

A PARENT'S GUIDE TO **YOUR CHILD'S EATING AND DRINKING AT END OF LIFE**

To live well is not always to eat well



It can be difficult and distressing to see your child change as their condition worsens.

This guide is designed to help you and your child tackle some of the most common symptoms (problems); particularly those associated with feeding and drinking.

IS THIS BOOKLET FOR ME?

Yes, possibly – are you ...

- A parent or caregiver to a child with a life-limiting or life-threatening illness who is at the end stage of life?
- A parent facing difficult decisions about feeding and fluids at the end of your child's life?
- A parent or caregiver seeking answers to difficult questions?
- A health professional who would like to support families with common concerns?
- Or is your child struggling to eat, listless or withdrawn?
- Are they disinterested in food or appear as though they are “wasting away”?

 *This booklet contains information designed to support you as you care for your child.*



“WHY ISN'T MY CHILD EATING ANYMORE?”

You may notice, or have noticed the following behaviours in your child. Signs that your child is losing their appetite:

- More frequently saying they are not hungry.
- Turning their face away to food, getting upset or keeping their mouth closed.
- Feeling sick.
- Saying foods smell or taste ‘funny’ or not nice.

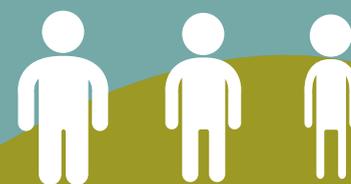
“WHY IS THIS HAPPENING TO MY CHILD?”

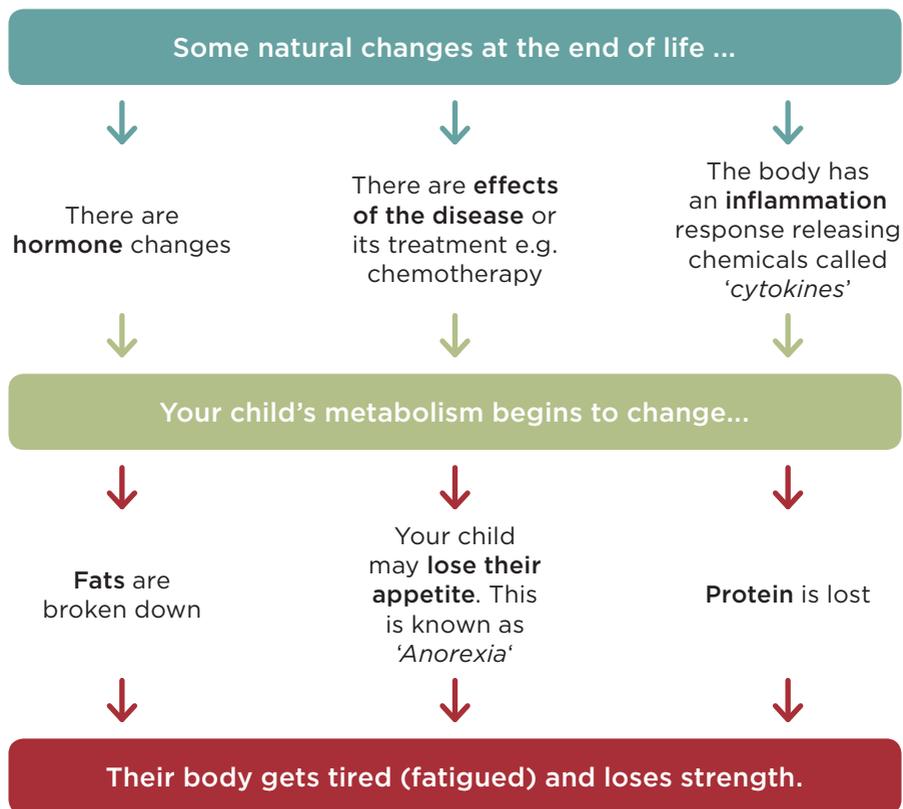
During the end of life, natural processes like metabolism (the body's breakdown process), breathing, digestion and elimination start slowing or changing. One of the results is a state known as Cachexia (ka-hex-ee-a), also known as wasting syndrome. [See diagram overleaf].

Some terms explained:

Cachexia is involuntary weight loss. It is a complex metabolic syndrome of weight loss characterized by a profound loss of body mass, caused by chronic and severe disease. Sadly, improved nutrition does not usually reverse this type of weight loss.

Anorexia is loss of appetite which can be caused by a number of different factors, ranging from an illness to psychological reasons.





GOALS OF CARE

Your goals are individual to your child and your family, but you may feel the following are worth considering and discussing with the healthcare team. Especially if your child is not enjoying their food anymore:

- Value your child's right to make choices.
- Maximise their comfort and safety.
- Create an environment which focuses on enhancing their quality of life.
- Make memories together.
- Aim to minimise distress and discomfort.

 See advice and tips overleaf on how to achieve these goals of care.

“IF I STOP FEEDING, AM I HARMING MY CHILD?”

Although it may feel difficult to understand, there can be risks with any type of feeding at this stage. As mentioned previously, the body is slowing down and giving your child food can increase risk of the following:

- Nausea, vomiting, diarrhoea and/or constipation.
- Stomach distention, blockages or rupture.
- Pushing food, which a child has no desire to eat, can be distressing and may challenge your goal to achieve a comfortable end of life.
- It increases the risk of sepsis (overwhelming infection).
- Extra food may be uncomfortable or pool in the lungs – making breathing difficult and increasing shortness of breath and risk of infection.

There can actually be a perceived “positive” benefit to not feeding. In addition to avoiding the risks above, and hopefully making your child more comfortable, the changes shown in the diagram alter the body's chemistry in a strangely “helpful” way at the end of life stage. As fats and muscle are broken down the chemicals produced can protect the body from feeling hungry, and even produce a euphoria (happiness and good feeling).



“DO I HAVE TO WATCH MY CHILD SUFFER? WHAT CAN I DO?”

Some parents have found the following tips useful, you may like or need to try the following:

1. Your child may be able to guide you; give them foods they suggest – even ‘unhealthy’ ones you avoided before!
2. Check for mouth ulcers/sore spots: they may benefit from liquid painkillers.
3. Good oral hygiene – it is important to regularly brush their teeth with a soft toothbrush.
4. Keep their lips moist with glycerine/vaseline and use ice chips to moisten their mouth.
5. Treat them to a favourite story at mealtimes, music, or games. Light massage can sometimes help.
6. As tempting as it may be, avoid threatening or bribing; take time to understand and listen.
7. You can fan them, this has been found to help breathlessness, it may feel nurturing and bonding.
8. They may enjoy eating together with you as a family, small regular meals help, and small pieces of food.
9. Medication options include anti-sickness medicine and sometimes the medical team may prescribe steroids to stimulate appetite. Medicines for thrush or to help the bowels may be necessary.

IF THEY WANT TO AVOID ALL FOOD AND DRINK:

- Ice chips/popsicles to suck may be soothing.
- Try pineapple ice blocks. Pineapple contains an enzyme that stimulates saliva and has anti-bacterial properties.



NB: Ask your medical team for help any time you need – it is okay to have lots of questions!

“WHAT CAN I DO? THIS ALL FEELS UNMANAGEABLE...”

We understand you might feel overwhelmed by what is happening to your loved one and your family. Here are a few tips for you to look after yourself:

- Reconnect with things you may have enjoyed before e.g. exercising, reading, praying, gardening at every chance.
- Focus on comfort, for you and your child, rather than calories and mealtimes.
- Don’t be afraid to show your emotions around your child and family.
- Continue to eat and sleep as best as possible.
- Take regular ‘sanity’ breaks e.g. coffee with friends etc.
- Keep a contact list of emergency numbers in case you need more help.
- Try to feel brave to tell people what you need and what you don’t need. Rather avoid people who don’t make you feel supported and don’t feel guilty!
- Confide in others, it is okay to need and ask for support – the medical and palliative team are there for you to ask all the questions you need and to walk alongside you and your family.
- Seek out spiritual and psychological counselling for your family and your child to discuss your fears and needs.



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info@patchsa.org

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