

**Nutrition Information for children with complex medical diagnosis:**

Cerebral palsy (C.P.) describes a group of disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing foetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, cognition, communication, perception, and/or behaviour, and/or by a seizure disorder

• **Good Nutrition and the Role of the Dietitian in Managing Dietary issues with Cerebral Palsy**

- Good nutrition is vital for any child to grow and develop and for adults to maintain good health. While many people with CP enjoy very good nutrition and diet, a child with CP should be frequently assessed by a dietitian as their nutritional needs change throughout childhood and adolescence. A dietitian can plot the weight and height of child with CP on CP specific growth charts.
- In addition to education about balanced eating from a dietitian, some children and adults with CP may require additional nutrition from prescribed oral nutritional supplements (ONS) or via enteral nutrition i.e. using a gastrostomy feeding tube. It is vital that a child or adult who is prescribed ONS or tube feeding be monitored by a dietitian.

**Feeding, Eating, Drinking and Swallowing Difficulties (FEDS)**

- Research indicates that up to one third of growing children with CP are poorly nourished due to feeding, eating, drinking, or swallowing difficulties (FEDS). This can result in mealtimes that are much longer or much more effortful than normal. FEDS difficulties range in severity. For a child or adult with CP it can sometimes be a struggle to achieve adequate nutrition or hydration to maintain health and weight. In severe cases, the inability to swallow effectively can cause a choking and safety hazard, or result in food entering the lungs (aspiration) leading to repeated chest infections and or pneumonia.

- It may be necessary to have your child referred to an eating, drinking and swallowing (EDS) team. The team can include a paediatrician, dietitian, speech and language therapist, and occupational therapist who each assess and advise on how to manage different aspects of FEDS difficulties. Based on the specific difficulty of each child, recommendations may include modifying the consistency of the foods offered, changing utensils or adjusting seating, and it may be necessary to thicken any liquids offered.
- It is vital to seek referral to a dietitian when a modified consistency diet has been recommended, as modifying the consistency of foods can dilute the nutrient value of a meal, leading to weight loss or malnutrition. Your dietitian can advise you on ways to maximise the nutrient value of each meal.

### **Lengthy Feeding Times**

- Offering smaller meals more frequently throughout the day can be less tiring for the person with CP, and for their parents or carers compared to three large meals a day. The 'little and often' approach can work well here.

### **Oro-motor Difficulties:**

- Oro-motor difficulties include tongue thrust, poor lip closure and inadequate tongue movements to manipulate food around the mouth. These difficulties cause food and drink to spill from the mouth, resulting in loss of calories and hydration. A modified consistency diet may be required for safe feeding.

### **Self-Feeding:**

- Some children with CP may have difficulties using standard utensils such as spoons, forks and cups. They may require adaptive utensils to promote safety and independence. This can increase the length of the mealtime which can cause fatigue for both the child and the carer. Some children and adults with CP are unable to self feed and are reliant on others for their nutritional needs.

### **Sensory Difficulties:**

- Children with CP can have sensory difficulties that make feeding difficult. They may be overly sensitive to touch in and around the mouth and face. The child may find the touch of food, bottle teat, a spoon or even a hand unpleasant. This may cause the child to bite down, turn away, refuse to open the mouth or even gagging or vomiting.

### **Gastroesophageal Reflux:**

- Children or adults with CP often have gastroesophageal reflux or regurgitation of acid and or food contents from the stomach back up into the oesophagus. This can develop further to produce symptoms of heartburn, pain and distress after feeding, or oesophageal ulceration. It can have a serious impact on feeding if symptoms are so severe that the child or adult is unwilling to eat. Diagnosis and treatment should be discussed with your consultant or G.P. Addition of thickeners to bottle feeds or tube feeds is often suggested. However there is no clear scientific evidence in favour of this method as an effective treatment.

### **Constipation**

- Constipation is common in CP and is caused in part by poor oral fluid intake, poor fibre intake, poor muscle tone, inactivity and certain medications. A variety of high fibre foods e.g. porridge or wholegrain cereals, bread, fruit and vegetables and an increase in fluid intake can improve symptoms. Daily physical activity can help, including use of a stander, walker, following a physio programme or swimming. It can be difficult to achieve sufficient fluid intake when thickened fluids are advised. Your dietitian can advise whether sufficient fluid and fibre are being consumed. Even offering 2-3 mouthfuls of liquid every hour plus a drink with meals and snacks will go a long way to achieving adequate hydration to manage constipation.

### **Overweight**

- Some children and adults with CP have a tendency to become overweight because of reduced physical activity. This can affect a child learning to mobilise, or an adult's ability to transfer from wheelchair to bed, the toilet or to a car. It can also increase

risk of developing pressure sores. Weight gain can be prevented by avoiding frequent intake of foods high in fat and sugar, sugary drinks, and by using appropriate portion sizes. Check this website for further information or on healthy eating and appropriate portion sizes for children and adults.

### **Tooth Decay**

- Children or adults with CP may develop tooth decay because of their diet, feeding difficulties, medication or gastroesophageal reflux. Tooth grinding can be common. Tooth decay increases discomfort during eating and drinking. It is best to avoid excess sugary foods and drinks, and to clean teeth twice daily. Your dentist can advise on this. Be mindful of oral hygiene when a child or adult is prescribed oral nutrition supplements as these are energy dense and can remain in contact with the teeth if the child or adult has swallowing difficulties. Milk and water are the most tooth friendly drinks.

### **Osteoporosis/Osteopenia**

- If a child or adult with CP has reduced mobility they are at increased risk of developing low bone density or osteoporosis / osteopenia. An adequate intake of calcium and Vitamin D is recommended. Calcium-rich foods include milk, cheese, yogurts, milk puddings, dark green leafy veg, tinned fish and sesame seeds / paste. Vitamin D is found in egg yolk, liver, oily fish, fortified milk or spreads, and through 15-20mins exposure to sunlight particularly between the months of March to September. If these foods are disliked, ask your dietitian, GP or consultant whether a Vitamin D supplement is needed. The child or adult with CP should have their bone health monitored by blood tests and or bone density scans. This is especially important if anti-epilepsy medication is used to control seizures. Consider some weight-bearing exercise, in consultation with a physiotherapist.