

## Caregiver Resources

### Nutrition & Hydration Tips

#### Nutrition and Hydration in End of Life Care

For centuries, food and drink have played a significant role in socialization within our society. We typically associate food and drink with pleasurable activities, such as birthday parties, holiday meals, or tailgating at our favorite football games. In our minds, food and drink symbolize caring, love and happiness.

The biological reason we eat is to provide our bodies with nutrients to promote good health and provide energy. But, when a body is no longer healthy, nutritional requirements dramatically change. The body of a person who has a life-limiting illness is in the process of shutting down. They no longer require a great deal of nutrients or calories to convert to energy and therefore, their appetite or desire for food diminishes. The person at the end of life does not experience hunger or thirst in the way a healthy person does. This is an expected and normal process and is nature's way of protecting the body.

The loss of a loved one's appetite may be one of the most difficult symptoms that hospice families experience. It is commonly feared that your loved one will "starve to death" or become dehydrated and you may fear that your loved one will suffer. In fact, the opposite is true. If a person with a life-limiting illness in the later stages of their disease is forced to eat or drink when they do not feel the need to do so, they may experience physical symptoms that can cause more discomfort or complications.

Complications such as bloating or an uncomfortable fullness can occur. This can lead to nausea and vomiting, diarrhea and/or constipation. They can experience gastric reflux (severe indigestion) and in extreme cases, it can cause someone to aspirate. Aspiration is when fluids or food are inhaled into the lungs. Even the introduction of IV fluids at this late stage of life can cause complications such as edema, which is swelling within the tissues, as well as "fluid overload". Fluid overload can cause many distressing symptoms.

The loss of appetite and thirst is a natural process by which the body begins to prepare itself for death. That's why we would strongly suggest your loved one be allowed to determine what, how much and how often they choose to eat or drink. Food and fluids should neither be actively forced nor actively withheld. Their bodies will tell them what they need and when they need it. Occasionally, your loved one may have a craving or request a particular food or drink. Generally speaking, it is fine to honor these requests unless there have been severe restrictions placed on your loved one's diet. If you are not sure about a specific item, please call your hospice nurse for verification before providing the requested food or beverage.

If you have any questions or would like further clarification, please don't hesitate to call your hospice nurse. Hospice of Natchitoches nurses are available to you 24 hours a day, 7 days a week.

### Caregiving Tips and Resources

#### 6 Simple Tips to Maintain Your Well-Being

Your loved one is your main concern right now, and it will not help them if you become sick. For this reason, you need to take care of yourself. The following are ideas to help you stay well:

1. Eat three meals a day. It may be hard to eat if your loved one cannot, but remind yourself of why you need to eat...to stay strong.
2. Get adequate rest. Some chores might not get done or there may be someone who would help if you let them know how. Can someone else shop for groceries or sweep up? Things probably won't be done perfectly now, anyway, so let others help.
3. Get outside for a few minutes every day. Twenty minutes in the fresh air will do wonders for your mood. Even better if someone goes with you. You will return to your loved one refreshed.
4. Talk honestly about how you are feeling. Good or bad, it helps to let some other person know what you are thinking and feeling. Choose wisely. It needs to be someone who is not critical of you. Support is what you need now.
5. Find some type of recreation. If you have a hobby, try to get to it at least twice a week. See a movie. Bowl. Golf. Do something different if you can.
6. There may be times when continuing in the same way is not possible. Ask your Crossroads team about respite care for your loved one.

#### Invaluable Resources for Caregivers

Being a caregiver is a difficult job, indeed. Whether it is your mom, dad, brother, sister, neighbor, or even your child, a serious illness or chronic condition can require all of your attention, energy, love and patience. The following websites can help you find more information and resources to make your role as a caregiver more manageable.

1. [SeriousIllness.org](http://SeriousIllness.org) is a FREE one-stop online resource to help caregivers find what they need. It provides information like:

- Local resources for support groups, transportation, nutrition and more
- Caregiving tips
- Advanced directive resources
- Finances and estate planning
- Medical concerns and health resources

[www.seriousillness.org/crossroads/](http://www.seriousillness.org/crossroads/)

2. [CaringInfo.org](http://CaringInfo.org) is another great one-stop resource to find information about issues like home safety, pain management, talking with a child about his or her illness and much more. [www.caringinfo.org](http://www.caringinfo.org)



3. CaringBridge.org offers free patient websites to help loved ones share information and support throughout serious health events, care and recovery. It is extremely easy to set up and use; and it will automatically notify family and friends each time you post new information. [www.caringbridge.org](http://www.caringbridge.org)



## Physical & Emotional Changes

### A Guide to Understanding the Process.

We created these guidelines to help caregivers better understand the physical signs associated with the process of the body shutting down as well as the emotional and spiritual changes taking place.

The following describes the physical symptoms you may observe:

#### Physical Changes and Helpful Tips:

1. **Coolness.** Hands, arms, feet, and legs may be increasingly cool to the touch. The color of the skin may change and become mottled. How you can help: Keep the person warm with comfortable, soft blankets.
2. **Sleeping.** An increasing amount of time may be spent sleeping. The person may become uncommunicative, unresponsive, and difficult to arouse. How you can help: Sit quietly with them. Speak in a normal voice. Hold their hand. Assume they can hear everything you say. They probably can.
3. **Confusion.** They may not know time or place and may not be able to identify people around them. How you can help: Identify yourself by name before you speak. Speak normally, clearly, and truthfully. Explain things such as, "It's time to take your medicine now." Explain the reason for things, such as, "So you won't start to hurt."
4. **Incontinence.** They may lose control of urinary/bowel functions. How you can help: Keep your loved one clean and comfortable. Ask your hospice nurse for advice.
5. **Restlessness.** The person may make repetitive motions such as pulling at the bed linen or clothing. This is due in part to decrease in oxygen. How you can help: Do not interfere with these movements or try to restrain them. Speak in a quiet, natural way. Lightly massage their forehead. Read to them. Play soothing music.
6. **Fluid and food decrease.** Your loved one may want little or no food or fluid. The body will naturally conserve energy required for the task ahead. Food is no longer needed. How you can help: Do not force them to eat or drink if they don't want to. It only makes them more uncomfortable. Small chips of ice or frozen juice chips might be refreshing. A cool, moist cloth on their forehead might help.
7. **Congestion.** There may be gurgling sounds inside the chest. These may be loud. This sound does not indicate the onset of severe pain. How you can help: Gently turn their head to the side to drain secretions. Gently wipe their mouth with a moist cloth.
8. **Urine decrease.** Output may decrease and become tea colored. How you can help: Consult your hospice nurse.
9. **Change in breathing.** The person may take shallow breaths with periods of no breathing for a few seconds to a minute. They may experience periods of rapid, shallow panting. These patterns are common and indicate decrease in circulation. How you can help: Elevating their head or turning them on their side may bring comfort. Hold their hand. Speak gently.
10. **Fever.** Increase in temperature is common. How you can help: Consult your hospice nurse. A cool, moist cloth on their forehead may bring comfort.

As the physical changes occur your loved one is completing important work on another level. Emotional and spiritual changes may be manifested. The next section describes the appearance of these tasks.

#### Emotional and Spiritual Signs

1. **Giving away belongings and making funeral plans.** Some people want to maintain control over their life, so they want to participate in making final decisions about their belongings or their person. How you can help: Although it is emotionally hard for families to talk about final arrangements, it is important to let your loved one do this if they want. Everyone, especially the dying, appreciate having their choices honored.
2. **Withdrawal.** The person may seem unresponsive, withdrawn, in a comatose-like state. They are detaching. This is a letting go of earthly things and earthly relationships. How you can help: Know that hearing remains. Speak in a normal voice. Identify yourself. Hold their hand. Say what you need to say. This helps them let go.
3. **Vision-like experiences.** The person may say they have spoken to people who are already deceased. They may say they have been places or seen things not visible to you. This is not hallucination or a drug reaction. It is common. How you can help: Do not contradict, explain away, or discount this experience. Affirm them. If the experience seems to frighten your loved one, reassure them it is common and that they are normal: "Yes, these things happen."
4. **Restlessness.** Repetitive and restless tasks may indicate something unsolved or unfinished is preventing them from letting go. How you can help: Talk with your hospice chaplain. Help the person recall a favorite place or good experience. Read to them. Play soothing music. Give reassurance that it is okay to let go.
5. **Unusual communication with or withdrawing from others.** Your loved one may make statements or requests that seem out of character. They may be testing you to see if you are ready to let go. They may want to be with only a few select people. Maybe they only want one person. If you are not included, it does not mean you are not important or not loved. It means your task with the person is fulfilled. If you are selected, it may mean the person needs your affirmation, support, and permission to let go. How you can help: Let your loved one know you will be alright. Say whatever words of love and support you need to say. Give them permission.
6. **They say goodbye.** This is their final gift. How you can help: Listen. Hold them. Say whatever you need to say. It may be just, "I love you," or recounting favorite memories you have shared. It may be an apology, or saying, "Thank you." There is no need to hide your tears. Tears express your love and help you let go. Remember, all these signs and symptoms are common. Your loved one may be as unique during this time as they have always been, so they may show some of these signs and not others. Or they may be different altogether. These signs and symptoms are just guides to help you understand what is common. With this in mind, the following summary might be helpful:

Summary Time-line:

#### One to Three Months

- Decreased desire for food
- Increased desire for sleep
- Withdrawal from people and the environment

**One to Two Weeks**

- Even more sleep
- Confusion
- Restlessness
- Vision-like experiences
- Change in temperature, respiration, pulse, and blood pressure
- Congestion
- Not eating

**Days or Hours**

- Surge of energy
- Decreased blood pressure
- Glassy, teary eyes
- Half-opened eyes
- Irregular breathing
- Increased restlessness
- Cold, purple, blotchy feet and hands
- Weak pulse
- Decreased urine output

**Minutes**

- Gasping breathing
- No awakening

**How you will know death has occurred?**

Dying may take hours or days. No one can predict the time of death, even if the person is exhibiting the signs and symptoms. This can sometimes cause fatigue and confusion; and although you may be prepared for the dying process, you may not be prepared for the actual death moment. It may be helpful for you and your family to discuss just what you would do at that moment.