

Understanding Nutritional Needs

with feeding tubes throughout illness and at the end of life

A guide provided by Julie Hauer, MD on recognizing the signs and symptoms related to overfeeding, underfeeding and how to work with your medical team to find the right balance.

- *risks of over-feeding in children with feeding tubes.*
- *signs of over-feeding as end of life is nearing*
- *concerns about underfeeding and lack of hydration at end of life*

Many children benefit from the use of a feeding tube to give nutrition, fluid, and medications, often over many years. The decision of placing a feeding tube is often met with many physical, emotional and logistical concerns for parents. Feeding our children is a cornerstone of parenting and when feeding is aided by medical intervention the instincts of parents are tested. **The information in this guide is intended to help in one part of that journey: lessening the harm that can come from excessive feeds and fluid at the end of your child's life journey.**

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 throughout 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 due to feeds and fluid that far exceed what the body can process as the body shuts down.

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. There are times to consider a trial that involves decreasing or holding medical fluids; this 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.

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. I wish this was easier, I wish there was a test to tell you when this is happening, and I wish you didn't need to worry. Your worry represents unconditional love for your child. I know 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. It is natural at

such times to experience doubt while having certainty in the decisions along the way. I am glad you have Courageous Parents Network as another tool to assist you in your child's journey.

Risk of over-feeding in children with feeding tubes

When a feeding tube is first placed, the worry is often over 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 that can be due to a higher volume of formula than the body needs and can tolerate. Children who expend the lowest energy are at risk for over-estimating calorie needs. This includes children with limited movement of their arms and legs, who have a low baseline body temperature (a temperature that may at times be under 95° F), and as decline in health results in decreased activity. Basically, as the body moves and spends less, it needs less energy. Further information can be found at <http://www.mdpi.com/2227-9067/5/1/1>.

Risk of over-feeding at the end of life

Another consideration, that can be distressing to consider, is the risk of over-feeding at the end of life as the body and intestines are slowing down. The goal of reviewing this difficult topic is to improve understanding and to lessen unnecessary problems at the end of life.

In the days, weeks, and months leading up to end of life, a child is often less active, resulting in a decrease in the energy expended and the 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 causing puffiness (peripheral edema). Such 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. These features can be temporary, though they can return again weeks to months later. Parents often say that it is important that their child is comfortable at the end of life. Awareness of these features can ensure a child's comfort by avoiding an amount of fluid and feeds that the body is unable to tolerate.

Abdominal distention/swelling due to ileus: a feature at the end of life

Sudden abdominal distention/swelling due to slowing of the intestines can 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 a new problem, such as respiratory illness or bladder infection, have triggered this 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). Abdominal swelling/distention and discomfort can occur when the same amount of fluid and nutrition is continued. A temporary decrease or holding of fluid and formula given by feeding tube can help the discomfort to decrease, while you and your child's care team consider what this might mean for your child.

Two stories of children who had similar situations and for whom I cared, "Emily" and Barry (whose mother has shared their story on Courageous Parents Network), may help you understand this information. Both children received nutrition and fluid by feeding tube due to impairment of the brain. Both started with the acute, sudden onset of significant abdominal distention, with both described as "the belly is so distended it looks pregnant." Management of the problem started with venting of the gastrostomy tube. A suppository or enema was given to promote a bowel movement. Both children had blood and urine tests in search of a new cause to treat, with tests negative. Formula feeds were held or suspended and medications continued until the distention decreased and comfort was maintained, 4 to 8 hours later. At this time, an electrolyte solution (i.e. Pedalyte) was started, first at a small volume of 20 ml/hour continuous by feeding tube. In "Emily" this was increased every 6 to 8 hours until she was at a rate of 80 ml/hour, and then eventually switched back to her regular formula feeds. This approach to care has now been part of Emily's care plan for 3 years, with these events occurring every 3 to 6 months.

For Barry, on the other hand, increasing the rate gradually from 20 ml/hour to 50 ml/hour resulted in the return of abdominal distention and discomfort. The fluid was held and this information reviewed by me with his mother. We discussed admitting Barry to the hospital as a place to provide fluids by an intravenous (IV) line and to obtain a CT scan of the abdomen. We also discussed how this could be managed without an IV and more tests, and why this might make sense. We acknowledged that the absence of bowel sounds indicated that the intestines had "shut down" and this function might not return. Fluid could be given into an IV while waiting to see if this function would return. We made the decision together not to take this approach. Our focus was on protecting Barry from more testing and interventions if this might be a time when the body and intestines were shutting down at the end of life. We also hoped that waiting for the distention to decrease and restarting Pedalyte could help Barry if this was a temporary event, while allowing him to be out of the hospital and avoiding more things being done to him. We also reflected that Barry had experienced decline in his function and health over the last several years along with intermittent features that could be due to changes in the brain. Discussion included: "I wonder if this change in intestinal function is part of the decline and changes we have seen in Barry over the years?" Ultimately, Barry's mother and I decided to focus on what Barry's body was telling us, instead of doing

mother and I reviewed each day. It also felt like the “right” decision that would best honor the comfort the family desired for Barry.

Edema at the end of life

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. This can occur in some children at the end of life due to generalized inflammation causing 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.

Will my child get dehydrated while we wait to see if this is temporary or permanent?

This is not a worry I have when children like Barry and Emily present with acute abdominal distention due to ileus or present with edema. There are other times when I would have this worry. To help understand, I will break this down into the following:

- *The amount of fluid and calories needed decreases as energy expenditure slows down*
To highlight an example, Barry had a 30% decrease in his calories and fluid at a time of a significant decline in his health and function. This was done to avoid problems due to excessive feeds at a time when it was unclear how he might do in the next few months. For the next 2 years, he maintained his weight within his goal range at this reduced amount. 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*
Emily, during the event described earlier, had 1200 ml (40 ounces) of fluid vented out of her feeding tube. She then had her feeds and fluids held for 8 hours until the distention and comfort improved. During this time she had no ongoing fluid loss. The gradual increase in fluid given by her feeding tube provided adequate hydration throughout this process. This likely reflected decreased fluid needs along with no ongoing fluid loss.

- *The need for experts to adjust the plan as needed at any hour of the day/night and to provide support throughout this stressful time*

It was necessary to adjust Emily and Barry’s care plan over days. This requires availability of a team to make these adjustments and support you throughout this

other areas this is best done in the hospital. When it is best to manage this in the hospital, this can be done without tests or intravenous lines, if this is the approach to care that makes best sense to you.

How will I know that this might not get better? And the role of tests.

Your child's story will be the information to guide you and the clinical team. Equally important are goals that are important to you. This can include you deciding what is important to you if your child may be transitioning to end of life, such as avoiding testing and invasive interventions, as well as deciding location of care. You may feel helpless as you worry about your child's medical problems. Determining such factors as testing, interventions and location of care for your child's care may feel like one part you have control over in your child's life.

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, similar to Barry, 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)
- Tests in the past have been normal at a time of seeing these features
- Blood and urine tests obtained now are normal
- A problem was identified, such as a bladder infection, yet the features persist or return following treatment
- There are minimal to no bowel sounds on examination

Tests can be considered but are not required. **Tests identify problems that can be treated and "fixed"**. Tests can identify when 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, tests with results often available within hours. Such tests can then identify if a problem such as a bladder infection or acute pancreatitis have caused the intestines to slow. Such tests can also assess for new causes of edema, such as changes in kidney or liver function. For both Emily and Barry, these tests were normal.

For both, a decision was made not to obtain an x-ray or CT scan of the abdomen. Such tests are important when features suggest a mechanical obstruction of the intestines that can be treated with surgery. For Emily, these tests were not obtained as previous x-rays and CT scan showed that her intestines were distended with no obstruction, a problem called ileus or intestinal pseudo-obstruction. And her assessment by nurses also identified no bowel sounds, a feature with ileus. In contrast, increased or "high-pitched" bowel sounds are features with mechanical obstruction. For Barry, there were other reasons not to order these tests: the identified decline in other parts of his body,

that he would not tolerate surgery if there was an obstruction.

There can also be a tipping point when it makes sense not to order or repeat any of these tests. First, it might make sense not to obtain tests if it requires your child to be

brought to the emergency department. Second, if a similar feature has been seen before and the same tests 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.

Will my child feel thirsty or hungry if we hold fluids and feeds?

The thought of stopping medical fluids and nutrition, as was done for Barry, can understandably cause people to worry that the child will starve or suffer from dehydration. The important thing to understand here is that there are changes in the body at the end of life that prevent a person, including a child, from experiencing hunger or thirst as the body becomes unable to process nutrition and fluid. Declining interest in food and fluid is a self-protective process at this time, resulting in a person naturally taking in less. 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. Adults have described ketosis as a “mild euphoria” when medical fluid and nutrition is no longer given at the end of life. 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 is resumed, including glucose in IV fluids; medical fluid and nutrition by feeding tube or intravenous line at this time can cause 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. When fluid and feeds are decreased or held, parents may notice a brief period of improved comfort and interaction, at times lasting for days to weeks, occasionally for several months.

This is complicated and loaded with all the issues that come from our practice and beliefs that one of the ways we show love and care of our children is through feeding 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 and hospice will support your decisions and assist you throughout this process.** They are here to help you and help with your child’s comfort along the way.

