

WHEN SOMEONE CLOSE TO YOU IS DYING

WHAT YOU CAN EXPECT AND HOW YOU CAN HELP



NICE

National Initiative for the Care of the Elderly

Initiative nationale pour le soin des personnes âgées

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When Someone Close To You Is Dying

What You Can Expect And How You Can Help

Helping someone through the last years of their life is one of the most difficult journeys anyone can take. As the illness progresses, you may have to make important decisions on behalf of someone close to you. You may be responsible for ensuring that their most basic needs for respect, dignity and physical comfort are sustained until the end of life.



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When Someone Close To You Is Dying

*Things A Person
Nearing End of Life
May Need from You*



Some emotions are common to those who are dying. These include fear of abandonment and fear of being a burden. They may have concerns about loss of dignity and loss of control.

Some ways you can provide comfort are as follows:

- Keep company—talk, watch movies, read, or just be with the person.
- Allow them to express fears and concerns about dying, such as leaving family and friends behind. Be prepared to listen.
- Be willing to reminisce about their life.
- Avoid withholding difficult information. They may prefer to be included in these discussions.
- Reassure them that you will honour their advance care planning and health care choices.
- Ask if there is anything you can do.
- Respect their need for privacy.

When Someone Close To You Is Dying

*What Happens
During The
Final Moments*



The body changes as it slows down and prepares for death, and the symptoms described in this section are a normal part of the process. Not everyone will experience some or all of these symptoms, but many people will.

Sleeping Patterns

A person nearing end of life may sleep for longer periods of time and have trouble waking. At times like this, bring a book to read or a small project to do to keep you occupied. Remember that they may tire more easily now. Plan your conversations and interactions during periods when they are alert. There is nothing wrong with making small-talk when they are alert, since restricting yourself to subjects that seem important enough to mention may mean that you never say anything at all. It is best to avoid overstimulation, as this may exhaust both of you.





Restlessness and Agitation

The changes that occur in the body towards the end of life can make the dying person restless or agitated. Sometimes people grab and pull at the bed linens or clothing. Some people hallucinate and even speak to these hallucinations. Those near death might even refer to people who have died in the past. As long as they are not distressed by the hallucination, try not to correct them. You can also help by holding their hand and speaking in a calm, reassuring voice. If they become distressed or anxious, you may wish to contact a health care professional. Medications may be given to help reduce this anxiety if their safety is at risk due to agitation.

Confusion and Forgetfulness

Fatigue, pain or the spread of the disease may cause “confusion” and forgetfulness. These common symptoms are often caused by side-effects of medication as well as changes in body chemistry in the last stages of an illness. A person nearing end of life may not be able to recognize you, your family or their surroundings. This can be distressing for everyone. If this happens, speak to them in a calm, reassuring voice, reminding them that you are there. Remember that a confused person is not “doing this on purpose” and is not doing it to you personally. Arguing with the dying person about these issues can be upsetting and harmful to everyone.

Immobility and Involuntary Movements

Occasional muscle twitches, involuntary movements, changes in heart rate, and loss of reflexes in the legs and arms are signs that the end of life may be near. Relaxation of the muscles in the pelvic area may cause a person near the end of life to lose bladder and bowel control. To keep them as clean, dry, and comfortable as possible, place disposable pads underneath them and remove these pads when they become soiled. Remember that weakness and immobility are often seen towards the end of life.

Changes in the Skin

Blue or purple markings can appear on the arms, legs and the underside of a person's body. Their skin may seem cool to the touch. These symptoms are often caused by poor circulation near the time of death. A person nearing end of life, however, is probably unaware of these symptoms and would not likely feel cold. There is really no need for extra blankets—in fact, these may cause distress by making him or her feel “held down.” Bring a mohair blanket or something similar, if you have one, as it can provide warmth without extra weight. Please do not use a hot water bottle or a heating pad; these items are dangerous and can cause burns.

Changes in Breathing

The person you are caring for may develop shortness of breath at this stage. Noisy breathing or gurgling may develop. This unpleasant sound is caused by small amounts of saliva collecting at the back of the throat and in the upper airway. This happens due to muscle weakness; the person is no longer able to swallow their saliva at this stage. This noise often distresses family members but not the dying person. Such noises are not a sign that they are in pain. You may also notice irregular, shallow breathing, or even brief periods when breathing may stop. These are signs that the body is slowing down. Sometimes, oxygen is used to provide symptom relief to a person at the end of life, if their blood oxygen level is low. This is not routinely required. Narcotics can also be effective in alleviating shortness of breath. Atropine is a drug that can dry up the saliva, but remember that a dry mouth, at this stage, can be quite uncomfortable.

Eye Care

Towards the end of life, a person's vision is often reduced, making it harder for them to see. You can often help by turning their head toward a light source. Leave soft, indirect lights on in the room. "Artificial tears" are a type of widely available eye drops which can relieve dry eyes. A health care professional or pharmacist can teach you how to use it.

Mouth Care and Difficulty Swallowing

Muscle weakness may cause swallowing problems as the illness progresses. If the person you are caring for refuses to eat or drink, do not try to force them. There is a risk that they may choke on food that “goes down the wrong way” or develop other complications, such as an infection or pneumonia. Instead, allow them to take small amounts of food whenever they show an interest in eating. If you are concerned with their lagging appetite, you may wish to give them ice chips and ensure frequent mouth care. This may alleviate some of the symptoms that prevent them from eating or drinking.



When Someone Close To You Is Dying

*Pain Control
And Opiate Use*



People who are dying from a malignancy often experience severe pain, sometimes chronic and sometimes acute. This pain may increase as death approaches.

Pain needs to be assessed and treated promptly, with the quantity and frequency of doses of pain medication adjusted according to the intensity and duration of the pain. Opiates (such as morphine and similar drugs) are among the most effective painkillers and often provide the backbone of an effective pain management program. They are sometimes combined with other medications that increase the effectiveness of analgesics or are combined with other classes of analgesics such as anti-inflammatory agents.

Not treating this often severe and at times incapacitating pain may mean that a person nearing end of life dies in pain that could likely be controlled or relieved. Many people are concerned about the dying person developing an “addiction” to opiate use. Vast experience with opiates used at the end of life and in palliative care situations has consistently shown that a dying person will not become addicted. The attending doctor should be able to determine whether or not there is a degree of physical dependence on the drug or whether tolerance to its effects have occurred. Tolerance is often a normal consequence of sustained use of opiates. If it occurs it can be addressed successfully by adjusting the dosage and frequency of the drug’s administration. With proper pain control medications available, no one needs to suffer unnecessarily from pain at the end of their life.

When Someone Close To You Is Dying

*Advance Care Planning
& Substitute Health Care
Decision-Making*



What is it?

Advance care planning is the process of planning for future health care choices. Its purpose is to allow people to make choices about future treatment and care should a time occur when they become incapable of making their own decisions and may need to rely on someone else (a substitute decision-maker) or a written document (an advance care plan or directive) to communicate their wishes.

Why do it?

Increasingly, people want to make their treatment choices known. They want the treatment that they receive to reflect their values and beliefs about what makes life worthwhile and they want to be able to specify under what circumstances they would not want to have their life prolonged.

If there is an advance care plan, is this a consent for treatment?

NO. It is important to remember that the existence of an advance care plan, whatever form it takes, is NOT a consent for treatment. Before providing care and treatment, the health provider must get a consent.



Do I have to write it down?

In many provinces / territories, wishes expressed verbally are as legal as wishes expressed in a document form of advance care plan.

What are the types of planning?

There is a common distinction made between:

- a written advance care plan that names a person to be the substitute decision-maker for a patient when they become incapable (often called a proxy directive), and
- a written advance care plan that sets out instructions for health care decisions (often called an instructional directive).

Most of the legislation across Canada allows for both – a directive that names a proxy (called by different names) and may also include wishes for future health care, as expressed by the maker of the directive while mentally capable.

***Where can I find out more about
Advance Care Planning in my jurisdiction?***

The laws about advance care planning and substitute health care decision making are different across the country. You need to look to the legislative scheme in the province or territory in which you live. Laws also may change from time to time. An updated list for each province or territory is available at www.nicenet.ca.

Also, look to the Advocacy Centre for the Elderly at www.advocacycentreelderly.org and the Canadian Centre for Elder Law Studies at www.ccels.ca for more detailed information about how advance care planning works across the country.



When Someone Close To You Is Dying

*Other Things
You Can Do
To Help*



An impending death impacts many people. Here is some additional information that may help you and your family cope.

Make Funeral Arrangements

If you have not yet made funeral arrangements, it may be appropriate to start as you notice the physical changes described in this brochure. Make a list of everyone who needs to be called and assign different people to call these individuals. Discuss arrangements with other family members and/or a funeral director. Your funeral home will help you with the arrangements you must make.

Talk About It

Many people are uncomfortable discussing death. A lack of open and culturally sensitive discussion may mean that the dying person's choices for life support and end of life care are ignored. Although health care providers may be able to estimate how much time someone has, they might be hesitant to do so out of concern for giving false hope or destroying a person's hope.



Physio and Occupational Therapy for a Person Nearing the End of Life

If a dying person is capable, engage in activities with pets and horticulture, listen to music or make use of music therapy, participate in creative crafts groups, play board and card games, or participate in religious activities and programs. Physiotherapy intervention for palliative care focuses on pain control and optimizing safety and mobility. An occupational therapist can assess needs, and make recommendations that can ease activities of daily living, protect skin or improve access to surroundings.

Care for Yourself

At this difficult time, it may seem natural to abandon concern for yourself and look only to the needs of others. However, you face the danger of depleting yourself so badly that you can no longer help. Please remember to take short breaks, eat and rest at regular intervals and walk each day so that you keep up your strength. Share the burden wherever possible. Let health care professionals and supporters know how they can help you too.

Remember that preparing for a death can be difficult. We hope the information provided in this booklet may reduce the amount of stress you feel by giving you some information about what to expect. While it is often not possible to know when someone will die, there are some common symptoms or indicators that may appear in the final hours, days and even weeks of life. Knowing what to expect may help.



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National Initiative for the Care of the Elderly
222 College Street, Suite 106, Toronto, Ontario M5T 3J1
Telephone: 416-978-2197 | Website: www.nicenet.ca