

## **Understanding disease progression and signs of dying**

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Attending to the needs of a loved one who is dying can certainly provoke a great deal of anxiety and be emotionally upsetting. The following signs and symptoms of approaching death are offered as a guide to help families understand the natural progression of the dying process. Here we will identify some of the changes that may occur in a person's final days and hours of life and how you can respond. It is impossible to predict exactly which of these will occur. However, the following signs and symptoms are common as bodily functions begin to shut down and death nears.

### **1. Withdrawal**

It is natural to not feel like socializing when a person is weak and fatigued. Speech may become slow or conversation difficult. Your loved one may even lose the ability to speak altogether. It can be disturbing to the dying person to have more than a few people visit at a time.

#### ***How to respond***

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*Keep the environment quiet and calm and reassure your loved one that it is OK to sleep. Limit visitors to brief periods of perhaps 15-20 minutes.*

### **2. Sleeping**

Your loved one may spend an increasing amount of time sleeping and may become unresponsive. At times it may become difficult to arouse him or her. This is due, in part, to changes in the metabolism of the body. Hearing is said to be the last of the five senses to be lost. Hearing may still remain very acute although the person may appear asleep.

#### ***How to respond***

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*Be available for whatever short periods they are awake. Sit with your loved one; gently hold his or her hand. Speak softly, naturally and reassuringly. Do not say anything in their presence that you would not say to them when they are fully awake.*

### **3. Change in Intake of Food and Fluids**

As your loved one's health declines, there will be little interest in eating and drinking. The reflexes needed to swallow may be sluggish.

#### ***How to respond***

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*Allow them to eat and drink whatever may be appetizing. Do not force them to eat as it may result in choking or aspiration. Remember that any nourishment should be taken slowly and in small amounts. Do not use a straw for fluids as it can also lead to aspiration. When they can no longer eat you may try offering them small chips of ice or popsicles. The use of oral swabs or sponges can be helpful.*

### **4. Restlessness and Disorientation**

Your loved one may make restless and repetitive motions, such as picking or pulling at sheets or clothing. Your loved one may seem confused about time, place and identity of people around them including close relatives and friends.

#### ***How to respond***

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*Talk calmly and reassuringly with your loved one so as not to startle or frighten him or her further. Lightly massaging the hand/forehead, reading aloud to the person, or playing soft music can also have a calming effect. Do not try to restrain such motions unless you become concerned for their safety, such as falling out of bed. If you become concerned, speak with your hospice nurse.*

### **5. Incontinence**

Your loved one may lose control of urine and/or bowel movements as their health declines and the muscles begin to relax. Just as food and fluid intake decreases, expect that urine output will decrease, becoming more concentrated and may become darker like the color of tea. This is due in part to decreased fluid intake and to

a lessening of circulation through the kidneys.

***How to respond***

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*Make every effort to keep them clean and dry. The hospice nurse may suggest that a foley catheter be inserted. Diapers or Chux pads may be helpful to protect the bed and assist in keeping your loved one comfortable.*

**6. Breathing Pattern Changes**

Your loved one's usual breathing patterns may change. Breathing may become shallow, irregular, fast or abnormally slow. They may develop a pattern of breathing irregularly with shallow respiration or periods of no breaths for 5 to 30 seconds, followed by a deep breath. They may also have periods of shallow and rapid panting. Sometimes there is a moaning-like sound on exhale. Be assured that this is not a sign of distress, but rather the sound of air passing over relaxed vocal chords.

***How to respond***

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*Elevating their head and/or turning them onto their side may help them feel more comfortable. Contact your nurse to explore the need for changes in medication to provide comfort.*

**7. Congestion**

Oral secretions may become more profuse and collect in the back of the throat. Your loved one may develop gurgling sounds coming from the chest. These sounds can become loud and distressing to hear. These normal changes come from fluid imbalance and an inability to cough up normal secretions. Although distressing to those present, these secretions do not cause discomfort to the patient.

***How to respond***

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*It may be helpful to raise the head of the bed or use pillows to raise the person's head so that the secretions will not pool and stimulate a gag reflex. You may try turning their head to the side and allow gravity to drain the congestion. You can also gently*

*wipe the mouth with a moist cloth. The hospice team may start medications to control the congestion.*

**8. Circulation Changes**

Due to changes in circulation, your loved one's arms and legs may become discolored and feel cold or hot to the touch. This may be especially noticeable in the extremities where the color may change to a shade of blue. This is normal and an indication that the circulatory system is drawing blood away from the extremities and towards the core to support the most vital organs. Irregular temperatures can be the result of the brain sending unclear messages. Sweating may occur and there may be an odor resulting from the many physiological changes taking place in the body. The heartbeat and pulse may become slower, weaker or irregular.

***How to respond***

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*If they appear cold, take steps to keep your loved one warm, however, do not use an electric blanket. If the person continually removes the covers, cover them with a light sheet. If they feel flushed, use a cool washcloth on their forehead and under their armpits to cool them down.*

**9. Visions or Visitations from Deceased Relatives**

In a person's final days or weeks, it is not uncommon for them to speak or report having spoken to people who have already died. They may see visions of places not visible to you. These are commonly referred to as hallucination, and are sometimes attributed to oxygen deprivation to the brain or as a reaction to medication. However, their origin and meaning remains a mystery to medical science. These occurrences often signify that a person is detaching from this life and preparing for whatever may follow.

### ***How to respond***

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*Accept this as transitional time. There is no need to contradict, explain away, belittle or argue about what your loved one claims to see or hear. Listen with respect to whatever the person has to say; allow free expression of feelings and offer comfort through touching and/or talking reassuringly and calmly.*

### **10. Permission to Go, Saying Goodbye**

It is also common to see a dying person trying to “hold on” even though it brings prolonged discomfort. It seems that they are often waiting for reassurance that those left behind will be all right. A family’s ability to give their loved one permission to “go” is sometimes a final gift of great love.

### ***How to respond***

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*You may want to reassure your loved one that it is okay for them to go. Tell them that everyone loves them and will miss them but that those who remain will be alright. Reassure them of your love and give them permission to let go.*

*Tears are a normal and natural part of saying good-bye, and should be allowed to be expressed freely and without apology. Tears often express more eloquently than words about the love that endures.*

### **11. At the Time of Death**

When someone enters their final moments, their body begins the process of shutting down, which ends when all the physical systems ceasing to function. The series of physical changes described here are a normal part of the dying process and are not medical emergencies that require invasive interventions.

It may be helpful for family members to discuss ahead of time what to do when the final moments arrive. At the time of death: breathing ceases, heartbeat ceases, the person cannot be aroused. The eye lids may be partially open with the eyes in a fixed stare, the mouth may fall open as the jaw relaxes, there is sometimes a release of bowel and bladder contents as the body relaxes.

### ***How to respond***

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*Honor and express your emotions. Attend to your spiritual needs. Comfort one another. Refer to the information on the following page to help guide you as to how to proceed.*