# Understanding and Managing Nutritional Needs at End of Life



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# **INTRODUCTION**

## **Managing Nutrition and Promoting Comfort**

Feeding our children is a cornerstone of parenting, and when the need for medical intervention arises the instincts of parents are tested. The information in this guide is intended to help in one part of that journey: working with the medical team to manage your child's nutritional needs, especially at the end of your child's life journey.





## **Understanding Nutritional Needs**

Many children benefit from the use of a feeding tube to give nutrition, fluid, and medications, often over many years. However, there is a difference between feeding throughout life, and the use of artificial fluids and nutrition that are not tolerated as the body slows down.

There can be times in the child's life when discomfort or vomiting is a result of feeds that exceed the energy needs of the child. Much more difficult to contemplate are symptoms at the end of life—symptoms that suggest that what has been working may now be doing more harm than good.

A trial that involves decreasing or holding medical fluids can be safe to try and useful information can be gained. A peaceful death takes planning. Planning for comfort at the end of life is not about giving up, but about protecting from increasing harm. The challenge for families and physicians is determining when that time has come.

When a feeding tube is first placed, the worry is often that the child is not receiving enough nutrition and fluid. Later, there may be a need to decrease feeds so as to avoid excessive weight gain, or when there is vomiting or gut pain because the child is receiving a higher volume of formula than the body needs and can tolerate. Basically, as the body moves and spends less, it needs less energy. Children who expend the least energy—who have limited movement of their arms and legs a low baseline body temperature (a temperature that may at times be under 95° F), or who move less as decline in health results in decreased activity—are at greatest risk of being overfed. Further information can be found at https://www.mdpi.com/2227-9067/5/1/1

Decreasing or discontinuing medical fluid and nutrition can be one of the most important steps you and your child's medical team can take to improve comfort in the last days, weeks, or months of your child's life. This information will never replace the supportive presence of experts in palliative care and hospice, along with other members of your child's medical team. With emotional support and relevant details, a parent can feel more settled about decisions, even when they will never feel good about the reason for the decision.



### **Changes at End of Life**

Parents often say that it is important that their child is comfortable at the end of life. Being aware of these features can help you manage the amount of fluid and feeds to what your child can tolerate, helping to avoid discomfort and distress.

#### Intestinal and Abdominal Changes

In the days, weeks, and months leading up to end of life, a child is often less active, resulting in a decrease in energy expended and calories needed. In some children, there can also be a gradual or abrupt change in the ability of the intestines to move content forward (motility of the gut), which can present with a swollen abdomen (distention of the belly). The small blood vessels throughout the body can also become leaky, with fluid then shifting into other tissue spaces. These changes can result in vomiting, fluid in the lungs (pulmonary edema), and fluid in the skin that causes puffiness (peripheral edema). These problems can result in discomfort and respiratory distress for a child. In some children, abdominal distention or edema can be the first features to suggest that a child is at end of life.

Abdominal swelling or distention due to slowing of the intestines can also be triggered by a new illness, or occur intermittently due to a change in the motility of the intestines. History and tests can determine if new problems, such as respiratory illness or bladder infection, have triggered the change. Return of intestinal movement/motility is expected after treatment of the identified problem. Sometimes slowing of the intestines is a temporary change without a defined reason, with a return to formula by feeding tube. In contrast, slowing or shutting down of the intestines may persist as a result of declining health and when there are changes in the areas of the brain that regulate the movement of the intestines (intestinal motility).

#### Edema (Swelling)

Edema can occur as fluid in the blood vessels leaks into other tissue spaces in the body. This can be noted as hands, feet, and eyelids becoming puffy, and increased congestion as fluid leaks into the lungs. Edema can occur in some children at the end of life, as generalized inflammation causes changes in the body or due to changes in the area of the brain that regulates pressure in blood vessels (i.e., vasomotor tone). Both of these changes can cause fluid to leak out of the blood vessels.



### Managing Nutrition and Hydration: Questions you may ask your child's medical team, with information for consideration

#### What is the role of tests?

**Information:** Your child's story will guide you and the clinical team. Equally important are your family's goals and values. You may feel helpless as you worry about your child's medical problems. Having a say in how much testing, which interventions, and where your child will be may feel like areas in which you really do have some control.

At this point, you might also have a discussion about changes in your child's baseline and how you see their condition progressing. For example, tests are important when features suggest that there may be mechanical obstruction of the intestines that can be treated with surgery. On the other hand, there sometimes are reasons not to order tests. When your child's body is already in significant decline, the symptoms may be a sign of intestines shutting down. In this and certain other cases, a child might not even be able to tolerate surgery for an obstruction.

There can also be a tipping point when it makes sense not to order or repeat tests. First, it might make sense not to obtain tests if your child must be brought to a hospital Emergency Department. Second, if a similar feature has been seen before and the tests results at the time were normal, it is unlikely that the repeat tests will be different. These can be reasons to protect your child from more tests and the need to be brought to another location.

These are difficult conversations to have and decisions to make. A palliative care specialist can be very helpful as you work your way through them.

#### How do I know what the symptoms mean?

**Information:** Ileus or edema is more likely to persist and suggest the onset of end of life when there is the following:

- Your child's history includes decline in physical function (e.g., amount of daily energy to participate in activities, loss in physical abilities, increased sleeping) and decline in health (e.g., decline in respiratory health, such as not having as many weeks or months between each illness or not returning to the same baseline)
- Test results in the past have been normal at a time of seeing these features
- Blood and urine tests obtained now are normal
- A problem (e.g., a bladder infection) was identified, yet the features persist or return following treatment
- There are minimal to no bowel sounds on examination



In these cases, tests can be considered but are not required. Tests identify problems that can be treated and addressed. They can indicate that a new problem has triggered slowing of the intestines or resulted in edema. Most of the problems can be identified by blood and urine tests, with results often available within hours. Tests can then indicate whether a problem such as a bladder infection or acute pancreatitis has caused the intestines to slow. These tests can also assess for new causes of edema, such as changes in kidney or liver function.

# • Will my child get dehydrated while we wait to see if the changes are temporary or permanent?

**Information:** This is not a worry when the child presents with acute abdominal distention due to ileus or present with edema. There are other times where there would be concern. To clarify:

- The amount of fluid and calories needed decreases as energy expenditure slows down. Decreasing calories and fluids helps avoid problems from excessive feeds at a time when it is unclear how things will go. Fluid needs can also be overestimated in children with a low metabolic rate, given that energy expenditure determines part of a child's fluid needs. It is naturally distressing to undo what has been considered the right amount, but in such instances less might be the better amount.
- Dehydration occurs when fluid output exceeds input. If distention and comfort improve, gradual increase in fluid can provide adequate hydration throughout the process.
- Experts must be available to adjust the plan as needed at any hour of the day or night, to provide support throughout this stressful time. In some communities, this can be done at home or in a hospice facility. In other areas, it is best done in the hospital. Even in the hospital, care can be given without tests or intravenous lines, if this is the approach to care that makes best sense to you and the medical team.

# • Will my child feel thirsty or hungry if we withhold fluids and feeds as they are nearing the end?

**Information:** The thought of stopping medical fluids and nutrition can understandably cause parents to worry that the child will starve or suffer from dehydration. The important thing to understand is that there are changes in the body at the end of life that prevent the dying individual from experiencing hunger or thirst as the body becomes unable to process nutrition and fluid. This change is likely due to the ketosis (a metabolic state that results in ketone bodies in the blood) that occurs when fluid and nutrition intake decreases significantly and is stopped. Ketosis results in an overall sense of well-being and a loss of appetite. Ketosis is sometimes described as feeling like a mild euphoria.



In addition, ketosis may lessen the risk of seizures at the end of life, based on the benefit of the ketogenic diet for seizure management. This natural process promotes comfort by avoiding excessive intake. The benefit of ketosis is lost when artificial nutrition such as glucose in IV fluids; medical fluid and nutrition by feeding tube or intravenous line, is resumed at this time; again, potentially causing more harm than benefit. A child with a feeding tube is at increased risk for problems when this natural process is not considered. Declining intake of fluid and nutrition is a process that can occur gradually over weeks to months, though in some it can occur more rapidly. There may be a brief period of improved comfort and interaction, at times also lasting for days to weeks, occasionally for several months.

## CONCLUSION

#### **A Complex Process That Challenges Our Values**

Decisions about managing nutrition and hydration, especially at the end of life, are loaded with all of the issues that come from our practice and beliefs that one of the ways we show love and care of our children is through how, and how well, we feed them. It can feel very unnatural to feed our children less or stop feeds altogether. You will not have to figure this out on your own. Experts in palliative care will support you and your decisions. If your medical team has not introduced you to a palliative care team, ask for one. These professionals are here to help you, and to help assure your child's comfort along the way.