

- Hands, arms, feet and legs may be increasingly cool to the touch.
- Respiration may increase or decrease. There can be a puffing, a blowing of the lips on exhaling, or shallow breaths with periods of no breathing of 5-30 seconds and up to a full minute. This is called Cheyne-Stokes breathing.

Congestion can also occur with a rattling sound in the lungs and upper throat. There may be coughing with this but generally nothing can be brought up. Suctioning usually only increases the secretions and causes discomfort. Gently turn the person's head to the side and allow gravity to drain the secretions. You may also gently wipe the mouth with a moist cloth. All of these breathing changes and congestion have a tendency to come and go, sometimes within a minute.

- Drugs may be given to ease the stress of this congestion
- Level of consciousness decreases.
- Swallowing becomes difficult with a loss of gag reflex and a build up of secretions in the throat.
- Urine output decreases.
- Incontinence occurs with a loss of control of urine and/or bowel matter as the muscles in that area begin to relax.

ONE TO TWO DAYS TO HOURS BEFORE DEATH

UNUSUAL COMMUNICATION

The person may make a seemingly out of character statement, gesture or request. Perhaps they might say, "I want to go home!" This may have a variety of meanings. Some requests may indicate that your loved one is ready to say good-bye and is checking you out to see if you are ready to let him or her go. Accept the moment as a beautiful gift when it is offered. Kiss, hug, hold, cry and say whatever you most need to say.

VISION LIKE EXPERIENCES

Your loved one may speak or claim to have spoken to persons who have already died or to see or have seen places not presently accessible or visible to you. This does not usually indicate an hallucination or a drug reaction. The person is beginning to detach from this life and is possibly being prepared for the transition to what is next. Do not contradict, explain away, belittle or argue about what the person claims to have seen or heard. There are many mysteries occurring as death draws near.



GIVING PERMISSION

This can be very difficult to give permission to your loved one to let go, without making him or her feel guilty for leaving or trying to keep him or her with you to meet your own needs.

A dying person will normally try to hold on even though it brings prolonged discomfort, in order to be sure that those who are going to be left behind will be all right. Therefore, releasing the dying person from this concern and giving them assurance that it is all right to let go whenever he or she is ready, is one of the greatest gifts you can give to your loved one at this time.



BURST OF ENERGY

Sometimes there is a surge of energy. A person may talk clearly and alertly when there had previously been disorientation. A favorite meal might be asked for and eaten when nothing had been eaten for days. A person might wish to sit up in a chair and visit with friends and relatives. The spiritual energy for transition from this world and into the next has arrived and it is used for a time of physical expression before moving on. This surge or energy is not always as noticeable as the above examples, but in hindsight, it may be recognized.



RESTLESSNESS

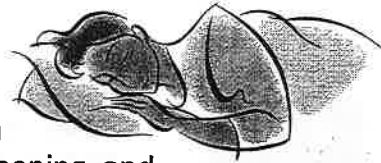
There may be picking at the bedclothes and agitated arm movements. This often happens and is due in part to the decrease in oxygen circulation to the brain and to metabolism changes. It may also indicate that something is still unresolved or unfinished that may be disturbing them, and prevents them from letting go. Your palliative care providers will be able to assist you in identifying what might be happening, and help you find ways to help your loved one find release from the tension or fear. Other things that may be helpful in calming the person are to recall a favorite place the person enjoyed, a favorite experience or read something comforting. You might try playing some music, speaking in a quiet tone, lightly massaging the forehead or hands and giving assurance that you love them and want the best for them.

PHYSICAL CHANGES

There are changes that show that the physical body is losing its ability to maintain itself:

- Blood pressure often lowers.
- Pulse beat either increases or decreases from 1-150.
- Body temperature fluctuates between fever and cold.
- Perspiration increases, often with clamminess.
Skin color changes – flushing with the fever, bluish with the cold, and pale yellowish pallor (not to be confused with jaundice) often accompanies approaching death.
- Nail beds in the hands and feet are often pale and bluish because the heart cannot circulate the blood through the entire body at a normal flow.

SLEEPING



The person may spend an increasing amount of time sleeping and appear to be uncommunicative or unresponsive and at times be difficult to arouse. This normal change is due in part to changes in the metabolism of the body. The person cannot seem to keep his or her eyes open. He or she can, however, be awakened from that sleep very easily. Sit with your loved one, hold his or her hand, do not shake and speak softly and naturally. Plan to spend time with your loved one during those times when he or she seems most alert or awake. Do not talk about the person in the person's presence. Speak to him or her directly as you normally would, even though there may be no response. Never assume the person cannot hear. Hearing is the last of the senses to be lost.

ONE TO TWO WEEKS PRIOR TO DEATH

DISORIENTATION

A person may become confused about the time, place and identity of people surrounding them including close and familiar people. This is also due in part to the metabolism changes. Identify yourself by name before you speak rather than asking the person to guess who you are. Speak softly, clearly and truthfully when you need to communicate something important for your loved one's comfort. Such as, "It is time to take your medication." Explain the reason for the communication. Such as, "So you won't begin to hurt or have pain."



ALL SIGNS BECOME MORE INTENSE AS THE WEEKS TURN INTO DAYS AND HOURS

Restlessness can further increase due to lack of the body's ability to function properly.

The breathing patterns become slower and more irregular.

Congestion can be very loud but can be easily managed by drug therapy. The eyes may be open or semi-open but not seeing. There is a glassy look to them, often tearing.

The hands and feet now become purplish, the knees, ankles and elbows become blotchy. The underside of the arms, legs, back and buttocks can also be blotchy due to poor circulation.

Generally people become non-responsive and unable to respond to the environment just before the time of death. They can still love you and you should assume that they can hear until they have died.

There is no desire to eat or drink.

SAYING GOOD BYE

Saying good-bye is your final gift of love to your loved one. It achieves closure and makes the final release possible. It may be helpful to lie in bed and hold the person, or to take his or her hand and then say everything you need to say.



How people approach death is going to largely depend upon how they approached life, participated in life and how willing they are to let go and venture into a new experience.

Tears are a natural and normal part of saying good-bye. Tears do not need to be hidden from your loved one or apologized for. Tears express your love and help you to let go. Tears are liquid emotions.



AT THE MOMENT OF DEATH

Although this booklet may help you to be prepared for the dying process, it is very difficult to be prepared for the actual death moment.

It may be helpful for you and your family to think about and discuss what you would do if you were the one present at the death moment. The death of your loved one is not an emergency; nothing must be done immediately. The signs of death include such things as not breathing, no heartbeat, release of bowel and bladder, no response, eyelids slightly open, eyes fixed on a certain spot, no blinking, jaw relaxed and mouth slightly open.

The essence of that person is gone to something new and he or she is no longer in need of a heavy, non-functioning body. This person is gone from your visual sight, but your relationship remains in your heart.



FOOD

Food is the way we energize our bodies. It is the means by which the body is kept going, moving and alive. A person may want little or no fluid or food. This may indicate the body does not need food and it is okay not to eat.

There is a gradual decrease in eating habits. Nothing tastes good. Cravings come and go. Liquids are preferred to solids. "I just don't feel like eating." Meats may be the first to go, followed by vegetables and other hard to digest foods until even soft foods are no longer eaten.

This is often one of the hardest concepts for a family member to accept. You may help your loved one by giving permission to let go whenever they are ready, at the same time affirm the person's ongoing value to you and that you love them. A different kind of energy is now needed. A spiritual energy, not a physical one, will sustain from here on.

ONE TO THREE MONTHS PRIOR TO DEATH *WITHDRAWAL*

This is becoming a time of withdrawal from everything outside one's self and going inside - inside to sort out, process one's self and one's life. Sometimes the inside has only room for one.

This processing of one's life is usually done with the eyes closed, so sleep increases. The person may seem unresponsive, withdrawn, or in a comatose-like state. This indicates preparation for release, a detaching from surroundings and relationships, and a beginning of letting go.



Naps may become more frequent and the person spends more time in bed. This appears to be just sleep but know that important work is going on inside on a level of which "outsiders" are not aware.

With this withdrawing comes less of a need to communicate with others. Words are seen as being connected with the physical life that is being left. Words lose their importance. Touch and a comforting loving presence take on more meaning. Since hearing remains all the way to the end, speak to your loved one in your normal tone of voice, identify yourself by name when you speak, hold his or her hand and say whatever you need to say that will help the person to let go.

SUMMARY OF THE GUIDELINES

ONE TO THREE MONTHS

- withdrawal from the world and people
- decreased food intake
- increase in sleep
- going inside of self
- less communication

ONE TO TWO WEEKS

Disorientation

- agitation
- talking with the unseen
- confusion
- picking at clothes

Physical

- decreased blood pressure
 - increase or decrease in pulse
 - color changes, pale, bluish
 - increased perspiration
 - respiration irregularities
 - congestion
 - sleeping but responding
 - body tired and heavy
 - not eating, taking little fluids
 - body temperature, hot or cold
-
- ill the bed

DAYS OR HOURS

- intensification of one to two week signs
- surge of energy
- change in blood pressure
- eyes glassy, tearing, half-open
- irregular breathing, stop and start
- restlessness or no activity
- purplish knees, feet, hands, blotchy
- pulse weak and hard to find
- decreased urine output
- may wet and soil the bed

MINUTES

- "fish out of the water" breathing
- cannot be awakened or aroused
- lack of muscle tone and strength

SAYING GOODBYE

- It may be as simple as saying, "I love you".
- It may include recounting favorite memories, places and activities that have been shared.
- It may include saying I'm sorry for whatever tensions or difficulties exist in the relationship.
- It may also include saying, "Thank you for..."
- Tears are a natural part of this process and one should not hide them or apologize for them.

AN INTRODUCTION TO THIS BOOK

Dying is a unique and personal experience which makes creating a booklet such as this one a challenge. The palliative care philosophy believes that each person is made up of body, mind and soul. All these factors of our being play a role with this experience of dying.

In the mid 1960's, Dr. Elizabeth Kubler Ross suggested that there were stages to the dying process. We now understand that no one experiences death in the same way. There is no step-by-step approach to dying. With that in mind, what is being offered here is a flexible guideline or a road map. Many roads can eventually arrive at the same place. This is true with dying. The road can be smooth, straight, bumpy, and full of curves, short or very long. Having a map can be very helpful in assisting you on your journey.

This booklet offers signs and behaviors that indicate that death is approaching. You may notice all of them, some of them or none of them. The booklet is divided into passages of time and these may not match your time frames and how your loved one experiences death. Each person will experience his or her own time line. Changes may begin one to three months before death occurs.

Death comes in its own time and in its own way. It is as unique as the individual who is experiencing it. If you have any questions as you read this booklet, please find a member of the palliative care team to assist you, your family and your loved one as you take this incredible and emotional journey. You are not alone.

This little booklet has been created to assist you
while you experience the death of
your loved one.

The staff shares in your grief and hopes that the
information on these pages gives you
support and comfort during this difficult time.



*“You matter because you are you.
You matter to the last moment of your life,
and we will do all we can
not only to help you die peacefully
but to live until you die.”*

Dr. Cicely Saunders
St. Michael Hospice, London UK

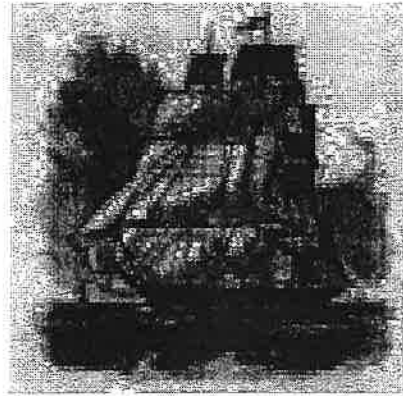
Ruth Richardson. An edited adaptation - Summer 2005
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I am standing upon the seashore. A ship at my side spreads her white sails to the morning breeze and starts for the blue ocean. She is an object of beauty and strength. I stand and watch her until at length she hangs like a speck of white cloud just where the sea and sky come to mingle with each other.

When someone at my side says: "There, she is gone!"

"Gone where?"

"Gone from my sight. That is all."



She is just as large in mast and hull and spar as she was when she left my side and she is just as able to bear her load of living freight to her destined port. Her diminished size is in me, not in her.

And just at the moment when someone at my side says, "there, she is gone!" there are other eyes watching her coming, and other voices ready to take up the glad shout:

"Here she comes!"

Gone From My Sight



Still In My Heart