

Making hard decisions about care

Critical choices about tube feedings and fluids

Not wanting to eat or drink is natural during the very end stages of life. It is hard to accept this. Food was the first thing we gave our child. Should it not also be the last? It is something we offer as a form of love. How can food not be part of “comfort?” But a time may come when the child will refuse all food and drink or be unable to hold the formula he may have had in tube feedings over many months or years. Part of planning the comfort and dignity of life, while dying, asks that we think about how long we push food. During active treatment we all tried hard to get those calories in whatever way we could. It is very hard, now, to consider not giving it.

Question: Won't my child suffer - be hungry, thirsty or even starve?

The body does not have the ability to digest food and has little use for it in the end phase of life. No amount of feeding changes this. All the evidence we have shows that changes in chemistry of the body turn the appetite off so that the person rejects food and does not feel thirsty.

Question: What is the harm in feeding and putting fluids into the body?

Maybe no harm – sometimes looking into what is needed for comfort will show that fluids will help calm a child that is upset and on edge.

But when there is no benefit, then you can ask yourself whether the tubes and IV needles are worth it. Maybe they irritate, make it hard to move. Is it worth the extra risk of infection? There is also a benefit of not having fluids in the body. There are fewer secretions collecting and so less coughing, less swelling, less vomiting. There is no longer food sitting undigested in the stomach causing gas pain and bloating. There is less risk of bowel blockage or constipation.

Question: Without nourishment, will my child die sooner than she otherwise would?

We don't know this. We do know that pushing food and drink when the body can no longer accept it, is not part of a calm and comfortable death.

We need to weigh the comforts and discomforts of feeding against our goal of the best quality of life and a gentle dying.

You will need to ask when to respond to the body's “No thank you” to food and drink and attend to the many other ways of loving that remain open.

This pamphlet is the result of a collaboration between
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