



What Can I Expect During the Final Journey?

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So often people have questions about the dying process: What happens in the final days and hours? What can I expect? Will I know when my or my loved one's final moments are near? Many times people don't know how to ask the sensitive questions, or where to go for the answers. At Niagara Hospice, we focus on providing support in every way that we can, including helping to find answers to these questions.

This resource essay is intended to serve as a guide for people who are near the end of their life, and for their families as well. Although we are all affected by death, many of us don't have much information or knowledge about the process of dying. It is a topic that is commonly avoided, leaving many unanswered questions. We hope this guide will help answer your questions, and put your mind at ease.

While death is a universal experience, it is also a very unique experience. Each person experiences death in their own way, much the same way that life is an individual experience. For some, death comes quickly; for others, it takes months for the body to stop functioning. The time-frame can vary and a variety of symptoms can be visible.

As you read, please keep in mind that the time-frame is extremely variable, and is offered only as a channel for understanding the common experiences. Some people will experience a majority of these symptoms, while others will experience only a few, or none. Each experience is described in summary form, to provide a general overview.

One to Three Months Prior to Death

People who have a terminal illness often experience poor health conditions for a period of time before they die. Often times this phase allows for the individual and their loved ones to think about how the disease is impacting their lives. For most, there comes a time where they experience a change from a cognitive understanding of the disease and the impending death, to a deeper acknowledgement and understanding of their own mortality. Some people face this time with hope; hope of a miracle, or hope of going to a better place after the death of their body. Some people are energized, with a renewed focus on satisfying their life goals. For the most part, an individual will deal with the challenge of dying in the same way they have reacted to the challenges of living. They may demonstrate signs of denial, depression, anger, or calmness and acceptance.

Sometimes people prefer to keep their thoughts to themselves, and other times they share their thoughts and feelings with a trusted loved one. It is common to spend time reflecting, facing the fact that life is going to come to an end; facing one's own mortality often takes time to absorb. During this time, loved ones might find that the dying person is withdrawn from the people and environment around them. The individual may begin to withdraw from activities that they used to enjoy, such as reading the newspaper, watching television, playing cards, or visiting with

friends. Sometimes families are concerned about this withdrawal, but there is nothing to worry about. The person is simply doing their “inner work”, and verbal communication with others isn’t as necessary as it once was. However, touching and simply being close are important, and can often provide the dying person great comfort and support.

This reflection and mental preparation for death takes a great deal of energy, so it is likely that the person will sleep more than they have before. Spending more time in bed with their eyes closed, or sleeping more is quite common. It is not uncommon for the individual to sleep most of the day, with only intermittent short periods of being awake.

In addition to the mental changes that take place and the withdrawal from the world in the few months prior to death, there are physical changes that develop as well. For example, often the appetite diminishes and people experience weight loss. What once was a favored food may now entice no interest. The person who is dying may only want liquids such as milkshakes, or may be satisfied with just small portions of food at any given time. The body no longer needs the same amount of nutrition, and the sense of taste is diminishing. While friends and family often become concerned about this decrease in interest and intake, it is a very natural part of the process. The body turns from needing nutritional energy to spiritual energy, so food is not necessary.

One to Two Weeks Prior to Death

As the body moves more toward death the individual experiences more changes in the final weeks. Frequently during this period it appears like the person is living in two worlds. They sleep most of the time, but can be awakened. Their eyes may appear very distant, as though they are looking at those around them, but not really seeing them. They might be confused at times; talking to people that cannot be seen by others. Time and time again, we hear of experiences where the dying person has talked with loved ones, or seen loved ones who have already died. These are all signs that the person is preparing for separation from this world. They are normal signs and nothing to be concerned about.

In the last few weeks of life, the body continues to change. The dying person becomes increasingly frail, losing the capability to preserve energy. Signs such as lowering of blood pressure, an increase in perspiration, skin color changes, and changes in heart rates are often observed. The person’s breathing may begin to appear quite differently; it may become fast, with fifty or more breaths per minute. At the same time, the respiration is shallow, and less effective. Sometimes the person may appear to be blowing through their lips, in a sort of puffing fashion, or they may actually stop breathing for a short time, and then return to normal breathing. If the lungs become congested, which is common, there might be a rattling sound in the chest and throat. Sometimes this causes the person to cough, but nothing clears. Breathing rhythms in the last couple weeks can oscillate from normal to taxing, and can change from one minute to the next.

The heart rate can fluctuate from going low to below fifty beats a minute, to a high of over a hundred beats a minute. Blood pressure may drop to numbers such as 70/40, and then creep back up to normal ranges. In addition, the body temperature may ebb and flow from too low to a fever. It is also common for the person’s color to appear pale yellow, or flushed (from fever). The person’s hands and feet are sometimes cold to the touch, and might be a pale blue. This is due to the inability of the heart to circulate the blood efficiently throughout the body.

The Final 48 Hours Prior to Death

Many families share stories of a sudden burst of energy about two days before the death of a loved one. Commonplace are the stories where the person slept most of the day or was confused or disoriented (confused about where they were, date, time, other people) and then suddenly was very alert and talkative. They may ask to visit with friends and family, or their appetite may spike and they might even ask to have a favorite meal. As with all the other experiences at the end of life, this phase is unique to each individual. While not everyone will experience such an obvious burst of energy, most will go through some noticeable changes.

The body's functions continue to deteriorate, with breathing becoming more irregular, and heart and pulse rates changing more often and generally becoming weaker. Breathing may now stop for ten to fifty seconds, and then start up again. Some people stop eating all together, and even refuse liquids. The body just doesn't need food or water any longer. If the person's lips are chapped or their mouth is dry, ice chips can be given to keep the mouth moist, and the lips can be wiped with a wet cloth or swab. The lungs and throat may become more congested, and respiration more shallow. The person can sometimes be made more comfortable by re-positioning, from one side to the other. Regardless, the breathing changes will continue as one moves closer to death.

The person may look right at their loved - ones who have gathered around, but there is a glossy look in their eyes, and they don't seem to be seeing anyone. Sometimes the eyes tear, but the person isn't actually crying. Their hands and feet may be pale blue in color, and their extremities may be blotchy looking.

Many times in the last hours of life, people become non-responsive. They flow in and out of a sleep state, unable to answer questions or acknowledge those around them. On the other hand, some people are able to talk even in the very last hours. Restlessness is also a common experience in the final hours. As the circulatory system is less efficient, there is a further decrease in oxygen flow in the blood, which contributes to this restless state. Cool compresses to the forehead can provide comfort if the person is perspiring, and loosely fitting sheets that don't bind the person's arms and legs can be helpful. As in earlier days, the person may appear to be seeing people that others cannot see; this is okay and there is no need for concern.

In summary, while you can expect to see some of these signs when death is near, please remember that each experience is unique to the individual, just like all other life experiences. How we experience death can vary, and a number of things impact that experience. Some people have unfinished business such as relationship conflicts that they want to resolve in their final days. Some people have fear about how they will die, or the dying process itself. Others may have a sense of calmness and readiness for their next journey. In the end, life ceases when the heart stops beating and breathing stops. This final breath may come after a couple long, far apart spaced breaths, and comes when the body no longer needs to function. Many believe that this is merely a transition from a bodily experience to a spiritual journey.

For Friends and Family

So often family members and friends express a feeling of helplessness as their loved one experiences the dying process. Below is a list of common changes that are experienced by the dying person, along with ways in which caregivers can make their loved one more comfortable. Not every suggestion will work for every situation, but these may help comfort both the dying person, and their loved ones who want so much to help.

- Perspiration – a damp, cool cloth can be used to wipe the person’s forehead, neck and arms to help keep the person a bit cooler and more comfortable. Bed baths may also be given for comfort.
- Dry mouth – a variety of things can be offered to help relieve a dry mouth including popsicles, ice chips, water through a straw, a moist cloth on the lips, or ointment placed on the lips to prevent drying and cracking.
- Nausea – offer clear liquids, control odors or sounds that may bring on nausea. Provide fresh air by opening a window or placing a fan in the room. Use relaxation techniques, or distractions.
- Dyspnea (labored or difficult breathing; air hunger) – a bedside fan, use of oxygen may be needed or may have a placebo effect, relaxation techniques, elevating the upper body slightly, and supportive words may be offered.
- Loss of appetite – it is common for a dying person to lose their appetite, and is a very normal part of the dying process. However, the person who is dying, and their family, is sometimes concerned about the loss of appetite. Small portions, snacks, favorite foods, and liquid nourishment such as milkshakes can be offered.
- Pruritus (itchy skin) – a tingling or slight burning sensation may be experienced near death. Washing with a warm wet cloth, applying moisturizer, increasing fluid intake, using soft sheets or blankets may help relieve the itchy feeling.
- Anxiety – the dying person may appear restless, fidgety, or anxious. Comforting conversation, allowing them to express emotions and share feelings and thoughts, simply sitting nearby or holding their hand often helps. Other strategies that help relieve the anxiety include soothing music, reading to the person, eliminating background noise that may be irritating the individual, massage, combing their hair, opening curtains or blinds to allow sunlight in the room, prayer, meditation, and supportive therapy. Talking with the person, especially asking about fears, and fostering conversations with family members may be helpful as well.

Finally, please remember that your Niagara Hospice family is here to help and support you in every way that we can.