



SAFE PASSAGE

Decisions About Artificial Foods and Fluids

Kansas City Hospice & Palliative Care  NorthCare Hospice
A Subsidiary of Kansas City Hospice & Palliative Care

Providing food and drink is one way we nurture those we love. But when the body is shutting down, the usual amount of food and fluid may not be needed or helpful. This is a natural part of the process and may be the body's way of making sure it takes in only as much food as it can handle. Often, this is distressing to caregivers.

Based on the experience of our hospice and palliative care professionals, let's ask — and answer — some questions about food, fluid and nutrition for someone in hospice care.

■ *When does nutrition become a concern?*

Someone nearing the end of life may lose their appetite or ability to eat and drink for a number of reasons. Among them:

- ▶ As the disease progresses, the person has limited energy available. In the end stages of a disease, the process of eating, chewing and digesting food may take more energy than is available.
- ▶ As a person's systems slow down, the body is less able to process food and fluids. Forcing food or fluids can cause physical distress. Fluids may pool in the arms, legs or lungs. Problems such as edema (swelling of the body), lung congestion, nausea, diarrhea or infections may occur. Rather than providing a benefit, food or fluids may cause discomfort.
- ▶ Activity levels slow down as energy decreases, and some people are asleep more than they are awake. So the body doesn't require the same nutrition it once did.

- ▶ Disease progression can prevent someone from being able to eat because of difficulty swallowing, for instance, or blockage to the stomach.
- ▶ Some treatments and medications affect appetite and the taste of food.
- ▶ Mouth sores or poorly fitted dentures due to weight loss can make eating uncomfortable and difficult.

FREQUENTLY ASKED QUESTIONS ABOUT ARTIFICIAL FEEDING AND FLUIDS:

■ *Does artificial feeding prolong life?*

People with advanced disease do not necessarily live longer with artificial feeding and may, in fact, suffer more as a result of the feeding. Artificial feeding often brings complications. This is more likely if the illness is cancer, chronic lung disease, dementia, kidney failure, chronic heart disease or liver disease. Also, there is some evidence that cancer grows faster with extra nutrition. This may be because in late-stage cancer the nutrients may feed the tumor rather than the body. Artificial feeding is most likely to extend life for patients with neurological disorders such as stroke or coma.

■ *If people don't eat, will they die of starvation?*

People who stop eating because they have end-stage disease die of their illness, not a lack of food. They can live for months on a few bites of food and a few sips of fluid a day.

■ *Without nutrition, will the patient suffer more?*

When the body no longer needs nutrition, there seems to be a mechanism that turns off the appetite and the desire for food. The body compensates for the lack of food by producing a chemical that acts as a buffer, preventing the hunger healthy people would experience if they stopped eating.

■ *Does dehydration cause suffering?*

Although dehydration can be a serious condition in a healthy person, in the end stages of life the body simply can't process all of those fluids. Many people are more comfortable when the body doesn't struggle with fluid overload. Ice chips and drops of water can help a dry mouth or feeling thirsty. Mouth swabs to help clean and moisten the mouth can be helpful. Putting fluids into an IV will not prevent a dry mouth and may cause fluid overload.

■ *Is artificial feeding just like eating?*

Artificial feeding is different from eating and drinking. When someone has a feeding tube in the stomach, the pleasure of eating, which comes from the flavor of the food and from sharing a meal, is lost. Many people are upset by having to be hooked up to a machine or by change in the body image. Also, when food and fluids are given through a stomach tube or into an IV, the body cannot control the amount of intake. This

can lead to problems with excess fluid in the system. Intravenous feeding requires close monitoring through blood tests and can lead to bloodstream infections.

■ *Will my loved one be stronger if fed artificially?*

Patients are rarely stronger if they receive artificial feeding or fluids.

■ *Will tube feeding prevent pneumonia in people who have swallowing problems?*

People who receive their feeding through a tube into the stomach are still at risk for pneumonia. Sometimes the feeding solution travels back up the esophagus and goes into the lungs. This is called *aspiration* and is often the cause of pneumonia.

Allow your loved one the right to make choices about food and liquids.

■ *Can someone who has difficulty swallowing eat safely by mouth?*

Yes. Many people who have some difficulty swallowing can handle small amounts of food or fluid at a time, although they may need to limit the diet to soft or pureed foods and thickened liquids.

■ *Will tube feeding prevent bedsores and other problems associated with malnutrition?*

Tube feeding has not been shown to prevent bedsores. In people with advanced disease, tube feeding has not been found to help with healing wounds.

■ *Is it legal to let people refuse a feeding tube or IV if they can't eat?*

Yes. Patients or the Durable Power of Attorney for Health Care have the ethical and legal right to refuse any treatment, including artificial feeding and intravenous hydration. These are medical interventions that people may not want. It is very important to discuss options early in the disease process, well before these decisions may become necessary.

BEFORE MAKING A DECISION TO BEGIN ARTIFICIAL NUTRITION, WHAT FACTORS SHOULD BE CONSIDERED?

- ▶ There should be a clear understanding of what the goal of artificial feeding is and the likelihood that this goal will be accomplished.
- ▶ Each person's wishes should be honored. If your loved one is unable to speak, his or her wishes may have been documented in an advance directive. Risks and potential side effects should be weighed against the expected benefit.

Be encouraging and accepting of the amount of food the person feels like eating.

WHAT CAN YOU DO TO ENCOURAGE EATING WITHOUT MAKING THE PERSON FEEL PRESSURED?

- ▶ Prepare small portions of foods the person usually enjoys, and offer these throughout the day instead of at traditional meal times. A large plate of food may overwhelm them, and that may deter your loved one from even trying.



- ▶ Be encouraging and accepting of the amount of food the person feels like eating. Don't try to bargain to have them eat just one more bite. The body is saying what the limit is, and eating just to please you may cause discomfort and offset any benefit or pleasure received from the small amount of food eaten.
- ▶ Find out what sounds good and keep a variety of easy-to-prepare snacks on hand.
- ▶ As appetite declines, people will tolerate only small amounts of food. Liquid nutritional supplements are one option. Some people enjoy the taste, and caregivers sometimes feel better when they know the person is taking in something nutritional.
- ▶ Keep the lips and mouth fresh, clean and moist between meals. Your hospice staff can recommend what to use.
- ▶ Provide an appealing setting for meals, away from the "sick room" if they are able to move. Avoid unpleasant smells in the room.
- ▶ Make every calorie count. Encourage them to have snacks that are high in calories and nutrition such as ice cream, pudding and milk shakes.
- ▶ Remember that thickened liquids, such as pudding, cottage cheese and creamy soup can be easier to

swallow than thin liquids, such as water or juice. Ask your nurse about powders to thicken liquids and ease swallowing.

HOW CAN YOU BEST SUPPORT YOUR LOVED ONE?

- ▶ Realize that the body is taking in the proper amount of food and fluids for its changing needs and that artificial feeding or fluids may create more distressing problems.
- ▶ Be assured that if you are offering food and liquids and it's clear the person doesn't want them, then there is nothing for you to feel bad about.
- ▶ Allow your loved one the right to make choices about food and liquids, and honor their wishes.
- ▶ Don't take rejection of the food as rejection of your love. Instead of spending a lot of time and energy on trying to find foods that please, spend time on more rewarding pursuits. Read, give a massage, talk about memories or simply provide a caring and nurturing environment.

Kansas City Hospice & Palliative Care



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We are a not-for-profit organization offering a range of services for people of all ages and at all stages of serious illness.

Our programs include:

- ▶ **Advanced Illness Support** — in-home consultation services to help guide you through complex healthcare systems and medical decisions
- ▶ **Kansas City Palliative Home Care** — supportive care for people at any stage of serious illness, offered at home before the need for hospice
- ▶ **Kansas City Hospice** — comfort, care and compassion at home or in a nursing home
- ▶ **NorthCare Hospice** — home care and nursing home hospice care in the Northland
- ▶ **Carousel** — care for seriously ill children
- ▶ **Kansas City Hospice House™** — inpatient care in the comfort of a homelike setting
- ▶ **NorthCare Hospice House** — compassionate inpatient care in the Northland
- ▶ **Solace House** — a center for grief and healing offering a nurturing place for children and adults following a death

For more information or to schedule a complimentary assessment to see if one of our programs may be helpful to you, call:

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