

Tips from Nurse DeAnna.

Knowing what to expect can make a difficult time less emotionally painful.



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Expect more from us. We do.

“THE AIM OF THE WISE IS
NOT TO SECURE PLEASURE,
BUT TO AVOID PAIN.”

~ARISTOTLE

Caring for a loved one with a life-limiting illness can be one of the most stressful and demanding duties a person has to perform. During the progression of an illness a person can experience many changes. As death becomes imminent, the changes can be more pronounced, and more painful for you to witness as the caregiver. However, knowing what is expected and what is a normal progression of death will hopefully make a difficult time less emotionally painful for you, the caregiver. This guide was designed to assist you in this process.

Death, much like life, is a process. Not unlike the birth of a child, there are different stages of death. Not every person follows the same pattern. Some individuals decline more rapidly than expected, others may exceed their prognosis. However, most individuals will experience similar patterns during the dying process. Please remember, these patterns are NORMAL and are nothing to fear.

ONE TO SIX MONTHS PRIOR TO DEATH

Withdrawal from social activities/withdraw from family and friends/may refuse visitors

Your loved one may no longer want to participate in normal activities. They may not want to go to their normal beauty shop appointment or group activity. This is a normal response and indicates their readiness to “let go” of this life.

Decrease in energy/increased fatigue

The body no longer has energy stored and their energy level drops. They may be more tired and fatigued.

Decrease in appetite or weight loss

The body no longer needs nutrients or calories because the organs are beginning to shut down. The body’s metabolism is slowing down. They can no longer absorb food. Because of this, they no longer “feel” hungry and this can result in weight loss.

Behavioral changes

Your loved one may begin to show signs of agitation or anxiousness. They may repeat conversations or ask the same questions over and over. Other behavioral changes may include anger, combativeness, or restlessness. Sometimes the individual may become tearful for no reason.

Increase respiratory difficulty, shortness of breath

It may become more difficult for your loved one to catch their breath. They may exhibit shortness of breath when eating or talking. They may have to stop to “catch their breath” when walking or exerting themselves. Their breathing pattern may change and they may exhibit shallow breathing. They may eventually require supplemental oxygen to help ease their symptoms.

May refuse to attend church or spiritual meetings

It is not uncommon for individuals to refuse to attend their normal church services, synagogue or prayer meetings that they have routinely attended. Other times, they may feel the need to attend church when they haven’t attended for years.

May begin to “give away” belongings or favorite treasures

It is common for those facing end of life to want to give away their prized possessions. They may begin to request specific items be given to certain individuals. Passing on treasured items to others may be their way of showing gratitude or that their special items will remain as a memento or heirloom.

May begin to reminisce about the past

Your loved one may begin to talk about the past. They may want or need to share stories, events, or even special recipes. This may be their way of ensuring that their legacy is carried on after they are gone or that their life has been meaningful.

Listening and allowing your loved one to share stories will be beneficial for both.

ONE TO THREE WEEKS PRIOR TO DEATH

Increase need for sleep

Due to the disease progression, the energy levels are depleted and your loved one will spend more time sleeping. This is a normal occurrence, regardless if they are on sedating medications or not.

Delirium

Delirium (confusion, disorientation) is a very common symptom at the end of life.

Sometimes they may experience hallucinations. This is due to many factors including a change in the body's chemistry. The major organs are not functioning properly.

Oxygen to the brain may be diminished. Other causes may be the very medications needed to treat uncomfortable symptoms and pain.

Decrease in oral intake

You most likely will see a decrease in your loved one's appetite and intake. Much like when you have the "flu" and you don't want to eat, the concept is similar. The other reason is that the body no longer needs the same caloric intake as when they were active.

Skin color changes

You may notice changes in the individual's skin color. They may appear "grey" or ashen.

They also may appear pale. They may exhibit a "blue" tint around the mouth. This is called "cyanosis" and is due to the decrease in oxygen. This is common but not uncomfortable.

Decrease in urinary output

Due to the decrease in oral intake, your loved one may experience a decrease in urinary output.

DAYS PRIOR TO DEATH

Respiratory/breathing changes

Breathing becomes erratic. They may breath faster or slower and may stop breathing for a few seconds before resuming breathing (this is called apnea). Breathing may become noisy. May exhibit a gurgling sound in throat. This may be scary for you, but your loved one is not experiencing any discomfort due to the breathing changes.

Changes in skin/body temperature

It is very common for individuals to run a fever prior to death. Another common occurrence may be their feet and hands may be cool to the touch. Reducing a fever will ensure that your loved one is comfortable during this time.

Difficult or unable to awaken individual

Your loved one may become hard to awaken. This is due to major organs are beginning to stop functioning properly. It can be due to the lack of oxygen to the brain. This is very difficult for you, but your loved one is not suffering due to this symptom.

DEATH IMMINENT (HOURS PRIOR TO DEATH)

Irregular breathing

Your loved one may begin to breathe very quickly, and then stop breathing for periods of time before resuming breathing. This is called "cheyne-stokes" breathing. The cessation of breathing is called apnea and is a very common indicator that death may be imminent. Again, this is more uncomfortable for you than the individual.

May appear to be gasping for air

This is another common symptom seen when death is imminent. You may notice that your loved one is "gasping" or breathing with their mouth open. This is a respiratory pattern is called "agonal breathing." Sometimes this pattern only lasts for two or three breaths. Other times it may continue for longer periods of time. If this breathing pattern continues, your nurse may administer oxygen as a comfort measure.

Blotchy colored skin

A discoloration or "blotchy" appearance to the skin is called "mottling." This usually starts with the feet and may move up to the thighs or hips.



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