



THE DYING PROCESS

FAMILY INFORMATION

Each person approaches death in his or her own unique way. This section is simply a guide to help you understand your loved one's physical, emotional, and spiritual transition from this life into the next.

This guideline is very flexible. Not everyone will experience all the signs listed in this section. However, it will be beneficial for you to be familiar with all the signs in order to recognize them in your loved one.

If we were to use a timetable, we could say these changes begin one to three months before death. A shift occurs within a person, from a mental processing of death to a true mental comprehension and a belief in his own mortality. Unfortunately, family and friends do not always understand these processes.

One to Three Months Prior to Death

Withdrawal

As the knowledge that he is dying becomes real, the patient begins to withdraw from the world around him. This is the beginning of the separation: first, from the world- no more interest in newspapers or television; then from people- no more visits from neighbors; and, finally, from the children, grandchildren, and other loved ones.

The patient is now experiencing a time of withdrawal from everything outside of himself. He is turning inward in order to sort out and evaluate himself and his life. Inside, there is room for only one. (Try not to take this personally- it is a natural part of the dying process.)

Since this processing of his life is usually done with the eyes closed, sleep increases. The patient will nap more often and may stay in bed all day. Important work is going on inside on a level of which "outsiders" are unaware.

The patient does not need as much communication with others. Words lose their importance; touch becomes more meaningful.

Food

Food supplies energy to our bodies. We eat to live. When a body prepares to die, it begins to stop eating. This natural part of the process is very hard for families to accept.

Remember that nothing tastes good to the patient. His cravings come and go, and he will probably prefer liquids to solids. He will reject meat first, then vegetables and other hard-to-digest foods and will eventually reject soft foods. It is okay for him not to eat. A spiritual energy-not a physical energy- will sustain him from now until the end.



One to Two Weeks Prior to Death

Disorientation

The patient will sleep most of the time. He literally has one foot in each world. He may become confused, talk to people who are already dead, and talk about places and events the family does not know. He may pick at the bedclothes, move his arms as though agitated, or perform other aimless activity. His focus is changing from this world to the next; he is losing his grounding to earth.

Physical Changes

The body begins to change and lose its ability to maintain itself.

- Blood pressure lowers
- Pulse either increases or decreases
- Skin color changes- flushed with fever, bluish with cold, pale yellow (accompanies approaching death)
- Nailbeds, hands and feet become pale or blue- heart can't circulate blood through body normally
- Respirations either increase or decrease
- Puffing, blowing lips on exhale
- Breathing may stop, only to resume again
- Congestion- rattling in lungs and upper throat
- Coughing- generally nothing brought up
- Breathing is sporadic- one-minute fine, the next minute labored

One to Two Days- Hours Prior to Death

Sometimes a patient becomes more energetic and seems clear and alert. He may ask for and eat his favorite meal, when he hasn't eaten for days. He may sit in the living room and visit with relatives, even though he had not wanted to visit with them for quite a while.

The patient's spiritual energy for his transition has arrived, and this is a time of physical expression before moving on.

After this surge of energy, the signs that were present earlier (in the one-to-two weeks' time frame) will return and become more intense. Restlessness can increase due to lack of oxygen in the blood. His breathing pattern becomes slower and more irregular. Breathing often stops for 10 to 30 seconds. Congestion can be very loud and sporadic. His eyes may be open, but look glassy and un-seeing. His feet and hands become purplish; knees, ankles, elbows, arms, legs, back and buttocks become blotchy. He will probably become non-responsive sometime prior to death.

How the patient approaches death will depend on his fear or love of life, how much he participated in life, and how willing he is to let go of this known world and venture into a new one. Fear and unfinished business are two big factors in determining how much resistance he will put into meeting death.

The separation from this world becomes complete when breathing stops totally.



Preparing for the Death of a Loved One

When a person enters the final state of the dying process, two things are happening. Physically, the body begins to shut down its systems, and will continue to shut down until all of the body's functions have stopped. This process usually happens gradually and does not need emergency care. These physical changes are a normal and natural way for the body to prepare itself to stop. The best thing to do is to provide support and comfort.

The other part of the dying process involves emotional, spiritual, and mental changes. The "spirit" of the dying person begins the final process of release from the body, its immediate environment, and all attachments. This release from the body has its own orderly flow, which includes finishing any unfinished business, coming to peace with people who are close, and getting permission from those people to "let go." These changes are the normal and natural way for the spirit to prepare for moving from the physical world into the next world. The best thing to do is to support and encourage the changes of releasing and letting go.

When a person's body is ready to stop, but the person still has unfinished issues, he or she will tend to hang on, even in the face of discomfort, in order to bring closure to important issues. However, a person may be emotionally, spiritually, and mentally prepared to die before the body is ready. In this case, the person will continue to live until the body has completed the shutdown process.

Death happens when the body finishes the natural process of shutting down and when the "spirit" completes the natural process of closure and letting go. In order for death to be a peaceful release for the patient, the physical and spiritual processes should proceed according to the person's own values, beliefs, and lifestyle.

The members of Freedom Hospice want to help you support and understand your loved one during the transition from this world into the next. Therefore, we have listed the physical, emotional, spiritual, and mental signs and symptoms of impending death to help you understand the natural course of the dying process. Not all of these signs and symptoms will occur for every person, nor will they occur in any particular order. Each person is unique, and deserves for his own unique process of shutdown and release to be respected. This is your time to give full acceptance, support, and comfort to your loved one.



Dying Patients Need Little Food

CHICAGO (AP)- “Patient’s dying of cancer usually want very little to eat and drink during their last months, and most of them spontaneously starve in a way that seems to ease their deaths, a study found. Terminally ill patients shouldn’t be given nourishment especially if they don’t want it; it only heightens their discomfort, researchers said.

- Patients terminally ill with cancer generally did not experience hunger, and those who did needed only small amounts of food for alleviation... They lost their appetite. They didn’t want to eat anymore... People dying from other ailments, including Alzheimer’s disease, have the same experience...
- Almost everyone studied consumed less than 25 percent of the food and/or fluids needed for basic nutritional requirements. Those who reported thirst or dry mouth sucked ice chips or hard candies and sipped liquids in far smaller quantities than needed to prevent dehydration, the researchers said.
- That eased their deaths, because dehydration lessens consciousness, promotes sleepiness, and diminishes pain... This is, of course, how people have always died, before there were hospitals with IVs and feeding tubes... It can be good medicine and good morality to forgo artificial feedings, when it can only impose additional burdens on a patient who is imminently dying from a progressive terminal illness...”



Normal Physical Signs and Symptoms—Appropriate Responses

1. Fluid and Food Decrease: The person may begin to desire little or no food or fluid. This means the body is conserving for other functions the energy, which would be expended in processing these items. Do not try to force food or drink into the person. Do not use guilt to manipulate him into eating or drinking something. This only makes the person much more uncomfortable. Small chips of ice, or frozen Gatorade or juice may be refreshing in the mouth. Glycerin swabs may help keep the mouth and the lips moist and comfortable. A cool, moist washcloth on the forehead may increase physical comfort.
2. Urine Decrease: The person's urine output normally decreases, due to the decreased fluid intake and the decrease in circulation through the kidneys. Consult your hospice nurse to determine whether a catheter should be inserted or irrigated.
3. Incontinence: The person may lose control of urine and/or bowels as the muscles in that area begin to relax. Ask your hospice nurse what can be done to protect the bed and keep your loved one clean and comfortable.
4. Sleeping: The person may spend an increasing amount of time sleeping and may appear to be uncommunicative and unresponsive. This is due, in part, to changes in the metabolism of the body. Sit beside your loved one, hold his hand, and speak softly and naturally.
5. Restlessness: The person may make restless and repetitive motions. This happens often and is due, in part, to the decrease in oxygen circulation to the brain and metabolism changes. Do not interfere with or try to restrain such motions. To calm him, speak quietly and naturally, lightly massage the forehead, read to him, or play soothing music.
6. Disorientation: The person may seem to be confused about the time, place and identity of people around him. This is due, in part, to the metabolism changes. Identify yourself by name before you speak. Don't ask him to guess who you are. Speak softly, clearly, and truthfully when you communicate something important for the patient's comfort (such as "It's time to take your medication") and explain the reason for the communication (such as "So you won't hurt") Do not use this method to manipulate the patient to meet your needs.
7. Suspicion: The person may become suspicious and not want to take his medication. He may even spit out the medication or attempt to hit or kick at the family. Do not attempt to forcibly restrain him. Instead, speak in a calm, quiet voice and contact your hospice nurse for further instructions.
8. Fever: The person may have an elevated temperature. Your hospice nurse will show you how to give cooling sponge baths and how to administer medication to reduce fever.
9. Congestion: Sounds like marbles rolling around inside may be coming from the person's chest. This normal change is due to the decrease of fluid intake and inability to cough up normal secretions. Suctioning usually only increases the secretions and causes some discomfort. Gently turn the patient's head to the side and allow gravity to drain the secretions. You may also gently wipe with a moist cloth. The congestion sound does not indicate the onset of severe or new pain.
10. Coolness: The patient's hands, arms, feet, and legs (in sequence) may become increasingly cool to the touch. At the same time, the skin may change color. 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 patient warm with a blanket—not electrical.
11. Breathing Pattern Change: The patient's regular characteristics breathing pattern may change, with the onset of long periods of no breathing followed by deep and faster breathing. This is called the "Cheyne-Stoke" symptom, which is very common, and indicates a decrease in circulation in the internal organs. Elevating the head may help bring comfort. Hold the patient's hand and speak softly.



Normal Emotional/Spiritual/Mental Signs and Symptoms- Appropriate Responses

1. **Withdrawal:** The patient may seem unresponsive, withdrawn, or in a comatose-like state. This indicates preparation for release—a detaching from surroundings and relationships and the beginning of “letting go.” Since the hearing is the last to stop, speak to the patient in a normal tone, identify yourself by name, hold his hand, and say whatever you need to say that will help the person “let go.”
2. **Vision-like experiences:** The patient may speak or claim to have spoken to dead persons, or to see or have seen places not presently accessible or visible to you. This does not indicate a hallucination or a drug reaction. The person is beginning to detach from this life and is being prepared for the transition so he will not be frightened. Do not contradict, explain away, belittle, or argue about what he claims to have seen or heard. Just because you cannot see or hear does not mean it is not real to him. Affirm his experience. If these experiences frighten your loved one, reassure him that they are normal.
3. **Restlessness:** The person may perform repetitive and restless tasks. This may indicate, in part, that something is still unresolved and unfinished and is disturbing him and preventing his letting go. The hospice team will assist you in identifying what is happening and find ways to help the patient find release from the tension and fear. Recalling his favorite place or experience, reading to him, playing music, and giving assurance that is okay to let go will help calm the patient.
4. **Fluid and Food Decrease:** The desire for little or no food may indicate that the patient is ready for the final shutdown. Give him permission to let go whenever he is ready. Also, affirm the person’s ongoing value to you and the positive ways he has influenced your life.
5. **Decreased Socialization:** The person may desire the company of a very few people, or just one person. This is a sign of preparation for release and a need for affirmation from those closest to him. If you are not part of this “inner circle” at the end, it does not mean you are unloved or unimportant. It simply means you have already fulfilled your task with him and it is time for you to say “good-bye.” If you are part of the final “inner-circle” of support, that means the person needs your affirmation, support, and permission to let go.
6. **Unusual Communication:** The patient makes a seemingly “out-of-character” statement, gesture, or request. This indicates that he is ready to say “good-bye” and is “testing” to see if you are ready to let him go. Accept the moment as a beautiful gift when it is offered. Kiss him, hug him, hold him, cry, and say whatever you need to say.
7. **Giving Permission:** It can be very difficult to give permission to your loved one to let go without making him feel guilty for leaving you or trying to keep him with you to meet your own needs. A dying person will normally try to hold on, even though it prolongs his discomfort, in order to be sure those he is leaving behind, will be all right. Therefore, your ability to release him from this concern and give him assurance that it is all right to let go whenever he is ready is one of the greatest gifts you can give your loved one.
8. **Saying Good-Bye:** When the person is ready to die and you are able to let go, it is time to say “good-bye.” Saying “good-bye” is your final gift of love to him, for it achieves closure and makes the final release possible. It may be helpful to get in bed with the person and hold him, or just take his hand and say everything you need to say to him, so that, afterward, you never have to ask yourself, “Why didn’t I say that to him?” Tears are a normal and natural part of saying “good-bye.” Do not hide your tears from him, nor apologize for them. Tears express your love, and they help you let go.

** The hospice social worker can guide and support you through the dying process.