

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 represented in this handout. These changes may occur over an extended period or may occur suddenly.

Please understand that death by disease(s) or the frailty of aging is a process. Changes take place over time. These changes are a normal way in which the body slows down and 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.

The Social Worker and your Funeral Director can help you with your loved one's passing by:

- Organizing funeral and burial arrangements
- Photocopying several copies of the "Proof of Death Certificated" from the funeral home (to be used when contacting government departments, financial institutions, insurance companies, etc)
- Helping you contact the following regarding your loved one's death:
 - Insurance companies
 - Banks/Financial institutions (to speak about bank accounts, RRSP's, estate, legal and financial matters, safety deposit box etc)
 - Human Resources Development Canada (regarding any pensions, benefits and savings plans, etc)
 - Department of veterans affairs (if applicable)
 - Cancellation of provincial health coverage (OHIP)
 - Contacting the Ministry of Transportation Office to cancel driver's license
 - Cancellation of any charge accounts (i.e. MasterCard, Visa, etc)
 - Notification of death to various community organizations, churches, etc and through the local paper (re: obituary, notes of thanks, etc)

Another excellent resource can be found on the internet at:

<http://www.thehealthline.ca/palliativecare/index.aspx?id=1> (South West End of Life Care Network on thehealthline.ca)

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Having a family member die can be one of the most stressful experiences of a person's life – it is normal to feel 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.

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.

WHAT TO DO AFTER THE DEATH OCCURS:

You need to contact the funeral home of your choice after the death to inform them of the death and set up a time to meet. The funeral home will then call the hospital's Health Records department to arrange a time to pick up the body. It is very helpful if you can let the nurses know which funeral home you will be using.

The nurses will give you time alone with your loved one after the death, and are available to give you support and comfort. Family members traveling from a distance can arrange a private viewing at the funeral home.

You will need to collect your loved one's belongings when you leave. Nursing staff can assist with this if you are uncomfortable. If you are not coming to the hospital, you may make arrangements to have someone come to pick them up within 24 hours on the unit.

Any valuables (i.e.; jewelry, glasses, dentures, etc.) should be taken home by the family as well. Any items that the family wishes to be buried with the body can be given to the funeral home directly.

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 died minutes after that person's arrival or once the patient and significant other have said their goodbyes. There are times when people will take their last breaths only minutes after they receive permission from a significant other to let go and have been assured that their family will be OK. Others will appear to wait to pass until the entire family, after holding a bedside 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. Know that we are available to support you and your loved one.

THE FOLLOWING ARE SIGNS THAT DEATH HAS OCCURRED:

- Complete absence of breathing.
- Lack of pulse and heart beat.
- Lack of eye movement.
- Relaxation of jaw with mouth open.
- Arms and legs cold and darkened colour of nails and knees.
- Inability to respond to stimulation.

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REDUCED INTEREST AND INTAKE OF FOOD AND FLUIDS:

Your loved one may have decreases in appetite and thirst, wanting little or no food or fluids. Their 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 would be expended in eating and drinking.

We do not recommend starting IV's on patient's who are dying, as their bodies cannot process the extra fluid. We find, in fact, that it makes them more uncomfortable by collecting in their hands, feet and lungs.

Do not try to force food or drink into their mouth nor try to use guilt to manipulate him or her into eating or drinking. ***Small chips of ice, frozen juices/soft drinks or popsicles may be refreshing in their mouth. If they want to eat, small frequent feedings of desired foods 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. ***It helps to position their head in an elevated position.*** This may help them with swallowing and alertness.

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. Glycerin swabs, applications of K-Y Jelly (a water soluble lubricant), and/or a fine mist spray may keep the mouth and lips moist and more comfortable.***

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DECREASED INTEREST AND ATTENTION:

As the body weakens and energy decreases, involvement with people, pets and things may also decrease. Your loved one may lose interest in once favourite activities (football games, cooking, small talk, etc.). He/she may want to be alone, with just one person or with very few at a time. They may tire easily and request that visits be shorter than usual. Understand that they are tired and weak. Although it is sometimes hard for caregivers and loved ones to feel shut out, understand that withdrawal from life is a natural part of our preparation for death.

REDUCED STRENGTH AND 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.

TAKING CARE OF YOU:

We recognize this is a very stressful time for you and your loved one. It is important for you as the caregiver to rest when possible, eat well, ventilate your feelings to friends and family, as you feel comfortable, and utilize assistance available to you.

TIPS FOR FAMILY MEMBERS AS A LOVED ONE NEARS THE END OF LIFE:

Talk with other people about your experiences – the only “cure” for grief is talking, sharing and processing your own reactions.

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 their death. These decisions include: changing jobs, moving, spending estate monies. Often people discover in retrospect that they were not thinking as clearly as they had assumed, and make decision they later regret.

Get information on grief. Grief can affect you 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.

CHANGES THAT OCCUR DURING THE LAST SEVERAL HOURS/MINUTES OF A PERSON'S LIFE OR "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 nurses will also administer Tylenol as a comfort measure.

In approximately the last 24-48 hours of a person's life, you may see several symptoms together which indicate that death may occur at any time. As death nears, it becomes difficult to awaken them for more than a few seconds at a time. Your loved one may be unable to speak with you when they are roused. Their hands and feet will usually be cool/cold to touch and marbled with darkened colouring. Their eyes and mouth may be half open. They seem to stare blankly into space. Breathing will either be rapid and shallow, like the breathing of a runner in a race, or with ever-increasing periods of no breath (also called apnea). Their heartbeat often gets very fast but sometimes can no longer be felt.

Besides the weakness, coolness of extremities, and changes in breathing, there is often a commonly made movement of their jaw, which is made just before or after their last breaths. This movement often looks as though they are stretching their lower jaw and moving it forwards and/or up and down. We want you to be aware of this because this can frighten many people, who do not know this is a very normal movement. Many people also worry that the person is trying to tell them one last thing and that they will never be able to know what that is. 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 process of dying.

CHANGING SLEEP AND REST PATTERNS:

It is not unusual for day and night sleeping patterns to become reversed with your loved one waking at night and sleeping during the day. Very often, as a person gets weaker, they become more aware of their worsening condition. This can often stimulate a person to think about their approaching death. At this time many people become afraid of dying at night, and have increased wakefulness and anxiety during the night.

It is important to remember that rest is very important for everyone (including your loved one and their caregivers). Please tell the nurse if this is becoming a problem, and we may be able to order some medication to allow the patient to rest more comfortably at night.

As the illness progresses, your loved one may begin to sleep with eyes and mouth open. This is a sign of increasing weakness and is not only normal but to 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 more important than "doing for". ***Sit with your loved one, sometimes hold their hand; do not shake them. Speak softly if you must and reassure.*** Since it appears that your words can sometimes rouse them, be careful to allow quality rest time. It is important not to hover and create too much stimulation, which would possibly agitate or prevent them from relaxing.

Speak directly and normally to your loved one, even though there may be no response. Never assume that they cannot hear you, or voices and sounds in the room. Hearing is said to be the last of our senses to be lost. Don't have a conversation in the room that you do not want them to hear.

LOSS OF CONTROL OF BLADDER AND BOWELS:

As the body weakens, the amount of urine normally decreases and becomes tea-coloured or darker. Your loved one may lose control of their bladder and/or bowels, as the muscles in that area begin to relax.

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 died. Generally, these experiences are described as "So and so came to see me" or "I just saw so and so". Although these may not seem believable to many people, they feel very real to the person experiencing them. For the person who has had significant anxiety about their approaching death, this is often a time when they feel less frightened. Often people are reported to be resting better and feeling calmer with less emotional strain/struggle after describing this type of experience. ***We encourage loved ones and caregivers to accept what they have to say and to not attempt to challenge them, even though we are often tempted to say things like "No, so and so has passed away; they couldn't have been here ...".***

Another change that can be somewhat surprising is a significant increase in restlessness. This may be demonstrated after a period of extreme weakness and deep sleeping, when the person suddenly becomes VERY alert. They may want to walk when they haven't for days or weeks; take their clothes on and off when they are normally quite modest and have not dressed themselves in weeks; pick at their clothes or bed linens, or at the air; eat an entire bowl of food when they have not eaten more than a spoonful for days, etc. Expect your loved one to have good and bad days. Needless to say, this is a very delicate and special time. Usually people have one final surge of energy just before they die.

Often this surge of energy confuses us, because what seems like renewed strength is actually a clear sign that death will probably occur within the next 24 hours.

CHANGES IN SENSES:

As our bodies weaken so does our eyesight. Vision may decrease in clarity, becoming dim or blurred. ***It is important to leave indirect lights on as vision decreases.*** Always assume your loved one can hear you because hearing is the last sense to decrease. ***Reassure them of your presence by telling them you are there and reminding them of who you are.*** Do not ask a very weakened or confused person to guess who you or other visitors are, let them use their limited energy for enjoying your company.

CHANGES IN BREATHING:

As your loved one gets weaker, you may notice that their breathing changes over time -sometimes slower, sometimes faster. ***Elevation of the head of the bed is often very helpful.***

Oral mucus may increase and collect in the back of their throat (sometimes called the "death rattle"). This is the result of a decrease in fluid intake and lessened ability to cough up saliva and swallow. ***The gentlest and fastest way to reduce this rattle is to turn them from one side to the other or from their back to their side.*** Generally after repositioning is done, the rattle sounds will stop. There is also medication available that will help "dry up" the secretions.