

FEEDING

As a parent, feeding your child is one of the most important elements of day-to-day care. It can be extremely distressing and sometimes isolating to discover that your child is unable to feed as you had hoped.

If your child has been born with a complex heart condition they may find feeding difficult. Their heart condition creates an increased need for energy. Feeding, especially for a newborn baby, requires the energy that we would need to run a race. The children often start a meal or milk feed with great enthusiasm because they are very hungry but gradually they become breathless and sweaty and often they are unable to complete their meal because they are so exhausted. Feeding is very hard work, and the problem is further complicated by the fact that children with heart conditions need more calories than those without.

Calories are needed to provide energy for living. If you have an inefficient heart pump, you require lots of fuel/food to run your body, but children with a heart problem also need to grow so they need to take in more calories than other children of their age.

Babies with single ventricle heart conditions often find feeding difficult. Many are fed through a naso-gastric tube in their early days and weeks; some need tube feeding for longer. Other babies successfully bottle or even breastfeed. Whichever feeding method is used, it is likely that extra calories will need to be added to the milk via special easy-to-mix supplements prescribed by a dietician.

It is not uncommon for babies and young children with these heart conditions to suffer from vomiting after a feed. This is incredibly upsetting for parents, and sometimes distressing for the baby. Taking plenty of time over a feed, feeding little and often, and keeping the baby upright during and after a feed may be helpful. Frequently medication has to be prescribed to help.

Weaning can sometimes be a helpful turning point for a baby who has had difficulties with feeding. Some babies find puréed foods easier to manage than milk - they can co-ordinate their sucking, swallowing and breathing better. Others have their Stage Two surgery around this time so are less breathless, which in turn helps them to develop their feeding skills. Very smooth purées, lots of variety, and introducing finger foods at an appropriate time are all ideas

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which have worked well for many families.

Children should be encouraged to eat a healthy and varied diet, rich in fruit, vegetables and starchy foods. As your child's body is working even harder than most toddlers and children (who are usually all very active), you may find they need more 'nutrient dense' foods to keep them going. Ideas include meat, eggs and full-fat dairy products. It is also helpful to make eating fun and involving: this could be by sharing family mealtimes, cooking with your child, and making sure small portions are offered initially so the child does not feel overwhelmed. The principle of 'little and often' is usually a good one, where nutritious snacks are planned during the day, and are seen as almost as important as meals.

Teenagers need to be supported as they learn to take responsibility for their own nutritional needs. They need to learn the importance of a balanced diet, but they must also learn how to ensure they have the calories they require, particularly during this time of growth and hormonal change. Whilst salads, fruit and vegetables should all be important components of their diet, they also need to eat plenty of carbohydrates (e.g. pasta, rice, potatoes) and protein (e.g. meat, fish, cheese, eggs, pulses, nuts).

If your child is experiencing difficulties with feeding or weight gain, don't despair, you are not alone. Ask for a referral to a dietician who has cardiac experience or contact Little Hearts Matter for a copy of our booklet 'Feeding at Home: a guide for parents' and to be put in touch with other parents who have experienced feeding difficulties with their own child. We can also help with more ideas for all age groups of children, and information on specialised diets if required.