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Kansas City Hospice
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SAFE PASSAGE

Decisions About Artificial Foods and Fluids



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KANSAS CITY HOSPICE & PALLIATIVE CARE

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Important Decisions as Nutritional Needs Change

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. At this time, decisions about whether to provide artificial feeding or IV fluid may be necessary.

At Kansas City Hospice & Palliative Care, we understand that these can be difficult decisions to make. We hope the information in this booklet will help you increase your knowledge about food, fluid and nutrition issues, which are so important to the care and comfort of your loved one. This booklet explains how a person's ability to eat or drink can change with serious illness and options to address these changes. Your Kansas City Hospice & Palliative Care team also is able to provide support, offer additional information and answer your questions. Your team is just a phone call away.

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WHEN NUTRITION BECOMES A CONCERN

Most people who are terminally ill gradually lose their appetite and are not interested in food. This is part of the disease process and may be the body's natural way of making sure that it takes in only the amount of food it can handle. Often, this is very distressing to caregivers because we know intuitively that you must eat to survive and to feel well. However, it is very normal for a seriously ill person to lose interest in food.

Someone who is nearing the end of life may lose his or her appetite or ability to eat and drink for a number of reasons.

- As the disease progresses, the patient has a limited amount of energy available each day. We have to expend energy to eat and digest food. In the end stages of a disease, the process of eating, chewing and digesting food requires more energy than is available.
- As the body's internal systems slow down, it is less able to process food and fluids. Forcing food or fluids into a body that is saying, "I don't want food or fluids" can cause physical distress. Because the body can't process the fluids adequately, it tends to pool in the arms, legs or lungs. Problems such as edema (swelling of the body), lung congestion, nausea, diarrhea or infections may occur. Therefore, rather than providing a benefit, food or fluids may cause discomfort.
- Activity levels slow down as energy decreases, and some patients are asleep more than they are awake. The body simply doesn't require the same nutrition it once did when the patient was more active.

- Disease progression can affect an area of the body associated with eating, preventing someone from being able to eat (i.e., difficulty swallowing, blockage to the stomach, etc.).
- 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

Q. Does artificial feeding prolong life?

A. Patients with advanced disease do not necessarily live longer with artificial feeding and may, in fact, suffer more as a result of the feeding. Artificially feeding the body often brings medical complications. This is more likely to be true if the illness is cancer, chronic lung disease, dementia, kidney failure, chronic heart disease or cirrhosis. Additionally, there is some evidence that cancer grows faster with extra nutrition. This is possibly because, in late-stage disease, 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.

Q. If the patient doesn't eat, will he die of starvation?

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

Q. Without nutrition, will the patient suffer more?

A. When the body no longer needs or benefits from the nutrition being offered, there seems to be a mechanism that turns off the appetite and the desire for food. At the same time, the body seems to compensate 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.

Q. Does dehydration cause suffering?

A. Although dehydration can be a serious condition in a healthy person, we have learned that in the end stages of life the body simply can't process all of those fluids. Research has shown that many patients are actually more comfortable when the body does not have to struggle with fluid overload. If a patient has a dry mouth or feels thirsty, ice chips and drops of water can address those symptoms to keep the patient comfortable. 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.

Q. Is artificial feeding just like eating, but the nutrition is given another way?

A. Artificial feeding differs from eating and drinking in many ways, and should not be considered natural. When patients have a feeding tube in their stomachs, they lose the pleasure of eating. The pleasure of eating comes from the flavor of the food and from sharing a meal,

neither of which occurs with tube feedings. Many patients are distressed by the change in their body image or by having to be hooked up to a machine. In addition, when food and fluids are given through a stomach tube or into an IV, the body cannot regulate the amount of intake relative to the amount it can handle. This can lead to problems with excess fluid in the system. Intravenous feeding requires very close monitoring through blood tests and can lead to bloodstream infections.

Q. Will my loved one be stronger if she is fed artificially?

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

Q. Will tube feeding prevent pneumonia in patients who have swallowing problems?

A. Patients who receive their feeding through a tube into the stomach still are 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.

Q. Can someone who has difficulty swallowing eat safely by mouth?

A. Yes. Many patients who have some difficulty swallowing can tolerate 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.

Q. Will tube feeding prevent bedsores and other problems associated with malnutrition?

A. Tube feeding has not been shown to prevent bedsores, and having a tube may make it harder for the patient to move around, causing more risk of bedsores.

Q. Is it legal to let patients refuse a feeding tube or IV if they can't eat?

A. 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.

WEIGHING THE BENEFITS AND BURDENS

Before making a decision to begin artificial nutrition, many 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.
- The patient's wishes should be honored. If your loved one is unable to speak for him or herself, his or her wishes may have been documented in an advance directive. The risks and potential side effects should be weighed against the overall benefit expected from this decision.

PRACTICAL TIPS

There are several easy things you can do to gently encourage eating without making the patient feel pressured to eat.

- Prepare very small portions of foods the patient usually enjoys, and offer these snack-size meals throughout the day instead of the traditional three meals a day. Seeing a large plate filled with food may overwhelm the patient, making it seem impossible to eat everything at once, which may deter your loved one from even trying.
- Be encouraging and accepting of the amount of food the patient feels like eating. Don't try to bargain to have the patient eat just one more bite. The body is saying what the limit is, and eating just to please you may cause discomfort and negate any benefits or pleasure received from the small amount of food eaten.
- Find out from the patient what sounds good and keep a variety of easy to prepare snacks on hand (pudding, Jell-O, etc.).
- As appetite declines, the patient will tolerate only small amounts of food. Liquid nutritional supplements are one option. Some patients enjoy the taste, and caregivers sometimes feel better when they know the patient is taking in something with nutritional value.
- Keep the mouth fresh and clean between meals.
- Provide an appealing setting for meals, away from the "sick room" if the patient is able to move. Avoid unpleasant smells in the room.
- Make every calorie count. Encourage the patient to have snacks that are high in calories and nutrition (ice cream, pudding, milk shakes, etc.).

SUPPORTING YOUR LOVED ONE

Eating and drinking are basic human pleasures and are vital to life for healthy people. When someone is nearing the end of life

and loses interest in eating and drinking, it's often very upsetting to caregivers. It may help to 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.

It also is common for caregivers to feel bad if they aren't feeding their loved one, even if their loved one doesn't show interest in food. Be assured that if you are offering food and liquids and it's clear the patient doesn't want them, then there is nothing for you to feel bad about. Your loved one is responding to the messages from the body about nutritional needs.

It is important to allow your loved one the right to make choices about food and liquids and to honor his or her wishes. Continue to offer your loved one food and liquids you think he or she may enjoy, but refrain from forcing the issue.

Feeding someone is how we show caring, and eating is often at the center of our social interactions. Sometimes it feels that rejection of the food is rejection of our love, especially if we have spent hours preparing a special meal to try to encourage our loved one to eat. Much time and energy can go into trying to find foods that please. Often, that time is better spent on more rewarding pursuits. To show your loved one that you care, you can do other things to help, such as reading, giving a massage, talking about memories, or simply providing a caring and nurturing environment.

ABOUT KANSAS CITY HOSPICE & PALLIATIVE CARE

Kansas City Hospice & Palliative Care is a nonprofit organization offering a range of services for people of all ages and at any stage of serious illness. Since 1980, we've been enhancing life for the seriously ill and their families in the greater Kansas City area.

Our programs include

- Kansas City Hospice, providing comfort and care at home or in a nursing home.
- Palliative Home Care, comfort care for people pursuing curative treatments.
- Carousel, pediatric palliative care.
- Kansas City Palliative Medicine, full-time physicians specializing in comfort care and symptom management.
- Kansas City Hospice House, an inpatient facility offering expert medical and nursing care 24 hours a day in the comfort of a homelike setting.
- Passages, counseling and resources for difficult transitions in life.

For more information or to schedule a free assessment to see if one of our programs may be helpful to you, call Kansas City Hospice & Palliative Care at 816-363-2600.

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