

PPSMP

The Palliative Pain and Symptom
Management Program

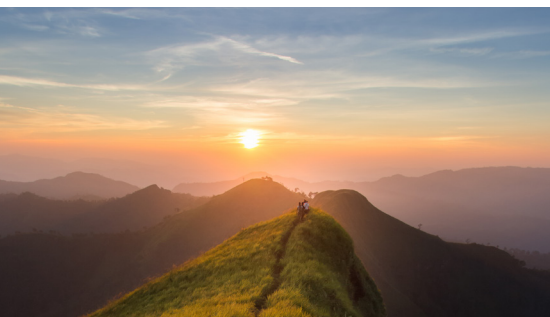


'Til Death Do Us Part

Ontario 

Is your loved one entering the final stages of life? Are you seeking ways to prepare yourself for this event?

This pamphlet has been designed to assist you with the challenges you will be facing. While the following information may be difficult for you, please know that the intention is to help prepare you for what to expect. Your physical and emotional well being is as important as that of the dying person. Please be aware that not all the described signs of approaching death will be seen in every dying person. If you have questions or concerns about the care of your loved one, please discuss these with your doctor or nurse.



Signs That Death Is Approaching and Helpful Responses

Sleeping

The person may spend an increasing amount of time sleeping, and appear to be uncommunicative or difficult to awake. This normal change is due in part to the changes in the body's metabolism.

How to help: Sit with your loved one; hold his/her hand, but don't shake it or speak

loudly. Speak softly and naturally. Spend time with your loved one at times when he/she is more alert or awake. Avoid speaking about the person in his/her presence. Speak to him/her directly even if there is no response. Never assume that he/she can't hear; hearing is the last sense to be lost.

Confusion

They may seem confused about the time, place, and identity of people around them, including close and familiar people. This is also due to metabolism changes.

How to help: Identify yourself before you speak, rather than asking the person to guess who you are. Speak softly and clearly.

Restlessness

Your loved one may make restless, repetitive movements such as pulling at the bed linen or clothing. This may be due to decreased oxygen circulation to the brain.

How to help: Don't interfere with or try to restrain these movements. Speak quietly and naturally; lightly massage the forehead; read to the person or play soothing music.

Reduced food and fluid intake

The person may want little or no food and fluid.

How to help: Recognize this as a normal part of the dying process. Do not try to force the person to take food and/or a fluid. to do so would increase the person's discomfort. Small amounts of a desired food, or ice chips will usually suffice.

Coolness

The hands, arms, feet, and then legs may be increasingly cool to touch. The face may be pale, and the feet and legs a purple-blue mottled colour. This indicates that the circulation of blood is decreasing to the body's extremities and is being reserved for the most vital organs.

How to help: Keep the person warm with blankets, using just enough to keep him comfortable. Avoid using an electric blanket.

Incontinence

The person may lose control of bladder and bowels as the muscles in these areas begin to relax. These symptoms occur commonly when death is imminent.

How to help: Ask the nurse to suggest appropriate padding, and/or use of an incontinence product.

Congestion

There may be loud gurgling sounds coming from the person's throat or chest. This is because the person is unable to swallow saliva, and doesn't mean she/he's uncomfortable.

How to help: Avoid suctioning, as this may cause sharp discomfort. Turn the person's head to the side and allow gravity to drain the saliva. You can wipe the mouth with a moist cloth.

Changes in Breathing Pattern

Breathing may be irregular and may stop for 10 to 30 second periods. He/she may experience periods of rapid, shallow pant-like breathing. After death there may be a "last sigh" or gurgling sound. These

common patterns are due to decreased circulation to the internal organs.

How to help: Raising the head of the bed or turning the person to the side. Hold your loved one's hand and speak softly.

Decreased Urine

Urine output normally decreases and may become tea coloured or concentrated.

This is due to the decreased fluid intake as well as a decrease in circulation to the kidneys.

How to help: Asking your nurse if anything needs to be done.

Withdrawal

The person may seem unresponsive, withdrawn or in a comatose-like state. This shows preparation for release, and the beginning of letting go.

How to help: Since hearing remains all the way to the end, speak to your loved one in a normal tone; identify yourself by name when you speak; hold the person's hand; say whatever you need that will help him/her to let go.

Visual-Like Experience

The person may speak or claim to have spoken to a person already dead, or to see places/people not visible to you. This isn't a drug reaction or hallucination. The person is detaching from this life, and is being prepared for the transition, so it will not be frightening.

How to help: Accept what the person is saying. Avoid explaining away or arguing. The experience is real to your loved one and is normal and common.



Decreased Socialization

The person may want to be with just a few or only one person. This is a sign of preparation for release. If you are not part of this, it doesn't mean you are not loved or are unimportant. It means you have already fulfilled your task with your loved one; it's time for you to say goodbye.

How You Will Know When Death Has Occurred?

- Your loved one will be entirely unresponsive.
- He/she will not be breathing.
- The pulse and heartbeat will stop.
- Your loved one's eyes will be fixed in one direction; they may be opened or closed.
- Loss of control of bladder or bowel may occur.

What to do Immediately After Your Loved One Has Died

Please know that there is no right or wrong way to be at this time. Do what you feel is right for you and not what you may feel is expected of you.

How to help: You may wish to spend time with the person; take as much time as you need. For some this may be hours, while others may not wish to stay. Do not be afraid to touch, hug or kiss the person. Some people may wish to lie down beside him/her. These reactions are normal

Please be aware that others may have needs which are different from yours, so be sensitive to and supportive of their special concerns.

Crying is a personal reaction. For some this is a natural reaction to grief. Others may internalize their feelings, and may not be able to cry. This doesn't mean that one grieves more than the other; both reactions are normal.

Prayer: For some prayers are very important, but unnecessary for others. Be guided by your inner self and do what is right for you.

Cultural rituals: It may be necessary for you to attend to special cultural needs at this time.

Spirituality: For some this is a very important consideration, while others may have a lesser need. Consult with the advisor of your choice.

Bereavement Issues

If you need help at this difficult time, please contact your spiritual advisor, social worker, or care provider. They can help you contact the best resources for you.

Plan Ahead

Know what your loved one's wishes are. The person and family may decide to make funeral arrangements ahead of time. This will help in the following ways:

- Ensures that the person's wishes are known and respected.
- Reduces the number of decisions that will need to be made right after death.
- Provides an opportunity to talk about arrangements, concerns and feelings.
- Allows for affairs to be in order for those left behind.
- Reduces family stress during the early time of grief.

Completion of Estate Plans: Ensure that affairs are in order where possible. If a will has been made, and financial matters organized, it will be easier for the family to take care of estate matters. It will also help to avoid legal issues involved in the disbursement of assets.

Substitute Decision Maker

Power of Attorney of Personal Care: It is important to appoint a person who will act in this capacity in the event that the person is no longer able to make decisions regarding medical care. Talking with the appointed person, family members, and the physician will ensure that the person's rights to dignified medical care are honoured.

Power of Attorney for Finances: It is important to appoint a person who will act in this capacity in the event that the person is no longer able to make

decisions regarding financial matters. Talking with the appointed person will ensure the person's wishes regarding personal business are honoured.

Caring for Yourself

Seeing your loved one dying can absorb all your energies. If the process is a long one, you are at risk of becoming mentally and physically exhausted. Please know that your well being is as important as that of the dying person. In fact, one of the best things you can do for your loved one just now is to care for yourself. Both you and the dying person may experience feelings of frustration, guilt, sadness, or anger

These emotions are common and normal. They occur in response to the losses you are now experiencing.

How to help: Paying careful attention to attend to your needs.

Rest: Sleep may not come easily, but do try to get adequate rest.

Nutrition: While you may not feel like eating, do attend to your nutritional needs.

Time for Yourself: Time away from your loved one is essential if you are to avoid mental exhaustion. Ask other family members or friends to stay with the person to give you an opportunity to reenergize.

Remember, there is no perfect way to care, be guided by your love for the person.



Resources and Additional Information

Hospice Palliative Care Ontario (HPCO): www.advancecareplanning.ca

Contact Information

Office Hours: Monday to Friday 8:30 a.m. to 4:30 p.m. (Local Time)

Thunder Bay

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