

Parenting a Dying Child

Loss of appetite

From the moment of birth, feeding becomes an important way for a parent to show love. For many, feeding their child is an act full of meaning. It represents caring for the health and life of the child. It represents giving pleasure or comfort to the child. But now, no amount of food will give life. You will need to think about food only in terms of the quality it adds or takes from the life. If feeding has been an important part of your parenting then changing your way of thinking about it will be hard for you.

We will all do the best we can to help your child take enough fluids and food to give the body what it needs at the time. But getting healthy children to eat a healthy diet can be a challenge. It is not worth the effort when there are no benefits for a child who feels sick and has very little energy to eat. Food becomes just another stress.

Parent voice:

My advice is let your child eat when and what he wants. Forget the Canada Food Guide!" P.S. The health professionals agree.

Signs that your child may not be enjoying food

- * complains that the food tastes "funny." Some drugs make food taste "tinny" or bitter or bad;
- * feels sick from the smell of many foods;
- * eats only one or two foods;
- * no longer wants even favourite foods or drinks;
- * finds chewing and swallowing too tiring after a mouthful or two;
- * chokes on food or drink;
- * children who are tube fed vomit or show signs of nausea. Their secretions may get thick, so breathing is noisy.

Consider how to respond to your child's loss of appetite

- * **Consider whether there is any treatment that might enable the child to enjoy food again.**

Sometimes we can treat the cause of loss of appetite – mouth sores, nausea, depression, certain medications etc. Sometimes we can't, and sometimes the treatment does not add to the quality of life.

Consult with health professionals about this.

Pushing food or tube feedings that your child doesn't want, or that make him uncomfortable, adds no value to his days.

Be clear to all members of the family that eating and drinking is not going to be a battlefield. Food and drink are for your child's pleasure or comfort. If they give no pleasure or comfort, then take them away.

An example of treatment that may help your child enjoy food again: if your child experiences nausea at mealtimes, give an anti-nausea medication 1/2 hour before the meal.

* **Think about ways to make food a pleasure and eating fun**

- ♦ Make a new rule: no more mealtimes. We eat whenever we feel like it. Have a bell beside your child's bed. Tell your child "ring the bell whenever you want to eat."
- ♦ Keep a number of small meals or snacks ready in the fridge. Make a menu and invite your child to choose from it.
- ♦ Keep a jug of juice and different sized glasses beside the bed. Pour a little juice into a huge glass sometimes and fill a doll's size cup at another time.
- ♦ Have a picnic on the bed.
- ♦ Keep a lunch box with snacks at hand to nibble on all day. (Remember that a child who is nibbling all day is less likely to eat a meal.)
- ♦ Try different temperatures for the food. Food may taste better at room temperature or cold.
- ♦ Be aware that the texture of food is as important as taste.
- ♦ Make pretty plates of food, green peas, red tomato, white rice. Draw a face on the boiled egg.
- ♦ Give a little food at a time so the child can feel good about eating it all.
- ♦ Offer food that is easy to swallow (if swallowing is hard) and easy to digest.

* **Consider food supplements**

Carnation Instant Breakfast®, Boost®, Ensure® or Pediasure®. These forms of food provide a lot in a small quantity. They may be good for a child who is hungry but has no energy to eat. The nurse or dietitian can help you decide which is best for your child.

* **Think carefully before putting your child on a diet or food that claims to cure**

Honest, well-meaning friends, as well as some dishonest people, may suggest special diets. It is hard to resist stories of miracle cures which come from a variety of diets low in one thing or high in another. If there were a diet shown to be an effective treatment, your doctor would know of it and use it. If you would like to try a special diet treatment, please discuss it with your doctor or nurse.

Avoid threats, bribes or rewards – all these are pressure tactics!

* **Prevent thirst when the child starts to refuse all fluids**

- ♦ Keep the mouth clean and moist. (Refer to the handout Personal care & hygiene). This will be the best way to provide relief if he is thirsty but cannot drink.
- ♦ Offer ice chips or a popsicle to suck.
- ♦ If you are worried about your child suffering dehydration call your doctor or nurse.

Be ready to tell when and how much fluid your child last had and when she last urinated.

Parent voice:

I was worried about Jen being thirsty because she couldn't swallow well enough to drink. It was good to know that just keeping her mouth wet with the toothette dipped in diluted juice was preventing thirst. And that was something we could all do for her to the very end.

Note: Many parents worry about thirst and dehydration. Keeping the mouth moist is as effective as drinking when a person is thirsty and approaching death.

* **Make a plan with the doctor or nurse for when your child is not willing to eat or drink.**

The body turns against food as a natural part of shutting down when it can no longer absorb or use it. Giving the food can cause pain and discomfort. It takes quality out of what is left of life. (See the handout Critical choices about feeding/fluids.)

Children who are tube fed may also become less able to absorb feeds. Instead of adding quality to their life, the feed will start to cause discomfort. You can try adjusting the feeds by diluting or reducing, as you may have in the past. You can talk with the doctor about medications or a change in formula. However, in the end stages of life your tube fed child will want less and less – maybe only a few mls an hour.

End note:

Remember to keep struggling against the idea that food will sustain life. Food can give pleasure; food can give pain. Concentrate on comfort, not calories, for your child. Trust the body to know what is best at this stage.

Never try to force food or drink on your child.

Parent voice:

I talked to some other families who were struggling with the food issue while we were in the hospice. Somehow it felt harder for me to stop the tube feeding than it was for other parents to accept food refusal from their children. I suppose the signs that the child really doesn't want it are less clear. I felt as if I was withholding rather than he was refusing. I felt a little better knowing that most dying people don't want food. When I skipped the feeds, I could tell myself that I was doing what he would have asked me to do, if he could.

This pamphlet is the result of a collaboration
between

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