



Patient & Family Guide
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Preparing for a Loved One's Death

Aberdeen Hospital
Palliative Care Unit



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Preparing for a Loved One's Death

As you prepare for the death of your loved one, remember that your support, understanding and care are the greatest gifts of love that you can offer.

This pamphlet gives information for families and caregivers who are caring for a dying loved one. This information will help prepare you for the dying process, including what you can expect to see, why these things may be happening, and practical advice for caring for your loved one.

The Dying Process

As one draws closer to death, there are changes that take place in the body (physical) and in the mind (mental). During the dying process, the body and mind work closely together.

On the physical level, the body starts to shut down. This process ends when all the systems in the body (circulation, kidneys, liver, etc.) stop working. These physical changes are normal and natural as the body prepares itself to stop. The best kind of care is comfort care.

On the mental level, the spirit of the dying person starts to release itself from the body and also from its loved ones. This release includes dealing with unfinished business and finding peace. These mental changes are normal and natural as the spirit prepares to move from this place to the next. The best kind of care supports and encourages release.

Sometimes a dying person's body is ready to stop, but their spirit still has things to work through. They may hang on even though they are uncomfortable in order to finish what needs finishing. On the other hand, even though a dying person's spirit is ready for release, the person will continue to live until their body shuts down completely.

Death happens when the body finishes the natural process of shutting down and the spirit finishes the natural process of releasing.

Each person goes through the dying process differently, both physically and mentally. It is important that each person goes through the process in their own way.

“Life is a journey that is homeward bound.”

– Herman Melville

Mental changes

Withdrawal

You may notice that your loved one doesn't seem to respond to you. They may seem withdrawn or almost like they're in a coma state. This means that they are preparing for release or starting to let go. Even though it seems like they cannot hear you, they may still be aware of what you are saying. Remember to tell them who you are and to say whatever you need to say to help them "let go."

Visions

Your loved one may speak to, or say they have spoken to, people who have already died, or say that they have been to a place that you know is not possible. This means that the person is starting to detach from this life and is preparing to die. **Visions are normal and common.** They are not a drug reaction or hallucination.

The best way to care for your loved one at this time is to try and understand their experience. This is a real experience for your loved one and it is important that you do not argue, or belittle what they say they have seen or heard. If the visions frighten your loved one, then you can explain that this is normal.

Not making sense

You may notice that your loved one says or does things that don't make sense. For example, they may talk about taking a trip. This may mean that your loved one is preparing to say goodbye and may be testing you to see if you are ready to let them go.

Refusing visitors

You may notice that your loved one may want to be with only a few people, or even just one person. This is normal and is a sign of preparing for release from this life. This does not mean that you are no longer loved, it simply means that it is time for you to say goodbye.

If you are one of the few people that your loved one wants to be with at this time, this means that the person needs your support and "permission" to go.

"Yet, even with serious illness, there may yet be golden days you will never forget."

– Earl A. Grollman

Saying goodbye (your final gift)

When your loved one is ready to die, it is time to say goodbye. This is your final gift of love, as it makes final release possible.

You can hug the person or hold their hand and say everything you need to say. It may simply be “I love you” and a few shared memories. It may also give you a chance to say, “I’m sorry” or “Thank you for...”

Tears are normal and a natural part of saying goodbye. You do not need to hide your tears; they are an expression of love and will help you let go.

Sometimes it is too difficult or there isn’t enough time to say all that you would like to say to your loved one before they die. If this happens, it may be helpful to write your message on paper and have it buried or cremated with them. You may also wish to go to their gravesite later and say what you need to say. Although it isn’t the same as talking directly to your loved one, it may help you find a sense of peace.

Physical changes

Coolness

Your loved one's hands, feet, arms and legs may become cool to the touch, and you may notice purple patches on these areas. This is called mottling. This tells you that blood circulation is shutting down.

The best way to care for a person with mottling is to keep them warm with a blanket. The skin is very sensitive and can easily burn, so it is best not to use an electric blanket, heating pad or hot water bottle.

Sleeping

Your loved one may spend more time sleeping, may not want to talk much, or may be difficult to wake up. This is normal and can be caused by changes in the body's metabolism.

The best way to care for your loved one at this time is to sit with them, hold their hand and speak softly and naturally. Plan to spend time with them while they are most awake. Speak directly to them, as you normally would, even though they might not seem to notice you.

Hearing is the last of the senses to be lost so it is important to think about what you say while you are near them.

Confusion

Your loved one may seem to be confused about the time and about where they are. They may become confused about their own family members, recognizing some but not others. This is normal and can be caused by changes in the body's metabolism.

The best way to care for your loved one at this time is to tell them who you are. Speak softly, clearly and truthfully. If you have a task to do, such as giving them medication, it is best to explain what you are going to do and the reason why. For example, "It is time to take your pill so you won't start to hurt."

Restlessness

Your loved one may become restless and repeat the same movement over and over, such as pulling on the bed linens or picking at their clothing. This often happens because the brain is not getting enough oxygen as the body shuts down.

The best way to care for your loved one during this time is to speak quietly and calmly. You can read to the person, play soothing music or lightly rub their forehead. It is important that you don't try to force them to stop.

Congestion

You may hear gurgling sounds coming from your loved one's throat and chest. These sounds may be loud and hard to listen to. This is a normal change that happens when secretions such as mucus and saliva collect in the back of the throat and your loved one is not able to cough them up.

The best care you can give at this time is to gently turn their head to the side and let the secretions drain naturally. You can also gently wipe their mouth with a moist cloth. Your doctor may be able to prescribe a medication to help dry up these secretions. Suctioning can frighten your loved one and cause discomfort.

Eating or drinking less

As the body shuts down, it no longer needs nutrition. Your loved one may have little or no interest in food or drink. Often, they are not able to eat or drink because they don't have much energy.

The best way to care for your loved one at this time is to offer ice chips or frozen juice that will freshen their mouth. If they are able to swallow, you may offer fluids in small amounts using a spoon.

You can also freshen their mouth with a moist washcloth and keep their lips moist with lip balm.

Do not try to force food or drink into your loved one's mouth as they could easily choke. Do not try to talk them into eating or drinking as this would make your loved one much more uncomfortable.

Incontinence

Your loved one may become incontinent (lose control of their bladder and/or bowels). This is normal as the muscles in that area start to relax.

The best way to care for your loved one at this time is to keep them clean and dry. Checking them often will prevent skin problems such as rashes and infections. A plastic mattress cover and incontinence pads (available at drugstores) will protect the mattress. Remember to protect yourself by wearing gloves.

You may also notice that your loved one may not need to urinate (pee) as often, or that their urine is dark and strong smelling. This is because they are drinking less and there is less circulation through the kidneys. Your doctor may decide that a catheter (tube to drain urine from the bladder) would be helpful. The best care you can offer is to keep your loved one's bedding clean and dry.

Breathing changes

Your loved one may have changes in their breathing pattern. It is common to notice a pattern that starts with periods of not breathing, called **apnea**. Apnea may last from 5 seconds to 1 minute. You may also notice that their breathing becomes like a kind of panting with periods of apnea.

Planning for death

It is very important to have a plan for when death happens. You will need to make some funeral arrangements before the death. This will take a lot of the stress off you after the death of your loved one.

Please ask the palliative care nurses if you would like information and support in making these arrangements.

How will I know when death has happened?

Although you are expecting the death of your loved one, you are never prepared for the actual moment. As you recognize the changes taking place and realize that death is near, it is important to have support from family and other loved ones.

Signs of death

Death happens when breathing stops and the heart stops beating. You can feel for a pulse on the neck just slightly to either side of the Adam's apple. You can check for breathing by watching to see if the chest rises and falls. Other signs of death include:

- › no response when spoken to or touched
- › eyelids slightly open
- › pupils (black centre of the eye) get bigger
- › eyes fixed in one direction
- › no blinking
- › jaw relaxed and mouth slightly open
- › release of bowel and bladder

Once death has happened, take time to say goodbye to your loved one. Call family and other loved ones to be a support at this time.

When death happens

Death in the hospital

When death happens in the hospital, the nurse or doctor will ask you what your plans are for the funeral. If arrangements have already been made, the hospital will contact the funeral home and staff will come to collect your loved one's body.

If arrangements have not been made, a funeral home will have to be contacted as soon as possible. You may stay at the hospital and, if you wish to call family, you may wait until they come. There is no hurry.

It is best to collect all your loved one's belongings and take them with you when you leave (except for things such as eyeglasses and teeth, which will need to go to the funeral home).

Death in the home

When death happens in the home, it is not an emergency. **Do not call 911.**

You will need to make funeral plans with a funeral home. When death happens, call your doctor or the funeral home, as you, your doctor and the funeral home have planned. The doctor may come to your home and then call the funeral home or the funeral home staff may come directly to your home.

There is no hurry; you may want to call family to be with you at this time. While you are waiting for the doctor or funeral home staff, it would be helpful to straighten your loved one's body in the bed and place a pillow under their head. You may also bathe and dress your loved one if you wish, although this isn't necessary.

Thank you

The Pictou County Palliative Care Team would like to thank you for the privilege of being able to help you care for your loved one. We appreciate all you have done: surrounding your loved one with understanding and care, giving your loved one comfort and calm, and helping your loved one to leave this world with a special sense of peace and love. You have given your loved one one of the most wonderful, beautiful and sensitive gifts we are capable of. In giving that gift, you have given yourself a wonderful gift as well.

“When someone you love becomes a memory, the memory becomes a treasure.”

– Anonymous

**What are your questions?
Please ask. We are here to help you.**

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Contact your local public library for books, videos, magazines, and other resources.

For more information, go to <http://library.novascotia.ca>

Connect with a registered nurse in Nova Scotia any time: call 811 or visit <https://811.novascotia.ca>

Learn about other programs and services in your community: call 211 or visit <http://ns.211.ca>

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If you have any questions, please ask your health care provider.

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The information in this pamphlet is to be updated every 3 years or as needed.