

# Feeding problems, failure to thrive and growth

## My baby is not growing

The most common “every-day” problem parents first notice is that their baby is not growing as well as he should. Height and weight are both usually below the 10th percentile on standard growth charts, causing concern and sometimes resulting in medical staff recommending supplemental tube feeding via a nasogastric tube (inserted through the nose down the back of the throat into the stomach) or gastrostomy tube (a small plastic tube inserted surgically through the abdominal wall into the stomach), with top-up feeds, overnight feeds or continuous daytime feeds via an infusion pump.

Unfortunately, this approach is often unsuccessful, as children with Barth syndrome have a tendency to vomit if they are overfed. New guidelines from the NHS Specialised Services Team advises against tube feeding where possible since long-term use of nasogastric or gastrostomy tubes can reduce a child's own drive to eat and so result in long term dependence on tube feeding. However, many patients will still require them at some stage during their life. If tube feeding is required, feeding plans are designed to reflect normal eating patterns, and to encourage and maintain oral eating where possible.

## Food fads

Many children with this disease also show distinct food fads, especially for very savoury foods such as pickles, olives or nuts and for very salty foods such as multiple packs of crisps. Cheese and chicken are often enjoyed.

## Diarrhoea

Diarrhoea is also common which may increase the risk of infection in the nappy area. Take special care during periods of protracted diarrhoea as the child's reduced muscle mass means they have less reserve and essential salts, particularly potassium, can become rapidly depleted. Care should also be taken if additional potassium is given to correct this, as the reduced muscle mass means the children are not able to store any excess potassium, so they may quickly land up with a dangerously high potassium level.