

Signs and Symptoms of Approaching Death



Dynamics of the Dying Process

Physical Signs

When a person enters the final stage of the dying process, two different dynamics are at work which are closely interrelated and interdependent. On the **physical plane**, the body begins the final process of shutting down, which will end when all the physical systems cease to function. Usually this is an orderly and undramatic progressive series of physical changes which are not medical emergencies requiring invasive interventions. These physical changes are a normal, natural way in which the body prepares itself to stop, and the most appropriate kinds of responses are comfort enhancing measures.

Emotional-Spiritual Signs

The other dynamic of the dying process at work is on the **emotional-spiritual plane**, and is a different kind of process. The spirit of the dying person begins the final process of release from the body, its immediate environment, and all attachments. This release also tends to follow its own priorities, which may include the resolution of whatever is unfinished of a practical nature and reception of permission to 'let go' from family members. These events are the normal, natural way in which the spirit prepares to move from this existence into the next dimension of life. The most appropriate kinds of responses to the emotional-spiritual changes are those which support and encourage this release.

The experience we call death occurs when the body completes its natural process of shutting down, and when the spirit completes its natural process of reconciling and finishing. These two processes need to happen in a way appropriate and unique to the values, beliefs, and lifestyle of the dying person.

How Palliative Care Helps

Therefore, as you seek to prepare yourself as this event approaches, the members of your Palliative Care team want you to know what to expect and how to respond in ways that will help your loved one accomplish this final stage with support, understanding and ease. This is the great gift of love you have to offer your loved one as this moment approaches.

The emotional-spiritual and physical signs and symptoms of impending death which follow are offered to help you understand the natural kinds of things which may happen and how you can respond appropriately. Not all these signs and symptoms will occur with every person, nor will they occur in this particular sequence. Each person is unique and needs to do things in his or her own way. This is not the time to try to change your loved one, but the time to give full acceptance, support and comfort.

Signs and symptoms of how the body prepares itself for the final stage of life

Coolness

The person's hands and arms, feet and then legs may be increasingly cool to the touch, and at the same time the colour of the skin may change. This is a normal indication that the circulation of blood is decreasing to the body's extremities and being reserved for the most vital organs. Keep the person warm with a blanket, but do not use one that is electric.

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. Sit with your loved one, hold his or her hand, but do not shake it or speak loudly. 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.

Disorientation

The person may seem to be confused about the time, place and identity of the people surrounding him or her including close and familiar people. This is also due in part to the metabolism changes. Identify yourself by name before you speak rather than ask the person to guess who you are.

Speak softly, clearly and truthfully when you need to communicate something important for the patient's comfort, such as, it is time to take your medication. Explain the reason for the communication, such as, so you won't feel the pain. Do not use this method to try to manipulate the patient to meet your needs.

Incontinence

The person may lose control of urine and/or bowel matter as the muscles in that area begin to relax. Discuss with your Palliative Care nurse what can be done to protect the bed and keep your loved one clean and comfortable.

Secretions

The person may have gurgling sounds coming from his or her chest. These sounds may become very loud. This normal change is due to the decrease of fluid intake and an inability to cough up normal secretions. Suctioning usually only increases the secretions and causes sharp discomfort. Gently turn the person's head to the side and allow gravity to drain the secretions. You may also wipe the mouth gently with a moist cloth. The sound does not indicate the onset of severe or new pain. Medication is available to help with this stage if desired.

Restlessness

The person may make restless and repetitive motions such as pulling at bed linen or clothing. This often happens and is due in part to the decrease in oxygen circulation to the brain and to metabolism changes. Do not interfere with or try to restrain such motions. To have a calming effect, speak in a quiet natural way. Medication is available to help with this stage if required.

Your Palliative Care team members will assist you in identifying what may be happening, and help you find ways to help the person find release from the tension or fear. Other things which may be helpful in calming the person are to recall a favourite place the person enjoyed, a favourite experience, read something comforting, play music or lightly massage the forehead and give assurance that it is okay to let go.

Reduced Production of Urine

The person's urine output normally decreases and may become tea coloured often referred to as concentrated urine. This is due to the decreased fluid intake as well as decrease in circulation through the kidneys. Consult with your Palliative Care nurse to determine whether there may be a need to irrigate or insert a catheter.

Reduced intake of Fluid and Food

The person may have a decrease in appetite and thirst, wanting little or no food or fluid. The body will naturally begin to conserve energy which is expended on these tasks. Do not try to force food or drink into the person, or try to use guilt to manipulate them into eating or drinking something. To do this only makes the person much more uncomfortable. Small chips of ice, frozen Gatorade or juice may be refreshing in the mouth. If the person is able to swallow, fluids may be given in small amounts by a syringe (ask the nurse for guidance). Cleaning the mouth with sodium bicarbonate mouthwash and/or swabs and using lip conditioners is also comforting. A cool, moist washcloth on the forehead may also increase physical comfort.

Breathing Pattern Change

The person's regular breathing pattern may change with the onset of a different breathing pace. A particular pattern consists of breathing irregularly, ie shallow breaths with periods of no breathing of 5 to 30 seconds and up to a full minute. This is called Cheyne-Stokes breathing. The person may also experience periods of rapid shallow pant-like breathing. These patterns are very common and indicate decrease in circulation in the internal organs. Elevating the head, and/or turning the person onto his or her side may bring comfort. Hold your loved one's hand. Speak gently.

Normal Emotional, Spiritual and Mental Signs and Symptoms with Appropriate Responses

Withdrawal

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. Since hearing remains all the way to the end, speak to your loved one in your normal tone of voice, identifying yourself by name when you speak, hold his or her hand and say whatever you need to say that will help the person let go.

Vision-Like Experiences

The person 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 indicate an hallucination or a drug reaction. The person is beginning to detach from this life and is being prepared for their death, so it will not be so frightening. Do not contradict, explain it away, belittle or argue about what the person claims to have seen or heard. Just because you cannot see or hear it does not mean it is not real to your loved one. Affirm his or her experience. They are normal and common. If they frighten your loved one, explain that they are normal occurrences.

Refusing food or drink

When the person may want little or no fluid or food, this may indicate readiness for the final shut down. Do not try to force them to take food or drink at this stage. You may help your loved one by giving permission to let go whenever he or she is ready. At the same time affirm the person's ongoing value to you and the good you will carry forward into your life that you received from him or her.

Decreased Socialisation

The person may only want to be with a very few or even just one person. This is a sign of preparation for release and affirms from whom the support is most needed in order to prepare for death. If you are not part of this inner circle at the end, it does not mean you are not loved or are unimportant. It means you have already fulfilled your task with your loved one, and it is the time for you to say goodbye. If you are part of the final inner circle of support, the person needs your affirmation, support and permission.

Unusual Communication

The person may make a seemingly out of character or non-sequitur statement, gesture or request. This indicates that he or she is ready to say goodbye and is testing you 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.

Giving Permission

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

Saying Goodbye

When the person is ready to die and you are able to let go, then is the time to say goodbye. Saying goodbye is your final gift of love to your loved one, for it achieves closure and makes the final release possible. It may be helpful to lay in bed and hold the person, or to take his or her hand and then say everything you need to say.

It may be as simple as saying I love you. It may include recounting favourite memories, places and activities you shared. It may include saying I'm sorry for whatever I contributed to any tension or difficulties in our relationship. It may also include saying thank you for...

Tears are a normal and natural part of saying goodbye. Tears do not need to be hidden from your loved one or apologised for. Tears express your love and help you to let go.

How will you know when death has occurred?

Although you may be prepared for the death process, you may not 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 a patient is not an emergency. Nothing must be done immediately.

The signs of death include such things as no breathing, no heartbeat, release of bowel and bladder, no response, eyelids slightly open, pupils enlarged, eyes fixed on a certain spot, no blinking, jaw relaxed and mouth slightly open.

What to do when death occurs

If the person has died at home, you will need to discuss with the GP, visiting nurse or palliative care worker what to do when death occurs. This can be a stressful and difficult time so it is best to be prepared with a simple plan which at least deals with immediate practical issues.

You do not have to do anything immediately. There is no need to call the police or an ambulance. You may wish to call the doctor or visiting nurse to confirm that death has occurred. A doctor will need to certify the death. If the death occurs in the night you may have to wait several hours for a doctor to visit and so it may be preferable to just wait, and call the person's own doctor first thing in the morning.

You may want a friend, minister, spiritual adviser or family to be with you at this time. Ask someone to be ready at short notice if you wish.

The body can remain at home for several hours for relatives and friends to visit and say goodbye. If this is the case the body will need to be positioned on the back with head and chest very slightly elevated on pillows and hands on the chest. A towel can be rolled up and tucked underneath the chin to close the mouth. This can usually be taken away after a couple of hours as Rigor Mortis (stiffness) occurs. The visiting nurse will help you with these preparations if you call them.

There will be another opportunity for people to say goodbye if there is a viewing at the funeral chapel.

Contact the funeral director when you want the body attended to. They can usually come within a short period of time. It is possible to have the body removed at night but there may be an extra charge for this. If a funeral director has not been arranged prior to death, you can choose one from the 'Yellow Pages'. You may wish for someone else like a friend or relative to do this for you. The funeral director will make an appointment to discuss arrangements and costs with you, when you are ready to do so and normally within a day or two after death has occurred.

If the person had died in a palliative care unit or hospital setting, there is no rush for you to leave the ward. The nurses will wash your loved one if needed. You may wish to spend some time with your loved one. You may have other relatives and friends that you wish to be there as well. However cultural diversity is respected and it is understood that this may not always be appropriate. If you have any particular traditions or cultural needs, discuss these with the staff. When you are ready to leave, the doctors will arrange the necessary death certificates and your loved one will be picked up by the funeral directors.

Copyright @North Central Florida Hospice Inc. 1996-2000

This publication is reproduced with the permission of the North Central Florida Hospice. Parts of this publication have been edited to reflect the Australian setting.

Courtesy of Home Hospice Care of Rhode Island
Thank you to Palliative Care South Australia and to Sacred Heart Hospice, Darlinghurst for the information on what to do once the person dies.