancer is not curable. They will talk to you about what these results mean.

Your health care team will give you an idea of the amount of time you might have left. This is called a prognosis. Your prognosis is the best estimate your health care team can give you. However, the prognosis may not be accurate for you as an individual.

Your prognosis may come as a shock to you and your loved ones. However, patients are usually aware when they are getting weaker and when their cancer is not responding to treatment anymore. Sometimes patients stop cancer treatments because they are not helping and are causing side effects.

When your health care team tells you that you will likely die from your cancer, this can be very upsetting. It can help to have a loved one to support you when you are having this conversation. Your loved one can ask questions for you and take notes.

Preparing for end of life

Almost all patients die peacefully and without suffering. There is usually time to prepare for death.



Advance Care Planning

While you are still well, it is a good idea to start making some plans for the end of your life.

This includes:

- Writing a will
- Writing a care plan (your wishes, hopes, values and goals for your care)
- Naming a person who can be your medical decision maker if you are not able to speak for yourself. This person is called a **Substitute Decision Maker**. They should be a trusted family member or friend.

You should talk with your substitute decision maker about your wishes for medical care. Make sure they understand what you want. If you do this now, your loved ones will not have to make difficult medical decisions on your behalf. If you are unwell or cannot speak for yourself, your loved ones will know what you would have wanted to do.

Once you pick a substitute decision maker, you may need to fill out a form called a Representation Agreement (Section 9), if the chosen person is not your legal default person.

If you have questions about Advance Care Planning, talk to your health care team.

Excellent advance care planning information is available online:

BC Cancer Recommended Websites for Advance Care Planning: www.bccancer.bc.ca/our-services/services/library/recommended-websites/living-with-cancer-websites/advance-care-planning-websites

What kind of care will I get near the end of my life?

Dying is different for every person. Every person has their own way of approaching this part of life.

Your health care team will respect your wishes and those of your loved ones. They will also support your loved ones during your illness and after you have died.

Your health care team will recommend homecare nursing support from your local community health centre. Most patients can die at home in the company of their loved ones, with homecare nurses supporting them.

Your health care team may offer you some treatments that will help your symptoms. These treatments will not slow down the growth of your cancer. However, they can reduce areas of cancer that are causing bad symptoms.

An example of treatment you may get is palliative radiation therapy for painful bone cancers.

For certain types of pain, palliative care doctors may refer patients for x-ray guided injections.

If your health care team is having difficulty managing your symptoms, you may need to go to a palliative care unit in a hospital. In this unit, specialists can help you manage your symptoms. You will likely only stay in this unit for a short time and then go home once you are feeling better.

Hospice

If you are close to end of life and your loved ones are not able to look after you at home, your health care team or homecare nurse may arrange for you to go to hospice. In hospice, the nurses will take care of you.

You can get more specialized palliative care treatments in hospice, like medicine injections and intensive nursing care. Your loved ones can still be with you in hospice.

You can visit your local hospice before you need to be admitted so that you are familiar with it.

The hospice care team includes nurses, care-aides, counsellors, social workers, occupational therapists, family doctors and specialist doctors. Family doctors are usually able to manage all of the common symptoms. If you have difficult or complex symptoms, you may be referred to a specialist palliative care doctor.

Talking about the final moments of life

Your doctor will talk with you about resuscitation. You will talk about cardiopulmonary resuscitation (CPR). CPR is used on people who have stopped breathing or whose heart has stopped beating.

CPR is not recommended when you have advanced cancer. It is usually not successful in bringing someone back to life when they have advanced cancer. It is also a very upsetting way to spend your final moments, especially for your loved ones.

All of this will be clearly explained to you. You will be given an opportunity to sign a 'Do not Resuscitate form' if you agree with this decision.

If you do sign this form it will not change the care you are receiving for anything that might be treatable. This form applies only if your heart suddenly stops beating and you stop breathing.

What does end of life feel like?

Sleepiness

As you near the end of your life, you will get more tired, spend more time asleep and may even become unconscious. You may not feel like talking much.

You will probably still be comforted from seeing or being aware of your loved ones sitting with you. You may enjoy listening to their conversation or to your favorite music or TV show.

Sometimes people are very aware of their surroundings right up to the moment of death. Some people may even choose when to die (medical assistance in dying). In other cases, people are unconscious and may not be aware of their surroundings.

If you are feeling anxious or are afraid to be awake until the very end, you should talk to your health care team. Very near the end of your life, your health care team may give you a medication to make you a bit sleepier if you want this.

Confusion

Sometimes people get confused as they near the end of their life. This is called delirium.

Delirium is very common and is caused by the brain shutting down. Confusion can also be caused by medications, infection or complications of advanced cancer.

You may get restless or anxious from the delirium. If this happens to you, your health care team may give you medications to calm you or to make you sleepy. They will do this if you are close to the end of your life. These medications do not speed up your death.

Your health care team may suggest that your family limit their visits to only your closest loved ones. They may also suggest that noise is kept down to reduce your confusion.

Eating and Drinking

It is normal that you will want to eat less and drink less as you near the end of life. As you get weaker and spend more time resting, you will need less food. You may have trouble eating and swallowing due to your cancer or cancer treatment.

In the last few days of your life, you will probably not eat at all and you will drink very little. This is normal as your body is shutting down.

Your body does not need food and drink at this time. You will not be starving to death.

If you are having trouble swallowing, your loved ones can give you thickened fluids, water on small sponges or ice chips for you to suck on. Vaseline on your lips can help with dryness and can be very soothing.

Your family may feel they need to keep feeding you to keep you strong. Your palliative care team will explain to them that they should not force you to eat and that it is natural to eat less at this time.

Palliative care teams do not give intravenous (through a tube put into a vein) feeding or intravenous fluids at end of life. If these were to be done, they could cause swelling or make it harder for you to breathe.

Pain

If you have pain at any time during your illness, you should tell your health care team. They can give you pain medications. Pain may limit your activity at end of life.

If moving is painful, you may have to stay sitting or in bed. Pain medications will make you more comfortable.

You can get pain medications in tablet or liquid form that you swallow, or as a skin patch, or by injection under the skin. Your health care team will talk with you about what is best for you.

There are many different kinds of pain medications including morphine or similar medications. This is quite normal at end of life and they do not cause addiction.

The dose of the medications will be adjusted to give good pain control and have the least side effects. Side effects include constipation (difficulty having a bowel movement or going “poop”) and drowsiness.

When you are near the end of life you may not be able to clearly express your pain. Your nurses will be very experienced in recognizing when you are in pain even if you cannot speak.

The nurses will teach your loved ones how to recognize if you are in pain and will give you pain relief when you need it. If you cannot swallow, they will give you pain medication by injection.

Bowel and Bladder

Constipation and urinary incontinence (when you are unable to control when your “pee” comes out) are common at end of life. Your palliative care team can manage these.

Constipation happens because you are less active and you are eating less. Also, morphine and similar pain medications will make you constipated. Your doctor will give you laxatives. Laxatives will help you go “poop”.

Pressure Sores

Pressure sores or ulcers, also known as bedsores, can happen if people are not able to move about in bed. These sores happen because of long-term pressure on your skin from lying still and because of weight loss. They can be minimized by close attention to position and cushioning.

Pressure sores are usually not painful.

Your home care nurse or hospice nurse will be checking your skin on your back, bottom, arms and legs for sores. They will put on bandages if needed. The nurses will help to move you or turn you in your bed or your chair to change the pressure on your bottom and back. The nurses will also help you get any equipment you need.

Breathing Changes

You may become breathless towards the end of your life. This may be due to your cancer or due to your heart not beating strongly. It may also be caused by chronic lung disease not related to your cancer.

You may find that breathlessness limits your activity level. You will need to rely more on walking support and wheelchairs for getting around as you get weaker. Your palliative care team will tell you how to cope with your breathlessness.

Your doctor can give you medications to help with breathlessness. These may include low dose morphine or similar medications.

If you have low oxygen levels in your blood, you may get oxygen from a mask or small tubes in your nose. However, most people who are breathless do not need oxygen.

As you come closer to the end of life your, breathing will get more shallow and less oxygen will get into your system. You will not be aware of this. This is a natural part of dying.

At the moment when you die your breathing will stop. You will not feel like you are choking or suffocating. Your brain will be shutting down and your heart will stop. Although this may seem frightening for you to think about, it will not be distressing to you at the time.

Pneumonia

Pneumonia (infection of the lungs) is common at end of life and is often the cause of death.

It happens because a patient becomes too weak to breathe deeply and fill their lungs with air. They get too weak to cough up mucus or phlegm from their lungs.

If you are close to end of life, your doctor will not give you antibiotics to treat pneumonia. This is because the antibiotics do not help in this situation and can actually make you feel worse.

Your palliative care team will help manage your symptoms and keep you comfortable.

You will likely die peacefully and quickly if you develop pneumonia at end of life. This is how most people would wish to die.

Other symptoms

Sometimes certain types of cancer can cause more complicated problems at end of life. Complications that can happen include bleeding, bowel blockage, breathing obstruction or seizures.

The palliative care doctors and nurses are very experienced in dealing with these situations. They can manage these well so that you do not suffer.

Usually when these complications happen, the patient will die fairly quickly. Although this sounds frightening, the doctors can help make it more comfortable for you. This may include giving you medicines to make you sleepy so that you are less aware of what is happening. This will only be done after your health care team speaks with you or with your medical decision maker. The doctors will explain everything to you and your loved ones.

After your death

Your loved ones will have a lot to think about and do after your death. It is a good idea to make a plan with them well ahead of time so that it is less stressful for them when you die. Talk with your loved ones and your health care team about:

- Any specific wishes or customs about the care of your body after death.

- The type of funeral, memorial or celebration of life you want after your death, if anything.
Arrange as much as possible before you die.

Your loved ones will have an emotional time through your illness and your death. Your palliative care team will do their best to support them in their grieving. They will also give advice to them about what to do at the time of your death.

You can help make this as easy as possible for your loved ones by talking about it well in advance. You can also leave things for them to remember you by, such as videos, letters and pictures. These are called “legacy” documents. A good way of making a video is the free program available at RecordMeNow.org.

Information for loved ones

Though you are expecting your loved one to die, it will still be a very emotional time for you. You may have spent a lot of time caring for your loved one.

You have probably lived with the fear of the day when they will die. Often it will feel like you are left with a great void. However, you may also be relieved that your loved one has finally found peace.

Many people have never seen someone die. You may have many questions about what is going to happen. Your loved one may be less concerned than you about what will happen.

Your loved one will likely want to make sure they will not suffer greatly when they die. Death is usually peaceful and a slow process over several hours or days.

You should read the information above about what your loved one may experience as they near the end of their life.

Here are things you can do to comfort or support your loved one:

- Sit with your loved one. Even if they cannot speak, they can be calmed by your presence.

- Play your loved one's favorite music or put on their favorite television show or movie.
- If your loved one is upset, stay calm. Get help if you need it.
- Try to be quiet and make sure there are only 1 or 2 people in the room with your loved one. Noise can be upsetting for people nearing the end of life.
- If your loved one is thirsty but cannot drink, try a wet sponge in their mouth, ice chips, or put Vaseline on their lips.
- Talk with the palliative care team if you have questions or are unsure about what you can do.

What should I do to prepare for the death of my loved one?

There are many things to do and think about once a person dies. If you have not done so, talk to your loved one to make sure you know their wishes. Write these wishes down.

You may need to organize a special religious ceremony before they die.

Plan ahead. Once your loved one dies, you may feel very overwhelmed. It is helpful to have a plan. Think about how you will tell family and friends and what should be done with your loved ones belongings.

Before your loved one dies, it is a good idea to contact your chosen funeral director. You can let them know of any traditions, customs or other wishes you want observed. The funeral director will give you contact details and advice on what to do after your loved one's death. The Provincial Do Not Resuscitate Form has lots of this information on the back.

If your loved one is in hospice or hospital, tell the nursing staff about any traditions, customs or wishes. It is good for them to know these things before your loved one dies. They will respect these wishes.

When your loved one is very close to end of life

Your loved one's breathing pattern may change as they near the end of life. They will probably breathe through their mouth. They may breathe very loudly and then very quietly.

Your loved one may stop breathing for 20-30 seconds at a time. This is very normal and is a sign the brain is shutting down. At this point, your loved one will likely be unconscious.

When your loved one dies, they may sigh a few times before breathing stops completely. At this time, their mouth will be open. Their eyes may be open as well. Their eyes will have large pupils and may look slightly cloudy.

At this time, you should call the nurse to confirm your loved one has died.

What happens after my loved one dies?

When your loved one dies, a doctor or nurse needs to confirm the death.

Make sure you know who to call if your loved one dies at home. Ask your nurse or doctor if you do not know.

After your loved one dies, you may want to spend some time with their body. You are allowed to do this. The medical and funeral staff will respect any customs or rituals that need to be done.

The doctor will issue a medical certificate of death that lists the cause of death. Very rarely, if a person dies unexpectedly, the coroner may need to investigate the cause of death. If a death is expected, the coroner will not be involved.

Grief

You might feel too busy to grieve properly while you are planning the funeral, memorial or celebration of life. This is normal. Often, family and friends feel their loss does not 'hit' them until after the funeral is over.

Grief is a process. It can take many weeks or months to properly grieve the death of your loved one.

BC Cancer has counselling services for grieving family members. Ask your family doctor or staff at BC Cancer for more information.

Grief resources that may help you

- BC Cancer handout: [Coping with Loss and Grief](http://www.bccancer.bc.ca/coping-and-support-site/Documents/Coping%20with%20Loss%20and%20Grief.pdf) <http://www.bccancer.bc.ca/coping-and-support-site/Documents/Coping%20with%20Loss%20and%20Grief.pdf>
- BC Cancer handout: [What to do After a Death](http://www.bccancer.bc.ca/coping-and-support-site/Documents/What%20to%20do%20after%20a%20death.pdf) <http://www.bccancer.bc.ca/coping-and-support-site/Documents/What%20to%20do%20after%20a%20death.pdf>
- BC Cancer Library Recommended Grief websites: www.bccancer.bc.ca/our-services/services/library/recommended-websites/living-with-cancer-websites/grief-websites

Other resources

- Vancouver Hospice Society: www.vancouverhospice.org
- Vancouver Coastal Health Bereavement Information <https://vch.eduhealth.ca/PDFs/GV/GV.200.22.B47.pdf>
- Vancouver Coastal Health pamphlet: When Someone Dies... <https://vch.eduhealth.ca/PDFs/GV/GV.300.W574.pdf>

