



When Comfort Becomes the Focus of Care

**ALEXANDRA MARINE &
GENERAL HOSPITAL
PALLIATIVE CARE**



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End-Of-Life Information for Family & Friends

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This handout provides important information about natural and expected changes that occur as a person's body weakens and approaches death.

As you read through these pages, it is important to understand that each person is unique. Not all of these changes will occur with every person, nor will they occur in the sequence presented in this handout. These changes may occur suddenly.

Please understand that death by disease(s) or the frailties of aging is a process. Changes take place over time. These changes are a normal way in which the body slows down then stops. Remember that these changes are NOT medical emergencies. The goal is not to stop the changes but to help your loved one to remain comfortable as the changes occur.

In the following listing, information is organized under descriptive headings. Each section includes a description of expected changes with suggested actions you can take to promote your loved one's comfort.

Know that we are available to support you and your loved one at anytime.

The following are signs that death has occurred:

- Complete absence of breathing
- Lack of pulse
- Lack of eye movement
- Relaxation of jaw with mouth open
- Arms and legs cold
- Darkened colour of nailbeds
- inability to respond to stimulation

What To Do After Death Occurs

The nurses will allow you as much time as needed to have time alone with your loved one after death, and are available to give you support and comfort. The nurse will inquire as to your Funeral home of your choice and will make arrangements for transfer of your loved one to the facility with instructions for them to contact you regarding future arrangements. The funeral director will be very helpful in guiding you through the next steps.

emotionally, physically, socially and spiritually. Many people begin to experience a profound sense of loss before a loved one dies, and this state can continue for months and sometimes years after a loved one's death. This can be normal although painful.

Seek out support - bereavement groups are offered through a variety of sources, churches, agencies and funeral homes.

Having a family member die can be one of the most stressful experiences of a person's life. It is very normal to experience a variety of conflicting emotions at this time. Remember that professional counseling is available to most people and may be of benefit to you or a family member during this period.

Waiting for Someone to Die

Many people have questions about whether people are able to choose their moment of death. We have known remarkable people who have lived and lingered for long periods of time waiting to see a distant loved one and then passed away minutes after that person's arrival or once the patient and significant other have said their goodbyes. There are times when others have taken their last breaths only minutes after being assured that the people they leave behind are going to be okay. Others will appear to wait to pass until the entire family, after holding vigil for days, leaves the room for only a short time.

We do not have explanations for these events. We recognize each person and family is unique. We encourage you to speak freely together, enjoy each other and treat this time as the precious gift that it is.

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Reduced Interest and Intake of Food & Fluids

Your loved one may have decreases in appetite and thirst, wanting little or no food or fluids. The body knows when it no longer desires or can tolerate food or liquids. As the person's body weakens, it naturally begins to conserve energy, which results in reduced eating and drinking. We do not recommend starting IV's on patients who are dying, as their bodies cannot process the extra fluid. The extra fluid collects in the hands, feet and lungs causing discomfort.

Do not try to force food or drink into their mouth or try to manipulate him or her into eating or drinking. Small ice chips, popsicles, juice or soft drinks may be refreshing in their mouth. If they want to eat, small frequent feedings of desired food and fluids may be more manageable and appealing than large meals.

Be aware of a decrease in swallowing ability. Reflexes needed to swallow may become weakened. Elevating the head may assist with swallowing and alertness and avoid choking.

Please know that as a person moves closer to death, dehydration does not cause pain and may reduce it.

Applying cool, moist washcloths to their head, face, mouth and body help relieve the feeling of dry skin and dry mucous membranes. Moisture swabs, moisture spray and lip balm can be used to keep the mouth and lips moist and more comfortable.

feet and changes in breathing, there is often a commonly made movement of their jaw. This is usually just before or after their last breaths. This movement often looks like they are stretching their lower jaw. Although we do not know if the person is trying to say something, we do know that many people do this and it appears to be a normal and expected part of the dying process.

Taking Care of Yourself

We recognize that this is a very stressful time for you and your loved one. It is important for families to rest when possible, eat well, express feelings to friends and each other, and to utilize the assistance of the health care team.

Tips for Family Members as a Loved One Nears the End of Life

Talk with other people about your experiences. One helpful "cure" for grief may be talking and sharing with others.

Plan ahead- know what you will do if your loved one's condition changes or if they die, and let others know what your plan is.

Try not to make any major decisions while caring for your loved one or in the year after his/her death. These decisions could include: changing jobs, moving, etc.

Often people discover in retrospect that they were not thinking as clearly as they had assumed, and make decisions they later regret.

Get information on grief. It may affect you

gurgling sound is the result of decreased ability to cough and swallow. The nurses will try different methods in attempt to reduce or eliminate this sound. Repositioning your loved one is one method that is used. There are also medications that are available that may help dry up the oral mucous. While this mucous is often distressing for family members, it does not usually cause discomfort for your loved one.

Inform the nurse with any concerns you may have.

Signs and Symptoms of Approaching Death

Often your loved one may become flushed and develop a fever. This is the body's way of reacting to the dying process. Cool cloths on the forehead are comforting at this phase. The nurse will also administer a medication to help reduce the fever and to help promote comfort. In approximately the last 24 -48 hours of a person's life, you may see several signs which indicate that death may occur at any time. Your loved one may be unable to speak to you when they are roused. It may become difficult to awaken them for more than a few seconds at a time.

Their hands and feet will usually be cool/cold to the touch and mottled with darkened colouring. Their eyes and mouth may be half opened or they may seem to be staring blankly into space.

Breathing maybe rapid and shallow, like the breathing of a runner in a race, or slow with ever increasing periods of no breath. {This is also called apnea}. Their heartbeat often gets very fast but sometimes can no longer be felt.

Besides the weakness, the coolness of hands and

Reduced Strength & Ability to Move

Your loved one may seem weaker, requiring more and more rest to perform even simple tasks such as walking, sitting or eating. It is important to assist and supervise all of their activities to promote their safety. Reassure them that it is all right to rest and sleep.

Decreased Interest & Attention

As the body weakens and energy decreases, involvement with people, hobbies, interests and pets may also decrease. Your loved one may lose interest in favourite activities.

He/she may want to be alone, with one person or with very few at a time. They may request short visits because they may tire easily. Try to remember that they are tired and weak. Understand that withdrawal from life is a natural part of our preparation for death. It is sometimes difficult for care givers and loved ones to accept, but it is important to respect their wishes. You can be there for them, just by sitting with them.

Change of Rest & Sleep Patterns

It is not unusual for night and day sleeping patterns to become reversed, with your loved one waking during the night and sleeping more through the day. Very often, as a person gets weaker, they become aware of their worsening condition. This may increase their thoughts of their approaching death. This may cause increased anxiety; many people become afraid of dying at night and have increased wakefulness.

It is important to remember that rest is very important for everyone. Please tell the nurse if sleeping becomes a problem, we will ensure that medication is available to allow your loved one to rest more comfortably at night.

As the illness progresses, your loved one may begin to sleep with their eyes and mouth open. This is a sign of increasing weakness and may be expected. They may spend an increasing amount of time sleeping and may appear unable to talk, to respond, or to be awakened. At this point “being with” them is far more important than “doing for”.

It is very important to let your loved one rest. Sit with them, hold their hand; do not shake them. Speak softly when speaking and reassure everything is ok. It is important not to hover or create too much stimulation, which can possibly agitate or prevent them from relaxing.

Loss of Bowel & Bladder Control

As the body weakens, your loved one may lose control of their bowels and/or bladder. The muscles in that area begin to relax. As the body weakens, the amount of urine normally decreases and it becomes tea-coloured or darker. A urinary catheter may be inserted for comfort.

Described “Supernatural” Experiences

It is common for many people, as they become closer to dying; to describe experiences of feeling they have been in contact with people who have already died.

This feels very real to the person who has

experienced this even though it may not seem believable. They may state “so and so came to see me” or “I just saw so and so”. For the person who has had significant anxiety, this may help them feel less frightened about their own approaching death.

We encourage care givers and loved ones to accept what they have been told, do not challenge them even though we may be tempted to do so.

A significant increase in restlessness is also possible. This may be demonstrated after a period of extreme weakness and deep

sleeping, when the person suddenly becomes very alert. They may want to chat, eat, and ambulate etc. when they haven't wanted to do any of these in days and/or weeks. Expect your loved one to have good and bad days.

Changes in Sense

Your loved one's vision decreases. It is important to leave indirect lights on for comfort. If they cannot see, reassure them that you are there and remind them of who you are. Hearing is the last of the senses to decrease; always assume that your loved one can hear you.

Changes in Breathing

As your loved one gets weaker, you may notice that their breathing changes over time. Sometimes it is slower, other times faster. Raising the head of the bed is often very helpful.

Oral mucous may increase and collect in the back of the throat, may result in a gurgling sound. This