

Palliative care – nutrition for children

Food is not only important for nourishment, but also as a source of pleasure and comfort. Parents and carers of children who are unwell are often worried about making sure their child's nutritional needs are met. Food is important for improving quality of life, relieving symptoms and to provide pleasure and comfort.

This information sheet provides advice on how to manage some of the common nutritional challenges during the palliative care phase of your child's illness. If you would like more information, ask your healthcare team to put you in touch with a dietitian.

Minimising weight loss

Loss of appetite resulting in weight loss is common in palliative care. It is very difficult for family and carers to watch their child lose weight. There are many reasons for weight loss including nausea and vomiting, anxiety and decreased food intake. However, the disease process itself plays the biggest role.

It is important to understand that your child's reluctance to eat is not a reflection of the foods you are offering.

Never blame the child for their reluctance to eat but instead try to focus on making eating an enjoyable experience.

- Let your child eat the foods that they feel like. It is better to eat and enjoy rather than struggle to maintain a balanced diet.
- Create a positive eating environment - share meals and eat together. If your child is not well enough to eat at the table, consider sharing meals in a room where your child can lay down.
- Try not to comment if food goes uneaten.
- Try to offer past favourite foods.
- Small frequent meals may be easier to eat. Offer food every couple of hours if your child has no appetite. Small meals are less overwhelming.
- Ignore set meal times - encourage your child to eat when they feel hungry.
- Food preferences will change often - offer a variety of foods.
- Soft foods that are easy to chew and swallow may be easier to eat.
- Chewing on gum, sucking on icy chips, sugar free lollies or ice blocks may help to stimulate saliva flow if your child experiences a dry mouth.

Fortifying foods

Your child may find it difficult to eat large volumes of food. Eating small amounts of energy dense foods may help your child maintain their weight. The following ideas help to increase the energy content of foods your child enjoys. It is important not to force a food if your child does not like it.

- Creamy milk drinks are easy to consume. Try adding ice cream, frozen yoghurt, milk powder (1 tablespoon / glass) or cream to fortify.
- Fruits can be blended with milk and ice cream to make smoothies.
- Add butter / margarine and oil to plain cooked vegetables. Salts and sauces can be used to improve flavour.
- Add cream to soups and scrambled eggs.
- Creamy dips can be nice to dip crackers into.
- Nutritional supplements can be a useful source of energy and nutrients. *Sustagen* can be found in the supermarket and *Pediasure* in the chemist. Obtaining supplements with a prescription can help reduce the cost. Altering the serving temperature may help. Some children like these drinks served very cold, others prefer room temperature. Supplements can be added to smoothies and milkshakes. For further advice about supplements ask to speak with a dietitian.

Tube feeding

There may come a time when your child is not able to eat or drink enough. Another way to provide food and fluid is via a gastric tube. There are number of gastric tubes available including a nasogastric tube which is inserted via the nose, passes down the back of the throat and into the stomach.

A special tube called a gastrostomy can be surgically placed directly into the stomach under general anaesthetic. A gastrostomy can be used if a child requires tube feeding for a long period of time.

Special feeds are given through the tube to provide nutrition. The feed may be delivered by a portable pump. Fluids and hydration can also be provided via gastric tube. Tube feeding may help your child feel more comfortable, and increase their energy and strength to play or join in family activities. It may relieve the pressure of trying to get your child to eat and drink. This may help improve their quality of life. Some medications can also be given via the tube.

Some families decide that tube feeding is not the right option for them. Sometimes feeds may worsen symptoms such as nausea or stomach pain, but this can be managed in most cases. You may feel that tube feeding will impact on your

child's quality of life. The decision to start tube feeding will be different for each child and family.

If tube feeding starts, the dietitian can help plan a feeding regime that suits your child's needs. If you would like more information about tube feeding you can ask your healthcare team, or the dietitian.

Nausea and / or vomiting

Nausea, with or without vomiting, is common during palliative care. The cause can be hard to identify. It may be related to your child's medications, anxiety or progression of the disease. Always notify your health care team, as they will be able to decide on the most appropriate treatment.

- Small, frequent meals are usually better tolerated.
- Smells of cooking foods can make nausea worse. Try to keep your child away from the kitchen, serve foods cold or cook in the microwave to reduce smells.
- Try dry salty foods such as vegemite on toast, crackers, plain boiled vegetables (salt can be added to taste) and plain potato chips.
- Fluid intake is important; try water, flat lemonade, ginger beer, ice blocks or sports drinks.

- Fresh air can help; try a gentle walk or push in the pram outside or open the windows and doors in the house.

Constipation

There are many reasons why your child may become constipated. Pain control medications are a common cause. Reduced food and fluid intake and decreased activity can also contribute. While diet alone may not be sufficient to treat constipation, there are some strategies you can try:

- Offer plenty of fluids.
- Offer small frequent meals during the day.
- Try to include some high fibre foods. Add fruits to smoothies or serve with desserts (e.g. banana and custard, strawberries and cream). To save on time and preparation, tinned or frozen fruit is a good alternative.
- Try soft mashed vegetables, or vegetables grated in meat dishes.
- Baked beans are high in fibre and easy to consume.
- Legumes and lentils can be added to casseroles and meat dishes.
- Try pear juice or prune juice.

Easy meal and snack ideas

- Extra creamy yoghurts (e.g. Greek style)
- Ice cream with topping / milo
- Chocolate dairy desserts
- Milk shakes (add ice-cream or cream, topping, *Milo*, *Nesquick*)
- Blended fruit smoothies with frozen yoghurt (add banana, mango, berries)
- Frozen coke
- Creamy custards
- Two minute noodles
- Cheese sticks or cubes
- Avocado on toast or crackers
- Hot potato chips
- Fish fingers
- Cheese on toast
- Iced paddy cakes
- Peanut butter
- Milo with milk or icecream
- *Shapes* biscuits
- Spring Rolls
- *Jatz* and creamed cheese, hommus or creamy dips
- Marshmallows
- Garlic / Herb bread
- Potato gems
- Small snack packs of children's biscuits
- Pikelets / pancakes with butter / jam / cream / icecream
- Creamy Potato Bake
- Potato Salad
- Sausage Rolls
- Fairy bread with margarine / butter spread thickly
- Roast vegetable fingers (in the freezer section)
- Caramel tarts
- Iceblocks
- Yoghurt tubes
- Chips
- Buttered popcorn
- Crackers and cheese
- Creamed rice
- Chicken nuggets
- Chicken Wings
- Home-made mini pizzas
- Cheese and bacon rolls
- Creamy vegetable pasta bake
- Scrambled eggs (add cream, bacon, cheese)
- Boiled eggs with toast fingers to dip
- Raisin toast with butter / margarine
- *Saos* with vegemite and cheese, cream cheese or avocado
- Toasties (Baked beans and cheese, ham and cheese)
- Sausage sizzles
- 'Spiders' – fizzy drinks with scoops of icecream

Alternative diets

There are an overwhelming number of diets on the market, some that make extraordinary claims. Many of the supplements and diets available on the market are very expensive.

You may wish to try alternative diets or supplements with your child. Some supplements can provide important nutrients and energy. Unfortunately most alternative diets are very restrictive and hard to stick to, can taste unpleasant and may have uncomfortable side effects. Sticking to a restrictive diet may be stressful for both you and your child and may reduce quality of life.

Your healthcare team can help you make decisions about these diets. For further information and support, speak to your healthcare team.

Nutritional needs of the carer

Caring for a child who is unwell is both physically and emotionally demanding. Your own nutritional needs are also important. To ensure you are well nourished it is important that you eat healthy meals as much as possible. During particularly stressful times, eat the foods you enjoy most and do not worry if your diet is unbalanced for a day or two.

- Meal preparation can be time consuming. Where possible cook in

bulk and freeze meal sized portions for later.

- Do your grocery shopping online, and have your goods home delivered, some online home delivery websites include:
 - <http://www.coles.com.au>
 - <http://www.woolworths.com.au>
 - <https://www.aussiefarmers.com.au/>
 - <https://www.groceryrun.com.au/>
- Friends and family will often ask what they can do to help. You could suggest they bring prepared meals for the freezer, fruit platters, ready to eat snacks or even a take away meal for you to share. There are a number of websites that can be useful for family and friends for meal coordinating such as:
 - Take them a meal: <https://www.takethemameal.com/>
 - Meal Train: <https://www.mealtrain.com/start/>
- Frozen supermarket meals are a good substitute for home cooking when you are too tired or busy to cook.
- Stock your pantry with easy to prepare snacks / meals: baked beans, tinned soup, eggs, pasta, pasta sauces, frozen vegetables, frozen meat and fish.

- Consider nutritional supplements such as *Sustagen* as a meal replacement for yourself.
- Consider a multivitamin/mineral supplement if you are struggling to eat a balanced diet.
- Don't deny yourself the pleasure of eating with friends and family. Ask visitors to bring over a sweet treat to share over coffee, or ingredients to make a meal together.

For further information contact your Dietitian or Nutritionist:
