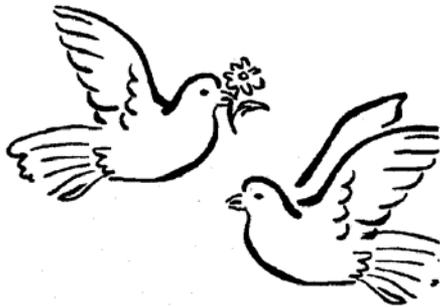


St. Joseph's
Healthcare  Hamilton



Precious Moments

Giving comfort and support when
someone you love is dying

www.stjoes.ca

When someone you love is dying

When someone you love is dying, you may want to know how you can provide comfort and support during this time.

Your care will help comfort your loved one by having a familiar face to talk to or sit with, and also may help you grieve for your loss.

You are not alone

We are here to help. Most people cannot do this alone. Please feel free to talk to any member of your health care team any time.

Palliative Care

Palliative care is the term used to describe providing the best comfort measures possible to allow your loved one dignity when dying. It involves working together to relieve and prevent suffering at end of life.

Palliative care supports your loved one physically and emotionally during his or her final days.

Physically, quality comfort care with minimal treatment is provided. For example, medications are given to control pain, manage breathing and settle restlessness. However doing things like giving intravenous fluids, continuing tube feeding, taking x-rays and testing blood sugars are no longer done.

Emotionally, we provide a lot of support, education, and 'being with' you and your loved one during this time.

This book is a look into what you as a friend, family member and/or caregiver can do to help comfort your loved one for his or her remaining life. The goal of this type of care is to always do what is in the best interest for your loved one.

Alone Time

Your loved one may be experiencing many different feelings and emotions. He or she may need time alone as well as with others.

At your loved one's request, consider:

- Limiting the number of visitors.
- Respecting the wishes of your loved one.
- Allowing for quiet or alone time.

Eating and Drinking

Your loved one may not show any interest in food or fluids. You may see changes in your loved one's appearance. Your loved one may also not be interested in taking part in any of the usual social activities around food. For example, he or she may no longer care about having a special Sunday dinner with the family.

Your health care provider will review what your loved one can eat or drink.

When your loved one does not feel like eating or drinking or has trouble swallowing:

- Talk to the nurse, dietitian and speech-language pathologist about how to help your loved one manage food and fluids. This depends on if your loved one can swallow or not.
- Offer moist mouth swabs and lubricant to help keep lips and mouth moist.
- Offer smooth textured foods such as applesauce or pudding if able to eat.
- Offer teaspoons dipped in fluids such as apple juice or coffee.
- Offer fluids but do not force drinking. It is not recommended that your loved one drink a lot as this may cause stressful breathing problems.
- Thicken fluids if needed with a thickening powder.
- Talk to your health care provider about using medications that do not need to be taken by mouth.

Mouth Care

When your loved one has a dry mouth or lips:

- Clean the mouth with moist mouth swabs often.
- Offer small amounts of water to keep the mouth moist if able to drink.
- Put favourite lip-gloss, balm or gel on lips if your loved one liked this in the past.
- Brush teeth and tongue with a toothbrush and toothpaste 2 to 3 times a day at least. Ask your health care provider to show you how best to do this.

Your loved one may not be able to clear sputum or oral secretions. Fluid may build up. The sound and appearance may worry you as a family member or friend, more than it worries your loved one. This is not a sign of distress.

Your nurses may also give your loved one medication, by needle under the skin, to help decrease secretions.

When you start to hear or see increased secretions:

- Provide gentle mouth care.
- Ensure your loved one is comfortable.
- Use pillows to promote breathing.
- Raise the head of the bed or place an extra pillow behind your loved one's head.

Breathing

One of the most frequent symptoms at the end of life is breathlessness. As a body begins to shut down breathing gets harder. Your loved one may begin to breathe irregularly or stop breathing for periods of time. These periods, when breathing stops, are called apnea.

When your loved one has trouble breathing:

- Raise the head of the bed.
- Place extra pillows under his or her head.
- Use a soothing voice to calm your loved one as much as you can.

When your loved one is breathing fast:

- Some people have periods of breathing fast and this can be monitored and managed in many ways.
- Your nurses may give a narcotic medication to slow breathing. These types of medications control pain as well as breathing and this is explained before they are given.
- The nurses may also position a fan to blow gentle cool air on your loved one. This controls breathing by cooling the trigeminal nerve that helps settle breathing.

During palliative care, members of the health care team monitor breathing and temperature as part of comfort measures. Oxygen is not given when a person is in a coma and the end of life is near as this does not help. The team will talk to you about this in more detail.

Pain and Anxiety Control

It is not easy to tell the difference between pain and anxiety at the end of life. Members of the health care team have found that pain medication as well as medication to control anxiety and hallucinations given at regular times helps people dying be more

comfortable. Before any medications are started, members of the health care team will talk to you and your loved one about the plan of care and the reasons why.

Giving Medications

When a person can no longer take medications by mouth, a small, thin tube is put under the skin and taped to the skin. This is called a subcutaneous catheter and medication can be given through this tube without disturbing your loved one.

Sleeping and Comfort

Your loved one may remain as alert as usual. However he or she may be very sleepy and only wake up for short amounts of time.

When your loved one sleeps more or is not interested in what is going on around:

- Allow him or her to sleep.
- Sit quietly together.
- Play soft music.
- Watch a movie.
- Hold hands.

When your loved one wakes, remind him or her of the time and place and who you are. Talk as if you are having a conversation.

Temperature

As the circulation to certain parts of the body slows, your loved one may feel hot one minute and cold the next. He or she may lose the ability to control body temperature. Legs or hands may become cold or blue in colour.

When your loved one is hot or cold:

- Take off blankets if hot.
- Put blankets on if cold.
- Do not use electric blankets or hot water bottles as they can cause burns.
- Put a cold or warm cloth on your loved one's head if it helps provide relief.

Restlessness

Your loved one may talk about seeing things such as gardens, libraries, vacation spots, or other people who have died. He or she may ask you to pack a bag, and find tickets or a passport. He or she may try to get out of bed to 'leave'.

When your loved one is trying to physically leave:

- Reassure that things are okay and he or she can 'go' or 'leave' without physically getting up.
- Stay close at this point.
- Share stories.

When your loved one is restless or trying to get out of bed:

- Calmly reassure him or her that you are here.
- Try to prevent your loved one from getting up by using relaxation techniques.
- Play soft music.
- Give a soothing back, leg or foot rub using a favourite lotion, oil or scent.
- Call the nurse for help if in the hospital.
- The nurse can give medication, by needle under the skin, to help settle your loved one.

Confusion

Your loved one may have times of high energy or confusion. This can happen because of a medical problem or the effects of some medications.

When your loved one is confused:

- Remind your loved one of the place and who you are.
- Use relaxation techniques such as music or a soothing back rub.
- Keep the lights on, off or dimmed, depending on what your loved one likes.
- Invite people to visit whom your loved one may recognize. You may need to limit visitors.
- Bring your loved one back to present time with gentle conversation, reassurance, and/or reading a newspaper or book out loud.

Loss of Senses

Your loved one may lose the ability to see, hear and speak. This may be frustrating to your loved one, and you can help decrease this feeling.

If your loved one has trouble seeing:

- Reassure who you are and why you are present.
- Reassure where he or she is.
- Touch your loved one.
- Keep the lighting the way your loved one likes it even if it is night.

If your loved one seems to have trouble hearing:

- Speak quietly and clearly.
- Carry on normal conversations.
- Be quiet when he or she asks for quiet.

Health care experts feel that hearing is the last sense a person loses. Although your loved one may not look like he or she is able to hear, your loved one may still be able to hear you and others talking. Be aware of what you are saying while in the room.

If your loved one has trouble seeing:

- Talk to him or her as normal.
- Ask simple yes or no questions that a head nod or hand squeeze can answer.

In the Final Moments

When the health care team and you have provided comfort care, the end of life is usually peaceful. Breathing may be more shallow and irregular or slower and less often. There may be increased time in between each breath before your loved one takes his or her last breath. Some people are comfortable 'being with' their loved one during this time and others do not want to be there. Each person is different and there is no one way that is the best way to go through this.

A doctor comes to confirm that your loved one has died. After you have time with your loved one, nurses prepare your loved one's body for the funeral home following the person's wishes.

When your loved one has died:

- You and your family can stay as long as you wish as there is no hurry to leave.
- You do need to call the Funeral Home and they will let you know when they will be coming to the hospital and your next steps to follow.
- We do our best to accommodate any of your religious and/or cultural practices when a loved one has died.
- We also have several members of the team who can help and support you. Our Spiritual Care Specialists (Chaplains) are excellent resource people to help and provide support any time during the day and night.
- Before you leave, remember to gather all of everyone's belongings in the room so they are not lost or misplaced.

Support in the Hospital

Spiritual Care Specialists (Chaplains) are available at any time to help you, your family and loved one. These members of our health care team provide spiritual, religious and emotional support. They help you take part in prayer, sacraments and worship and/or help you connect with your faith leader.

We will also do our best to accommodate any religious or cultural requests associated with the care of your loved one. Please feel free to talk to a member of the health care team about any requests you have.

Support in the Community

You may need or want to have some support after the death of your loved one to help you manage your grief. Here are some resources for you to consider:

Bereaved Families of Ontario

www.bereavedfamilies.net

Bereaved people helping bereaved people learn to live with death

Bereaved Families of Ontario – Hamilton/Burlington

905-318-0070

www.bfo-hamiltonburlington.on.ca

Bereavement Network of Hamilton and Burlington

905-574-5070

Support groups, brochures and more

Notes:

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