

Nutrition and Feeding

Introduction

Within Neuromuscular conditions there can be a range of issues with feeding and nutrition. This may vary with different diagnoses.

Normal, healthy growth is measured according to weight and height. Charts are available which outline the ranges of weight which are considered to be healthy. For people with neuromuscular disorders this range is extended slightly to account for different amounts of muscle.

Growth patterns that may require attention and monitoring are either being overweight for height (an indication of excess nutrition), or underweight for height (insufficient nutrition).

What causes someone to become overweight?

This is caused when energy used by the body is less than energy eaten. In neuromuscular conditions it could be due to a reduced ability to walk around (so less energy is burned off) or increases in appetite (which may be a side-effect of some medication eg steroids). Eating an “average” portion of food in some cases may be larger than the energy required and lead to too much weight gain.

How can you lose extra weight?

Up until the end of the adolescent growth spurt all children grow in height and require adequate nutrition to grow. It is important that the diet is balanced and takes into account the amount of energy a child is using. Generally, prevention is better than cure. It is easier to monitor and keep weight stable than lose it.

Different strategies can be used to lose weight. One is increasing energy expenditure by exercising. This can be difficult for individuals with limited mobility. Certain exercises may not be beneficial and before starting an exercise programme you should always discuss this first with your clinician and/or physiotherapist. Eating lower calorie foods (eg, fresh fruit and vegetables) and less of the foods which are high in calories (eg, those containing a lot of fat and sugar) can help weight reduction in individuals with limited mobility.

Banned foods can become more desirable and it may be helpful to still have some treats. Advice from a specialist dietitian can be helpful in setting goals and making more specific suggestions.

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What is underweight?

This is not putting on enough weight. Not putting on weight is due to not having enough energy (calories) in the diet. By frequently not being well, weight may not be maintained over a long period of time. If not enough calories are eaten, blood sugar levels may also drop. This can cause weakness, dizziness, mood swings, hot/cold flushes and shakiness.

There are a number of reasons why children with muscle disease may be underweight:

It is a common misconception that all children with a muscle condition will be thin because of their reduced muscle bulk or as a result of loss of muscle or weakness. There are a wide variety of shapes and sizes in individuals with muscle conditions. While on one hand it is easier for the thin child to perform some movements and reduced weight makes transferring for parents/carers easier, it is also important to realise that maintaining good nutrition is fundamental to maintaining good health.

It is important to realise that, whatever the cause, there are often strategies that can be used to help lessen the problems associated with eating and it is important to discuss these with a specialist.

- ▶ **Nocturnal hypoventilation**
Some children who have nocturnal hypoventilation (not breathing well at nighttime) wake-up with a headache and do not feel well rested in the mornings and as a consequence may have a reduced appetite.
- ▶ **Illness**
When children with a muscle condition become unwell (eg, with a chest infection) they often lose weight. This is because they may lose their appetite and do not eat so much. At the same time, they need more calories and protein than usual to fight off an infection and help the body recover. Children can also have increased requirements for repair when they have had surgery and this is an important time to make sure they are receiving the right amount and kind of nutrition.
- ▶ **Swallowing and Chewing**
Children with a muscle condition sometimes have weakness of the muscles of the face and neck involved in chewing and swallowing. Weakness in these muscles can make chewing prolonged, particularly if the food is hard, chewy or textured. Additional problems that can be found in some children are teeth malposition, limited jaw opening, high arched palate or limited tongue movement. In order to overcome these difficulties often children take a long time to eat or eat only small amount of food. Some children who eat like this are labelled “fussy eaters” as they will often avoid certain textures and will opt for foods they find easy to chew.

In some cases the muscles involved in swallowing are not well co-ordinated and the child can be at risk of swallowing problems. When food or liquids go down the wrong way (aspiration) the child may cough and choke to try and stop it. If food

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goes down the wrong way and the child doesn't cough (silent aspiration) the food or liquid passes into the lungs and could cause a chest infection.

- ▶ **Gastro-oesophageal reflux**
Reflux is the backflow of stomach contents from the stomach into the food pipe (oesophagus). Reflux may be due to poor muscle tone or scoliosis and can result in feeding problems. If an individual vomits or has frequent small regurgitation of stomach contents this can lead to pain and oesophagitis more commonly referred to as heartburn (irritation of the oesophagus). If the reflux is very frequent, the child will often associate eating as being a painful experience and not want to eat. This is known as "food aversion". If regurgitated food comes back into the throat it could go down into the lungs and cause a chest infection or choking as described above.
- ▶ **Getting full quickly**
Sometimes poor muscle tone in the stomach can cause its contents to "empty out" slowly making a child feel full quickly or not feeling hungry. Again, this can result in small volumes of liquids and solids being taken.
- ▶ **Reduced mobility**
Reduced mobility can affect self-feeding abilities. A child may be unable to lift cutlery to their mouth or may be in an awkward position for feeding, or may get progressively more tired during the course of the meal. If the sitting position of a child is not good because of a curvature of the spine or neck, chewing and swallowing can become difficult. Because of these difficulties, mealtimes can last a long time or only small volumes are taken.
- ▶ **Psychological/social factors**
Some physical problems can lead to worries and fears about eating. If an individual is reluctant to eat or drink it may be because of a previous bad experience with choking. Long mealtimes can also result in a child feeling left out socially as their friends may finish their meals earlier and leave the table. Parental worries about poor weight gain and small volumes can lead to over enthusiastic approaches to eating such as lots of coaxing or force feeding. This approach may make a child reluctant to eat. Mealtimes are sometimes feared rather than being enjoyed.

Assessment of feeding may help to identify difficulties and suggest various management options.

The specialist assessment team may consists of:

- ▶ **Dietitian** – will be involved in making an assessment of the types and amounts of food eaten via a food diary and assessments of growth chart measurements. This involves measuring weight and height and plotting these measurements on a growth chart. Height can be difficult to accurately obtain due to being wheelchair dependent or having limitations of joint range in the ankles or a curvature of the spine. There are other ways to estimate height eg by taking demi arm span measurements. Mid-arm circumference can also be a useful measurement if weight

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or height cannot be obtained. Repeated measurements over time are essential to look at change over time and assess growth.

A diet history or food diary can give information about types, quantity and textures of food eaten. This also gives an indication of how balanced the diet is and which nutrients may be missing. Good growth is an indication of good nutrition. The dietitian is able to give advice on how to alter nutrients in the diet and also advise on alternative forms of feeding.

- ▶ **Speech and Language Therapist** – will take a feeding history and look at how the muscles of the tongue, lips and throat are working. In addition s/he will look at any other problems that may affect chewing eg, with teeth. The safety of swallowing and if there are any risks of food or drink going down the wrong way (aspiration) needs to be assessed to enable safe management. The doctors and speech therapist will evaluate if this needs to be assessed in more detail. A videofluoroscopy, which is an X-ray of swallowing, may be done to look closely at how food is chewed and swallowed.
- ▶ **Doctors/Gastroenterologist** - may investigate gastro-oesophageal reflux by doing a pH study or barium meal.
- ▶ **Psychologist** - may help with some of the social or emotional problems for the child and family that may result from eating and drinking difficulties.
- ▶ **Occupational Therapist/Physiotherapist** - may make suggestions on seating and positioning or any cutlery or equipment that may make eating easier.

Management

- ▶ **Safe swallowing advice**
This is often the first line of management after assessment. It aims to reduce the risk of aspiration. It may include advice to: sit upright after meals to prevent residues of food in the throat going down the wrong way or not to wash food that gets stuck down with liquids but rather to encourage dry swallowing after mealtimes. This can help to clear the throat of residue rather than introducing more which can then be aspirated. Sometimes there is desensitisation to residue so a child may need reminding to dry swallow/swallow saliva after mealtimes as they can't feel the residue there anymore. Keeping mealtimes short (20-30 mins) can help reduce the risk of muscles getting tired and food going down the wrong way.
- ▶ **Food texture modification**
Food consistencies can be altered to make them easier to manage eg, mashed or chopped. Sauces can be added to make things easier to swallow. Liquids can be thickened so they move more slowly through the throat and don't go down the wrong way.

There are a variety of teats, bottles, cups and straws which may make eating easier. It is best to discuss their use with your therapist to help find the best solution for a problem.

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▶ Oral motor exercises

We are not aware of specific exercises that can strengthen the feeding muscles of children who have a muscle disease. Any exercise however will not induce harm, but it is important to monitor whether it is beneficial.

▶ Oral hygiene

It is helpful for everyone to regularly brush their teeth and visit a dentist for removal of plaque or treatment of cavities if required. This will help keep the mouths clean and healthy. If saliva is full of food residues or bacteria, and goes down the wrong way, a chest infection may quickly develop.

▶ Diet Therapy to maintain adequate growth

The aim is to prevent weight loss and maintain a suitable level of growth. There are a number of steps in treatment which you are likely to progress through until growth is satisfactory. Their use and effect on growth should be monitored regularly.

Altering the diet

This is done by increasing the frequency and amount of food eaten: eg encouraging in-between meal snacks (i.e., eating “little and often”) and having a pudding after meals. Or by increasing the density of nutrients in the diet. For example: eating high calorie and high protein foods (eg peanut butter, fromage frais, chocolate spread) enriching foods by adding protein powders (eg skimmed milk powder) or adding fats and oils to foods (eg double cream in yoghurt, cheese in sauces).

Prescribed dietary supplements

(usually prescribed by your GP following advice from a dietitian.)

These can be special fat emulsions or carbohydrate supplements which are added to high protein foods or ready-to-drink high-calorie drinks which are almost nutritionally complete. They are either fruit or milk-based, or other high calorie powders added to milk.

Supplements are easy and convenient to use. They are particularly useful if eating enough food is difficult. However, there are only a limited number of flavours available and this may lead to becoming fed-up with the taste over time.

Tube feeding

Nutrition can be put directly into the stomach by tube. Giving extra nutrition by tube can relieve the pressure at mealtimes when trying to eat and drink enough and can help a child to gain weight and grow. For individuals with swallowing difficulties it can protect the airway from aspiration by putting the food/liquids straight in to the stomach, avoiding swallowing. There are two different ways of tube feeding:

1) Nasogastric feeding (NGT) is recommended for a child who needs short term tube feeding (4-6 weeks). A nasogastric tube passes up the nose down the throat and into the stomach. Usually this is not an acceptable solution for long term use, although sometime it can be well tolerated.

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The advantages of nasogastric feeding are that it can provide extra nutrition during times of acute illness and therefore aid recovery. Disadvantages are that the tube can cause a sore nose, ulceration and irritation of the throat or food-pipe. Reflux can get worse as the muscle at the top of the stomach can't close tightly with the tube in place. The tube can move and come out of the stomach. If an individual is tube-fed when the tube is not in the stomach it can cause problems. An nasogastric tube is also very visible and its purpose can be misunderstood by other people.

2) Feeding via a gastrostomy tube, that goes directly into the stomach, is the most successful option for longer term tube feeding.

See Muscular Dystrophy UK's Gastrostomy fact sheet for further information.

Summary

Adequate feeding and nutrition is essential for all children. We need to monitor growth and feeding difficulties carefully to make sure we are providing the best support and advice to compensate for any problems individuals may have.

Do raise any concerns you have with your or your child's feeding with your Consultant or a member of their team.

With thanks to staff and patients from the Paediatric Neuromuscular Team at the Hammersmith Hospitals NHS Trust for their support and help in producing this fact sheet.

If you have feedback about this factsheet please email info@muscular dystrophyuk.org.

Disclaimer

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Here for you

The friendly staff in the care and support team at the Muscular Dystrophy UK's London office are available on **0800 652 6352** or info@muscular dystrophyuk.org from 8.30am to 6pm Monday to Friday to offer free information and emotional support.

If they can't help you, they are more than happy to signpost you to specialist services close to you, or to other people who can help.

www.muscular dystrophyuk.org

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