

FEEDING PROBLEMS IN NOONAN SYNDROME

Some children with Noonan Syndrome will have feeding difficulties. They can be very difficult for parents but the good news is that they will get better and improve with time.

Children with Noonan Syndrome may have some of the following feeding problems:-

- Poor or slow sucking as newborns (this may include a period of tube feeding).
- Lack of interest in eating or an aversion for eating (this may follow prolonged tube feeding).
- Difficulty in progressing to solid food, particularly if this contains lumps.
- Poor chewing, which means meals take a long time. The older child may store food in the cheeks or forget to swallow.
- The development of a cyclic pattern of vomiting which appears to have no definable cause.
- A sensitivity to particular flavours of food and certain feeding utensils such that strong flavours may be preferred as may certain spoons or cups.

Some of the following may be specifically useful:-

- The child may show increased sensitivity of the mouth, both internally and externally and even of the neck area. A desensitisation programme can help here. This should be done with the parents and the child should be encouraged to take part rather than just be a passive recipient of the programme. Any way in which the child can actually feed themselves is to be encouraged, including finger feeding, using small sticks of semi soft food, like cheese or fruit, and dipping them in other substances and guided feeding using a spoon, etc.

- Small helpings of food are generally better than loading the plate with a lot of food which will not be eaten. Equally, it is better to have two or three different kinds of food on the plate in small amounts, so that the child may be encouraged to try different kinds of food rather than continually sticking to the same mashy, sloppy bland food.
- If the child shows a preference for strong flavours of food this should not be discouraged. However, where the child shows a preference for very sweet foods including chocolate, it is important that regular teeth cleaning is a part of oral care.
- Force feeding of any child should be avoided at all times. Where nasogastric tube feeding is being used, it is probably more helpful to confine this to night feeds and ensure that the child has good oral experience during the day.

The pattern of feeding development we have seen in the majority of children with Noonan Syndrome whom we have examined is as follows:

- A failure to suck adequately from the breast. Professionals often label this as the mother's fault. It is however, directly attributable to the slow and poor sucking of the child.
- The child is then often moved onto bottle feeding with the same result. Once again this is often frequently blamed on the mother. However, it is similarly a result of the child's poor sucking ability.
- The child may then fail to thrive and lose weight. At this point, nasogastric feeding is sometimes introduced. This may continue for a variable period, but the longer the period of nasogastric feeding, the more important it is to continue oral stimulation and to continue to interest the child in oral food. After a prolonged period of desensitisation. Equally, a cycle in which persistent vomiting follows each feed may develop. This can be a very distressing experience for the parents and become quite difficult to manage. One way of dealing with this in the short term, is to stop oral feeding, return to nasogastric feeding, at least at night and desensitise the child to this aversion for food which is probably developing. This may include ordinary oral stimulation work, in which food is not used to get the child used to having a pleasurable oral experience again. Children can usually then be introduced to mashed, soft or liquidised foods gradually, providing these have no lumps in them. Most children with Noonan Syndrome

find it difficult to manage lumps and these will often bring on retching or vomited. This is a feature of their poor co-ordination of swallowing. Even when they move onto more solid foods, most children with Noonan Syndrome do not exhibit mature chewing patterns. Rather their chewing is described as vertical. This is an important stage to pass through and it is quite difficult to get them to move onto mature chewing. In the early stages of chewing it can be helpful to introduce foods that can be held in the hand and which are quite soft, for example, marmite fingers, sticks of cheese, banana or pear.

It is important to remember that children with Noonan Syndrome will learn to eat. However, for them, eating remains a major potential learning problem. There is no point in rushing a child through the stages of eating before they are ready to move on to a new stage or placing them under any other kinds of pressure about eating. This just increases anxiety and leads to food aversion. The child with Noonan Syndrome will probably always eat slowly and should never be rushed. Try to progress at the child's speed, introducing as wide a range of foods at the stage as possible. Most of all the parents should be supported rather than undermined. It is difficult to cope with a child who has feeding problems in a family.

A summary written by Janet Lees, Research Speech Therapist as an aid to help parents.

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