

# End-of-Life Care Behavioural Health Program

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This booklet is for the families and loved ones of our patients with dementia who are in their final stages of life. We hope it prepares you for what to expect at the end-of-life and death.

We are here to help. We encourage families to discuss decisions about the end-of-life with us. If you have any questions about the care of your loved one, please ask any member of the Behavioural Health Care Team.



*Behavioural Health Program*

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People with dementia who are near the end-of-life are often not able to communicate. They cannot tell us if they are in pain or about other problems they may have. Our goal is to provide comfort care.

## Comforting your loved one

- Sit close by; hold hands.
- Touch, kiss, hug or lie next to your loved one.
- Spend time with your loved one when he or she is more alert or awake.
- Ask the staff or help in making him or her more comfortable, if your loved one seems restless.
- Offer small amounts of soft desired food, drinks or ice chips, if your loved one is able to swallow.
- Wipe his or her mouth with a damp cloth. Apply chapstick to lips.

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- Speak softly and clearly, even if there is no response.
  - Say your name, “Mom, it’s ...”, rather than “Mom do you know who I am?” Other communication ideas are on pages 13 and 14.
  - Talk about good times or memories, hobbies and enjoyable moments.
  - Avoid speaking about medical or sensitive matters in your loved one’s presence. Hearing is the last sense to be lost.

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- Play soft music. Choose music you know your loved one enjoys.
  - Massage his or her hands and feet with lotion.
  - Place a favourite quilt and pillow on the bed.
  - Place favourite photos near the bed.
  - Take your loved one outdoors, if possible.
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When you first arrive to the Behavioural Health Program, you will be asked to share your family member's wishes for end-of-life care.

These wishes will be recorded on the Physician Ordered Scope Of Treatment or POST form. This form is kept in your loved one's health record so that everyone who takes care of your loved one can respect these wishes.

End-of-life care starts with a choice between Cardiopulmonary Resuscitation or Allow Natural Death.

## **Cardiopulmonary Resuscitation (CPR)**

CPR is used when a person's heart and/or breathing stops. A health care team member applies force to the chest with the hands, and fills the lungs with air through the mouth.

Full treatment and resuscitation may include moving to an intensive care unit (ICU/CCU). Other measures that may be done include: shocking the heart (cardiac defibrillation), putting in a breathing tube and being connected to a breathing machine.

People with multiple medical problems, or a terminal illness usually do not survive CPR because they are too sick to respond to these treatments.

Most health care professionals think that more harm than good results from performing CPR on persons who are in the end stages of dementia. The chance of remaining in a coma-like state after performing CPR is high if the person was unconscious for a long period of time before CPR was started. Further, there is a high risk of injury such as breaking the ribs.

The decision about performing CPR should be made with the family and health care team, and the dying person's wishes should be followed and best interests considered.

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## Allow Natural Death (AND)

Comfort is the focus of care and death occurs naturally. If there are heart or breathing problems no resuscitation measures are taken (no CPR).

Comfort measures include:

- The person is treated with dignity and respect, kept clean, warm and dry.
- Pain and symptoms related to discomfort are addressed to ensure as much comfort as possible.
- Spiritual and emotional support are provided.
- Appropriate offers of food and fluids by mouth are given.
- Medication, positioning, oxygen, wound care and other ways are used to relieve pain and suffering.

A choice will also be provided with some things we can do to support quality of life. This may include:

- antibiotic treatment
  - intravenous (IV) fluids
  - feeding tube
  - checking heart rate and blood pressure (vital signs)
  - x-rays
  - blood testing
  - giving blood/blood products
  - moving to an intensive care unit (ICU/CCU)
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## Comfort measures for pain, anxiety, breathing problems, infection and secretions

### How can we tell if our loved one is in pain?

It is often hard to know if someone is in pain; especially in someone who is unable to talk or express him or herself.

Signs you see that may be due to pain:

- facial expressions: grimacing, furrowing the brow
- vocal sounds: moaning, crying, calling out
- movement: flinching, pulling away from touch
- restlessness or agitation

### Pain medications

Being in a comfortable position and/or listening to music can be helpful and are encouraged, however pain medications are often needed.

**For mild pain:** Tylenol is most often used.

**For moderate to severe pain:** Narcotics (also called opioids) are used, such as morphine, hydromorphone (Dilaudid), Percocet or Fentanyl.

To control pain, giving pain medications at routine times is best. Giving extra doses of pain medication in between routine times may also be needed. Because the body becomes used to certain amounts of pain medications, the dose is usually increased to keep it effective.

**Concerns about pain medications:** Many people believe that it is the last dose of a narcotic (such as morphine) that a person is given that causes breathing to stop and death to happen, but this is untrue. Patients can handle high doses of narcotics if the dose is slowly increased.

Pain medications are also not addictive at the end-of-life when they are given to control pain. The drowsiness associated with pain medications, such as morphine, usually decreases after several days of taking the medication.

There are many reasons for pain, our goal is comfort. Please call your nurse if you think your loved one is in pain.

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## **How can anxiety or agitation be relieved?**

It can be hard to tell pain and anxiety apart when a person is agitated or restless. Medications for anxiety are often given along with pain medications.

## **Is it helpful to give oxygen?**

When a person has a hard time breathing, oxygen may help with breathing problems and provide comfort. However, when the end-of-life is near, it is okay to remove oxygen if your loved one does not want to keep it on.

## **Should antibiotics be given for infections?**

Antibiotics can also provide comfort if the person has an infection that causes discomfort such as a bladder infection. In the case of pneumonia, antibiotics may be needed if the patient has a high fever or secretions with pus. However, antibiotics may not always cure infections. The difficult question becomes: should the person with pneumonia be treated with antibiotics or should the focus be on ensuring a comfortable end-of-life?

## **How are secretions controlled?**

When there are a large amount of secretions at the back of the throat, changing the head of the bed so it is slightly raised and giving medications may help to decrease new secretions from being formed. It may mean trying different positions to see what works best.

Noisy breathing is usually not uncomfortable if the person is in a coma-like state or is receiving enough medication to be kept comfortable. Clearing the throat with suction is only done when needed, as it can cause discomfort.

## **Food and fluids**

### **Do individuals who are dying experience hunger and/or thirst?**

When nearing the end-of-life, people do not feel hunger or thirst the way we do. At the end-of-life, it is natural that individuals may reduce the amount they eat or drink, or stop eating and drinking.

The body is slowing down, so food and fluids are not needed. It is as though nature provides for comfort, knowing that the person will not be able to eat or drink. At this time, the goals of care are to provide your loved one with physical comfort. Treatments that might prolong life are typically stopped, as the care becomes comfort care.

### **Mouth care**

We will provide ongoing comfort care, and that includes keeping the mouth and lips clean and moist. If you wish, we can show you how to do this. Having a clean, moist mouth reduces feelings of thirst.

### **Food and liquids**

While your loved one can still swallow, soft, easy to chew and swallow foods and liquids may be offered. Our team will check if a change in the textures of the food and liquids may help with swallowing. We need to be careful that your loved one does not choke or that food or liquid does not go into the lungs.

### **Intravenous fluids (IV)**

For some, fluids with sugar and salt can be given by IV or butterfly needle. This is not recommended for individuals who are dying. If the key goal of care for your loved one is to maintain comfort, fluids by IV or butterfly are not needed.

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## Feeding tubes

Feeding tubes provide nourishment through a tube that is placed through the nose or abdomen into the stomach. A feeding tube can be beneficial for a person who cannot swallow, when the goals of care are to prolong life and give strength. Current medical research shows that feeding tubes do not prolong life or improve quality of remaining life for individuals with end stage dementia.

## Pneumonia

Pneumonia in the end stages of dementia is very common because food and fluids are often not swallowed properly and enter the lungs.

This leads to trouble with breathing, coughing, choking and infections. Even if pneumonia is treated, it often occurs again due to trouble with swallowing.

## How do I know that death is near?

Everyone is different. Not all the signs of approaching death are the same for everyone. Your loved one has dementia, some of these signs may already be present or the signs may worsen.

**Please keep in mind that your loved one may only have some of these signs:**

**Sleeping.** There is an increased amount of time sleeping, difficulty waking the person up and less talking/responsiveness. This change is normal and is due to changes in the body's chemical make-up.

**Confusion.** There is more confusion about the time, place or the names of people. This is common and may be due to many reasons including a lack of oxygen or fluids, infection or organ failure.

**Visual-like experiences.** Seeing things that you cannot or claiming to have spoken to a person that is not there. This is usually not a drug reaction; it may be due to changes in the brain and body. It is best not to argue. Accept what they are seeing or saying because the experience is real to them.

**Restlessness, anxiety and agitation.** Becoming restless and making movements such as pulling at bed linen, objects or clothing; or becoming anxious or agitated. This may be due to decreased oxygen in the brain, pain, or the fear of death and the unknown.

**Reduced food and fluid intake.** There is less or no desire for food and fluids. There may also be nausea and vomiting. The person may not be able to take medications by mouth.

**Changes in skin.** The arms, hands, legs and feet may become cool to touch. Skin may be pale or turn a purple-blue mottled colour. This is because the circulation of blood is decreasing to reserve blood for the most important organs.

**Incontinence** (leaking urine and stool). There is a loss of control of the bladder and bowels. The muscles in these areas begin to relax.

**Decreased urine.** The amount of urine produced decreases and may become darker or concentrated. This is due to not drinking fluids and a decrease in kidney function.

**Congestion.** There are gurgling sounds coming from the throat or chest. This is normal and is due to not swallowing well.

**Changes in breathing.** There may be periods of fast and shallow breathing. Breathing becomes irregular, and may stop for 10 to 30 seconds. Breathing difficulties may be due to food or fluid going into the lungs, lung infections or heart failure.

**Social withdrawal.** There is no response, the person may withdraw or go into a coma-like state. Your loved one may only want to visit with a few people, or only with one person. If this happens to you it is not because you are not important or loved. It may mean that it is time to say good-bye.

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## When will my loved one die?

It is not easy to know exactly when someone will die. As the end-of-life draws closer it becomes more difficult to know when death will happen. Some people will slowly show the signs of approaching death before they die. Others will show signs of death but then will perk up or become stronger for periods of time before dying. Everyone is different.

## What happens when death occurs?

The heart stops beating and breathing stops. Pupils become fixed and large. The body may also become cold and rigid. Your doctor or nurse will confirm the death. They will call you if your loved one has died and you were not present.

Please tell the nurses ahead of time how you would like to be informed if you are not present when your loved one dies. Let us know who you would like us to call and when, such as call anytime or not at night.



We will do our best to respect and honour your religion, culture and rituals.

Family and loved ones may wish to come and view the body before transfer to the funeral home.

You may take your time to say good-bye.

## Planning ahead and making decisions

Knowing your loved one's wishes will help you make decisions, organize finances and make funeral arrangements ahead of time.

It will also help to ensure that your loved one's personal wishes are known and respected. It will reduce the number of decisions to make after death.

It also provides a chance to talk about feelings and concerns, which may reduce family stress during the early time of grief.

**Substitute Decision Maker.** Your loved one may appoint someone to make decisions when he or she becomes unable. This person is called a **Substitute Decision Maker** and is appointed ahead of time, while the person is still able to make decisions.

There can be more than one Substitute Decision Maker (SDM). The SDM may be appointed Power of Attorney for Personal Care and/or Power of Attorney for Property. This may be two separate people for care and property, or just one person for both.

If no one was appointed Power of Attorney for Personal Care, than a spouse/partner or a family member may make personal care decisions under the Health Care Consent Act (1996).

If no one was appointed Power of Attorney for Property, than a Guardian of Property may be appointed by a court or by the Office of the Public Guardian and Trustee to make decisions under the Substitute Decisions' Act (1992).

- **Power of Attorney for Personal Care:** A person, appointed by the dying person when capable, who can make medical and personal care decisions when the dying person is no longer able. Talking with your loved one ahead of time, and with family members and the health care team will help ensure that rights are respected.
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- **Power of Attorney for Property:** A person, appointed by the dying person when capable, who will make decisions about property and finances when the dying person is no longer able. Talking about financial matters ahead of time will help to ensure that wishes regarding personal business are respected.
- **Will:** Your loved one may have made a Will to show his or her wishes about personal belongings after death. Sometimes the Will directs wishes about funeral arrangements. The Executor of the Will is required to follow these wishes.

It is important to know that Power of Attorney ends when your loved one dies and the Executor of the Will carries out the directions in the Will.

**Funeral arrangements.** You will be asked to make funeral arrangements ahead of time; this includes choosing a funeral home. The funeral home may be able to help you with things such as the purchase of a cemetery plot and cremation. They may also help you take care of some legal documents and forms.

**Valuables and belongings.** Please consider taking care ahead of time of any valuables and personal belongings your loved one may be keeping in the hospital.

**Palliative Care Program.** You may be asked if you would like to move your loved one to one of the palliative care units at St. Peter's Hospital. You may decide that you want him or her to stay on the Behavioural Health Unit because you and your loved one know the staff. Staff at St Peter's Hospital will do their best to accommodate your wishes. Please discuss the issue with staff ahead of time.

We encourage the family and the health care team to take time to talk about choices and decisions. Share your questions or concerns with us, your health care team. The questions that need to be asked are:

- What is the most appropriate/best choice for this person at this time?
  - What would your loved one choose?
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## Caring for yourself

There is no right or wrong thing to do at this time. Do what you feel is right, and not what you think is expected of you. Your well-being is just as important as that of your loved one. Both you and your loved one may feel sad, guilty, frustrated or angry. These emotions are common and normal.

**Staying connected:** You may wish to spend time with your loved one; you may take as much time as you need as there are no set visiting hours. Some may visit for longer periods of time, while others may not wish to stay very long. Do not be afraid to touch, hug or kiss the person. Some people may wish to lie down beside the dying person. This may also help you to say good-bye.

**Crying:** This is a personal reaction, and for some it is natural. Others may hold their feelings inside, and may not be able to cry. This does not mean that one person grieves or cares more than another; both reactions are normal.

**Prayer:** This is important for some people, but not needed for others. Do what is right for you.

**Religion and cultural rituals:** You may wish to attend to certain religious or cultural rituals. Staff at St. Peter's Hospital will do their best to respect your culture and religion, and to accommodate your needs. Communicating your needs ahead of time may help staff meet your needs.

**Pastoral care:** This is available to you and your loved one at your request. St. Peter's Hospital has a full-time chaplain on staff.

**Take care of yourself physically and emotionally. Please ensure you rest, eat and do what you feel is right, not what you think is expected of you.**

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## Communication tips

As an individual with dementia progresses to late stage dementia, he or she may be quite limited in the ability to talk and/or understand what others are saying.

Common difficulties include:

- ineffective writing skills
- reduced attention and memory
- word-finding trouble
- difficulty understanding pronouns such as he or she and adverbs such as here or there
- trouble following faster-paced, lengthy and/or complex speech
- trouble reading
- not initiating speech, being much less social
- reverting back to his or her first language, or mixing languages

Recognizing these changes is important. By changing how we communicate with our loved one with dementia is the key to a successful and enjoyable time together. Here are some ways that help:

- Reduce distractions: turn off radio/TV, close door.
- Visit in a well-lit area, and face him or her when talking.
- Respect personal space – avoid standing too close.
- Stay still when speaking.
- Ensure your loved one has his or her glasses on and hearing aid(s) in.
- Speak in an adult tone, with a slightly slower rate of speech.
- Talk in short phrases, 5 to 7 words.
- Give one-step instructions.

## **Communication tips** (continued)

- Use nouns such as "John", "Hamilton" instead of "he", "there".
- Ask two-choice or yes/no questions.
- If he or she is able to read, print out key words in large print to help your loved one understand what you are saying.
- Be patient; allow extra time for your loved one to respond.
- Use gestures and a change in voice pitch (intonation) to help convey what you are saying.
- Refer to photos or pictures to help him or her understand.
- Smile – be positive and upbeat.
- Tell your loved one what you are doing before you do it.
- Understand that your loved one may call you the wrong name.
- Understand that your loved one has poor short-term memory; he or she may not recall your visits, recent events.
- Talk about the past, as long-term memory is often a strength.

**Please listen to and accept your loved one's feelings or thoughts even though they may not fit with what is really going on. The experience is real to them.**

**Correcting and/or attempting to re-orient will often make the situation worse.**