



VON Durham Hospice Services



Dear Caregiver,

Although it is impossible to totally prepare for the death of a loved one, it can be helpful to have a sense of what to expect.

Death is a natural but unique process.

Some of the physical, emotional, spiritual, and social signs of approaching death are described here, to help prepare you for what may happen. Please know that not all of these signs and symptoms will occur with every person, nor will they occur in any particular sequence. There is no set way that a person dies – each journey at this stage is different and unique.

It is important to share your concerns and fears with those around you, including your family, friends, and healthcare providers. These people can help you consider decision options and inform you about other services that are available to support you.

Suggestions to Ease the Final Journey

As you support a family member or friend through a terminal illness, feelings such as guilt, anger, frustration, and sadness are common. For some, tears are a natural

expression of feelings. Others internalize feelings and may not be able to cry. Your routines may be disrupted and you may feel you have lost your ability to concentrate. You may wish sometimes for things to be over because of the uncertainty, helplessness, emotional or physical exhaustion you may be experiencing. However, it's not all concerns, fears, helplessness, and uncertainty. Tears of gratitude are profound and may be experienced without guilt and ambiguity – are in fact quite lovely when family members need to attach meaning to their feelings and experiences of last hours of life. All of these reactions are normal.

Some Ways You Can Provide Comfort

Some of the following suggestions may be helpful as you are caring for your loved one with a terminal illness:

- ❖ Be present and keep them company – talk, watch movies, read, listen to music, just be present in silence.
- ❖ Allow them to express their fears and concerns about dying. This can also include leaving family and friends behind. Listen.



VON Durham Hospice Services



- ❖ Reminisce about the past.
- ❖ Be honest and avoid withholding difficult information: Allow them to be involved in the conversations that they want to be involved in. Acknowledge the difficulty of letting go or the awkwardness of the moment.
- ❖ Do not speak in front of the individual as if they are not there; hearing is often present even when someone appears to be sleeping or unconscious.
- ❖ Respect their need for privacy.
- ❖ Ask if there is anything you can do.
- ❖ When giving care, always explain what you are doing and why.
- ❖ Say “thank you” for the good memories and offer forgiveness for hurtful ones.
- ❖ Give reassurance of your well-being for the future.
- ❖ For some people, it may be important to receive a religious sacrament or to have a sacred rite performed.
- ❖ Discuss funeral wishes ahead of time and, when possible, make funeral arrangements in advance. This lessens the decisions that need to be made at the time of death – and provides an opportunity to talk about concerns and feelings.

As death nears, saying “goodbye” and giving permission to die can be appropriate and sometimes an important part of the ‘letting go’ process.

How the Body Prepares for the Final Stage of Life

As the body begins to prepare for death, many physical and metabolic changes take place. Remember that everyone’s journey at end of life is different, and even individuals with the same disease may experience it differently. Here are a few common signs that indicate that your loved one’s condition is changing.

Sleepiness

The person who is dying may spend more time sleeping and appear to be uncommunicative or unresponsive, and at times, difficult to wake up. This provides an opportunity for friends and family to spend time at the bedside. Try to be with your loved one during the times when they are most alert and awake, but allow them to rest when they are asleep. Talk to the individual as you normally would, even if they are unable to respond – they may be too weak to respond or unable to speak, but may still be able to hear and understand what you say. It is okay to hug, touch, and cry.



VON Durham Hospice Services



Loss of Appetite and Thirst

It is normal for appetite and thirst to decrease as someone approaches the end of their life. The person may want little to no food or fluid in the final days or weeks. This is natural for the body, and does not mean that the individual is 'giving up'. At this stage it is good to provide your loved one with food or drink that they enjoy, and are able to safely swallow.

Small chips of ice, popsicles, or juice may be refreshing the mouth. If the person is able to swallow safely (without any coughing), you can provide them with small sips of fluid or soft/pureed food when they are fully awake and sitting completely upright to minimize the risk of choking.

Good mouth care is also important. Keeping the mouth and lips moist can provide comfort and alleviate the sensation of thirst as someone approaches end of life.

Bladder & Bowels

Your loved one may experience incontinence (a loss of control of their bladder or bowels) as the muscles begin to relax and the individual is unable to control these muscles anymore. You can discuss with your PSW, Nurse, or Hospice

Navigator how to assist your loved one in maintaining good hygiene.

As a person gets closer to end of life, there is often a decrease in urine output and frequency. The urine may also become very concentrated or odorous.

Disorientation & Confusion

The person may become confused about the time, place, or identity of people surrounding them. They may see people or things that are not there. Sometimes these hallucinations can be distressing, and it is important to report them to your nurse or physician, as sometimes medication can be provided to make your loved one more comfortable in these situations.

You can identify yourself by name before you speak so your loved one does not have to guess who you are. Speak clearly. When you need to communicate something important, such as "It is time to take your medication", explain the reason- such as, "So you will be more comfortable".



VON Durham Hospice Services



Restlessness & Agitation

The individual may appear restless, like they cannot get comfortable or are pulling at their clothes or bed linens. Sometimes this can be related to pain, but restlessness can also be due in part to the physical or metabolic changes that are part of the normal dying process.

Severe agitation can sometimes occur. It is important to remember that these instances are related to the disease process and do not reflect how your loved one truly feels about you.

Do not interfere with or try to restrain the individual if restlessness occurs. For a calming effect, speak in a quiet and natural way. Reading, playing soothing music, or complementary therapies (massage or therapeutic touch) can sometimes soothe the individual, but you will also want to talk to your nurse and physician about medications to relieve these symptoms and make sure everyone is safe and comfortable.

Skin Changes

You may notice changes in the temperature or colour of your loved one's skin. The arms, leg,

hands and feet can become increasingly cool to touch. The face may also become pale, and the extremities (legs, knees, feet, hands) may have a purple/blue pattern. This is referred to as "mottling", and can come and go at end of life. These changes are a normal indication that the circulation of blood the extremities is decreasing.

Respiratory Congestion

When a person is nearing death and becoming less conscious, they often lose the swallowing reflex. The muscles around the throat begin to relax and secretions begin to accumulate. This can cause gurgling sounds in the throat and/or chest. Although this sounds distressing, it is believed that this does not cause discomfort and is experienced more like snoring. You may gently turn the individual from side to side and allow gravity to help drain the secretions. You can also ask the nurse or physician about medications that can help to dry up these secretions if you believe the individual is in distress.

Changes in Breathing Patterns

As death approaches, the breathing pattern, rate, rhythm, and volume often change or become irregular. If the person appears to



VON Durham Hospice Services



- ❖ There is sometimes secretions that come out of the mouth once the muscles are all relaxed

When your Loved One Dies

This is a special time for you to express your grief and spend as much time as you need with your loved one. Do not be afraid to touch, hug, kiss, or lie down beside your loved one, if that is what you are comfortable with.

When you are ready:

- ❖ Follow the procedure outlined by your doctor and nurses
- ❖ Contact the Funeral Home, once advised the appropriate paperwork is complete
- ❖ Notify the other members of your health care team (Hospice Navigator, Family Doctor, Specialist, etc.)

Grief & Bereavement

You may have dealt with many intense emotions and challenges through your journey. It is important to realize that grief is a highly personal response to life losses. Grief may last longer than society recognizes, so be patient

with yourself and allow for the expression of your feelings.

Remember, VON Durham Hospice Services will be here for you if you wish to have our support. We offer bereavement services to family and caregivers following the death of a loved one. We can accompany you on this journey through grief – a journey that can be painful and lonely. We offer one-on-one and group supports.

If you are interested in Bereavement Supports, ask your Hospice Navigator or contact the VON Durham Hospice Services office at 905-240-4522.