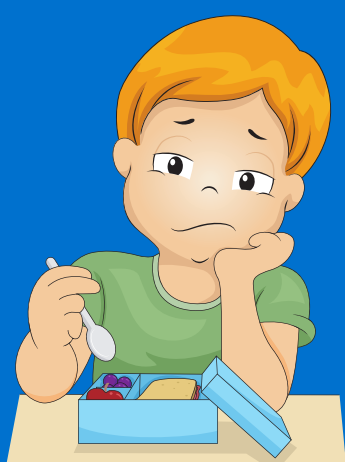


FEEDING CAN BE ONE OF THE MOST DIFFICULT DAILY CHALLENGES PARENTS OF CHILDREN WITH BARTH SYNDROME FACE.

It is not a case of them not wanting to eat, rather a case of not being able to for a variety of reasons



**FATIGUE-
NOT ENOUGH ENERGY TO CHEW**



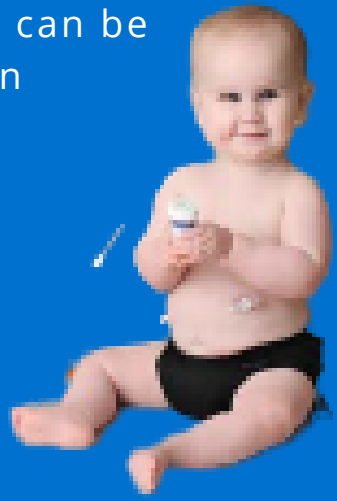
NAUSEA



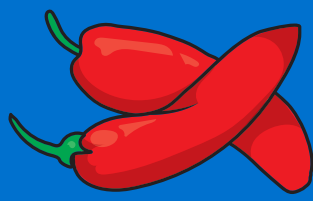
**SENSORY ISSUES-
GAGGING**

FEEDING TUBES

More than 50% of individuals with Barth syndrome have used a feeding tube at some time in their life. These can be nasogastric or gastrostomy (also called PEG) tubes. Once they are able to eat by mouth, these tubes can be removed, or kept to supplement or 'top-up' when necessary.



SELECTIVE EATING IS COMMON



A restricted variety in the diet is extremely common for Barth individuals. Chewing can continue to be difficult, and easy to eat foods often make up most of the diet. Many young individuals with Barth syndrome have a strong preference for savoury or 'sharp' tasting foods and combination of foods. Often they will have cravings for excessive quantities of salty foods, sometimes just licking the salt off, but not eating the food. Adding soya sauce or other sauces and gravies to food, can promote its acceptance.

