Dietary Considerations for Children with Spina Bifida and Hydrocephalus

What is Spina Bifida?
Spina Bifida (SB) is a form of neural tube defect (or NTD). It occurs when the spine of a child fails to develop fully in the womb. A split in the vertebra or back bone can cause the spinal cord and nerves to be exposed. Where the split occurs and how severely, will determine how extensive the disability is. In Ireland, approximately 1 in 1,000 children are born with a neural tube defect.

Up to 80% of children with SB will also have hydrocephalus. This refers to a build up of fluid in the brain. Many children require insertion of a shunt to drain the excess fluid away.

How is it diagnosed?
It is usually detected in antenatal scans.

What effect does it have?
A cleft or lesion in the spine usually leads to some level of physical disability, depending on where on the spine the lesion was. In general, a paralysis is seen from the area of the lesion downwards. Some children can walk others maybe wheelchair dependant.

Hydrocephalus
Hydrocephalus can influence a person’s visual perception (be able to judge distance, size, speed of objects by looking at them) and influence fine sensation in the hands which can make self-feeding difficult (ability of moving food or drink from hand to mouth). Hydrocephalus has been shown to affect higher level thinking skills such as language and memory, in turn affecting decision making, logical thinking and organisational skills, all of which have implications on a person’s ability to shop, cook and prepare a healthy diet. Both comprehension and expression can be affected in subtle ways in this condition, affecting how well an individual can take on board recommendations either written or verbal, or express their own views effectively.

Spina Bifida and Diet
There are 3 main diet related issues for those children with Spina Bifida.

1. Obesity:
It is reported that in the USA, 50% of children with SB are obese. This level has also been seen in other studies. There has been no such survey in Ireland, though it is acknowledged that risk of overweight and obesity is high in this group.

Generally the problem increases as a child gets older and moves into teenage years and adulthood. Less activity, less lean body mass (calorie burning tissue), lower metabolic rate (lower rate of burning calories) have all been implicated as causes. Excess weight can have many negative implications:
- Reduced mobility. Whether walking or in a wheelchair, excess weight can limit a person’s ability to move, change positions or transfer from chair to toilet or bed. This can limit development of independence and self care.
- Increase pressure on skin. For those in wheelchairs or using orthotics, increased weight will put increasing pressure on skin in contact with seats or tight straps. Sustained pressure on skin is a risk for pressure sores, a break in the skin which can become infected.
- Breathing problems. For those in wheelchairs, the weight gain is usually concentrated on the chest area which will affect breathing and may make bone abnormalities such as scoliosis (a bend in the back) or kyphosis (a forward bend) worse which in turn impedes the lungs ability to expand properly.
- Development of obesity related disease such as high blood sugars (diabetes) and high cholesterol.

It can be difficult to determine what the ideal weight for a child or adult with spina bifida should be as it can be difficult to measure height accurately. In general, weight should be monitored regularly using a centile chart to ensure no rapid gains in weight. Some studies have recommended measuring of fatness using skinfold callipers but this can be difficult to do and requires specialist knowledge and training.

2. **Bowel health / constipation:**
Most people with disability will develop difficulties with constipation at some point. The main dietary causes are poor diets with low amounts of fibre, fluids. Reduced mobility also plays a role.

3. **Pressure Sores:**
Reduced intakes of fluids and low intakes of protein and some vitamins and minerals can impair the healing of skin and increase the risk of pressure sores.

**Nutrition Advice for Children with Spina Bifida**

**Healthy eating to prevent excess weight gain**
There is a wealth of advice to prove that the wider the choice of food offered to a child as they are being introduced to diet, the higher the chance of developing a varied healthy diet in to child and adulthood. Use the Food Pyramid as a guide. Excess high fat, high sugar foods such as crisps, sweets, chocolate, ice-cream, fast foods and fizzy drinks should be limited to once or twice per week. As children with Spina Bifida get older, portion sizes should be monitored as those using wheelchairs will be less mobile than their peers and so will require far less energy. Linear growth or height will also be slower than peers due to paralysis of lower limbs which also reduces calorie requirement. Many adults require quite low intakes of calories to avoid obesity.

Some children especially those with hydrocephalus can appear to be ‘fussy eaters’. It is not known if this is related to the disease or a behavioural development. In general, unless there is a particular difficulty, a broad range of food should be offered and attention to fussiness or selectiveness avoided.

**Include fibre daily**
Sources of fibre include fruit, vegetables, wholemeal bread and wholemeal cereals. A mix of all types is best to help avoid constipation. However, inadequate fluid intakes will make constipation worse as the fibre becomes hard and dry and immovable in the bowel. Many children and adults limit fluid intake to limit toileting or need to self catheterise but due to nature of disability, risk of kidney urinary tract and bladder infections are increased and adequate fluid intakes help prevent
these difficulties. Constipation can also make urinary infections worse as it increases fluid retention in the bladder.

**Vitamins & Minerals**
There is no evidence to suggest that people with Spina Bifida need extra vitamins or minerals. A balanced diet with fruit and vegetables should provide what is needed. However, some adolescents and adults whose calorie intake is low, should have their intake reviewed by a dietitian to ensure they are meeting their requirements. Those with wounds or pressure sores may need supplementation and this should be discussed with your doctor or dietitian.

**Finding a Dietitan**
Ask your General Practitioner or Consultant for a referral to a Dietitian or consult the INDI website for a Dietitian working privately in your area.

If you want to see a dietitian in your area please go to our Find a Dietitian section on the homepage www.indi.ie. The contents of this fact sheet have been reviewed by INDI Council. This fact sheet was prepared for the general public. Questions regarding its content and use should be directed to a qualified dietitian.

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