asbah
Association for Spina Bifida and Hydrocephalus
(Limited by guarantee)

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FACTS ABOUT SPINA BIFIDA AND HYDROCEPHALUS

WHAT IS SPINA BIFIDA?

Spina Bifida is a fault in the spinal column in which one or more vertebrae (the bones which form the backbone) fail to form properly leaving a gap or split. This happens some time within the first 25 days of a pregnancy. The cause at present is not known and therefore cannot be prevented. The fault may occur at any level of the spine but is most common around waist level.

IS THERE MORE THAN ONE KIND OF SPINA BIFIDA?

There are 3 main kinds of spina bifida, but they differ in the amount of disability they cause:

1. Spina Bifida Occulta (L - hidden). This is a very common form and very rarely causes disability. Many people never know they have this condition which is detectable by X-ray. It usually takes the visible signs of a dimple or small hair growth on the back.

2. Spina Bifida Cystica (L - cystlike). The visible signs of this are a sac or cyst rather like a large blister on the back covered by a thin layer of skin. The amount of disability it causes depends on what is inside the sac.

   (a) Meningocele In this form the sac contains tissues which cover the spinal cord, and cerebrospinal fluid. This fluid bathes and protects the nerve cells. The spinal cord is not suually damaged and is able to function normally with little or no disability. This is a less common form of spina bifida.

   (b) Myelomeningocele This is the most common form which occurs and also the most serious. Here the sac or blister not only contains tissue and fluid but also nerves and part of the spinal cord itself which may be damaged or not properly formed. As a result there is always some degree of paralysis below the damaged vertebrae and very often incontinence. The amount of disability depends very much where the spina bifida occurs involving a greater or lesser number of nerve roots.

3. Cranium bifidum Here the bones of the skull fail to join at the back of the head. The sac which forms here is known as encephalocele, and may only contain tissue and cerebro-spinal fluid. However, in some cases brain tissue may also be present and as a result some children are born blind. The most severe form of cranium bifida is anencephaly where the brain does not develop properly, and the baby is either still-born or dies shortly after birth.

HOW AND WHY DOES SPINA BIFIDA HAPPEN?

Spina bifida is caused by the neural tube which forms the spinal cord and brain not developing properly very early in pregnancy. The reasons why this happens are not known but it is thought to be connected with some genetical and enviromental factors.

It is the most common disability present at birth, and the incidence in Britain as a whole is high, although it does vary in geographical areas.

IS SPINA BIFIDA HEREDITARY?

Only partially so. This means that parents are not "carriers" of the condition and will pass it on to their children. However, once a child with spina bifida has been born into a family, then there is an increased risk of another child with a deformity of the central nervous system being born. The risk of an adult with spina bifida having a child with a similar condition is 5% or 1 in 20. However, genetic counselling is available for parents at risk so they can be made more aware of the possibilities of their having a handicapped child, and can thus decide whether to have children or not.

WHAT IS HYDROCEPHALUS?

80% of babies born with spina bifida also have another condition - hydrocephalus - although it can happen separately. Hydrocephalus literally means "water on the brain" but the water is actually an excess of cerebro-spinal fluid in the brain caused by a blockage of the ventricles or cavities of the brain through which the fluid flows. This is due to overproduction or defective absorption of the fluid. The main outward sign of hydrocephalus is a large head which, if not treated, will get bigger due to the build up of fluid. As a result of the pressure caused by excess fluid, brain damage often occurs.

HOW ARE THESE CONDITIONS TREATED?

Twenty years ago, most babies born with spina bifida died in the first weeks due to meningitis, infections and hydrocephalus. However, in 1958 a way of draining the excess fluid by means of a shunt was developed, thus making hydrocephalus controllable. Improved methods of surgical treatment to close the lesion, deal with incontinence, and correct orthopaedic (bone deformities) problems, together with new anti-biotics, has meant that since the 1960's many more children have survived.

HOW CAN INCONTINENCE BE MANAGED?

There are various methods of keeping dry, and it will depend on the individual as to the one most suitable for them, but these methods include expression of the bladder, catheterisation, urinary collecting appliances (e.g. urinal, incontinence pads and protective rubber pants, or a urinary diversion operation).

WHAT DOES THIS MEAN FOR CHILDREN WITH SPINA BIFIDA?

1. Possible Health Risks

   (a) Associated with paralysis of the lower limbs and poor blood circulation.

   Spontaneous fractures, pressure sores, ulcers, burns and even frostbite because they are unable to feel change in temperature of the skin.

   (b) Associated with treated hydrocephalus. Life threatening blockage of the shunt system - symptoms of this are severe headaches, vomiting and drowsiness; infection of the shunt system, causing fever and listlessness; eye defect, particularly squint; poor balance and bad hand control.

Associated with urine incontinence. Risk of urinary tract infection and kidney damage.

Possible Learning Difficulties

The intelligence of children with spina bifida tends to come within the lower IQ range. There are differences according to the type and amount of disability and in particular between those children with and without hydrocephalus, although there are some exceptions to this.

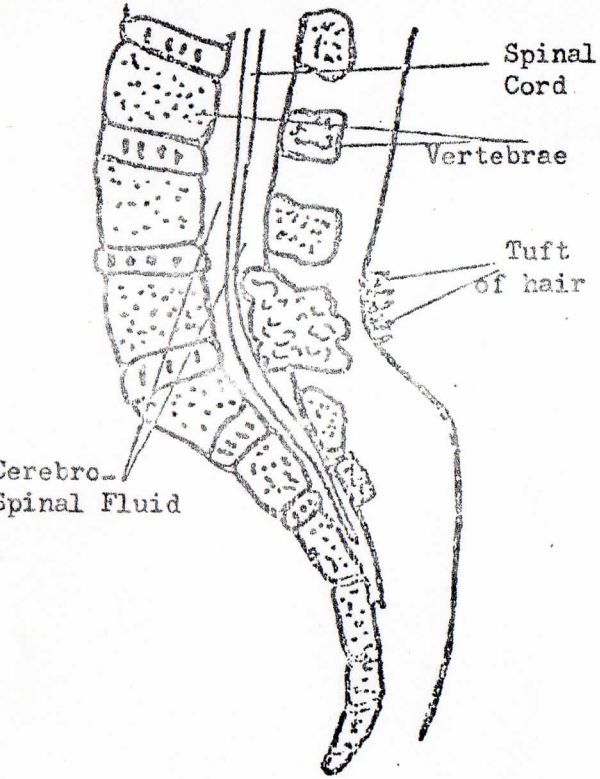
Where there is lessened intelligence, performance ability tends to be more affected than verbal. The main difficulties are in perceptual visio-motor skills so that reading, comprehension, number work and handwriting may present difficulties. The concentration is common as is lack of motivation and a tendancy to be easily distracted.

Other reasons why children with spina bifida may have problems in learning and achieving are; frequent stays in hsopital, lack of normal early experience, sensory impairment, emotional problems. It is important therefore not to have lowered expectations. Teachers have a special responsibility to parents to help them to recognise and accept their children's limitations. This is not easy if, as so often happens with handicapped children, parents have become over-protective.

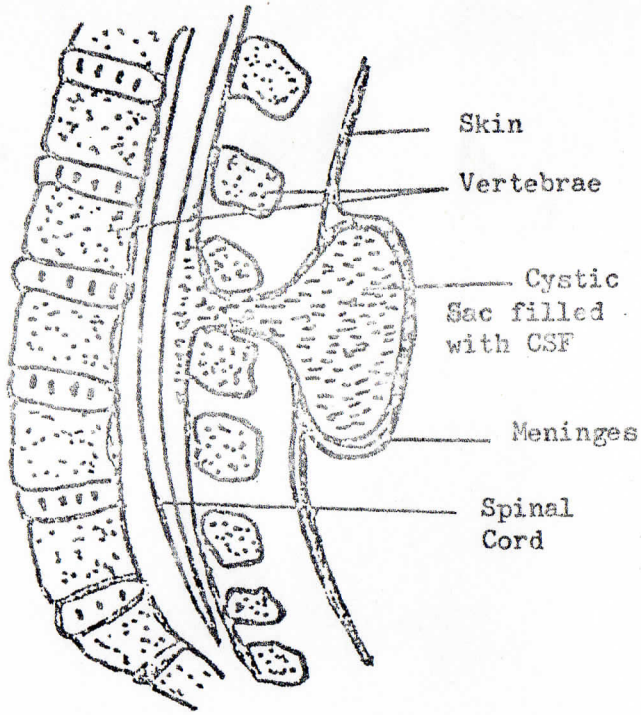
Teachers can also help by encouraging able-bodied and disabled children to mix together naturally and share the experiences of childhood. The disabled child is no different from any other in needing to give and receive friendship.

WHAT SUPPORT IS AVAILABLE FROM ASBAH?

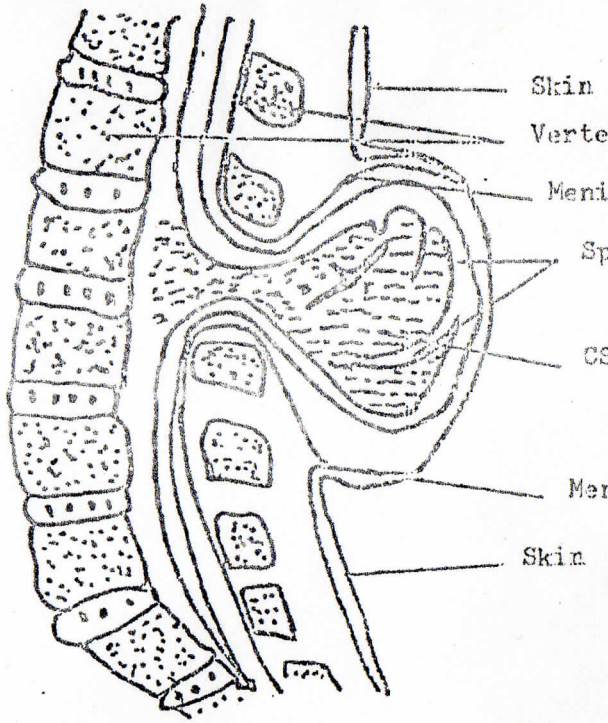
Families where a member has spina bifida and/or hydrocephalus have gained valuable support from over 80 local associations in England and Wales. This support has meant that families do not experience the isolation of families in earlier years where there were no local associations and little, if no, opportunity to get advice and practical and financial help. The National Association has departments dealing with information and advice on aids and appliances, holidays, social rehabilitation and independence training and employment, as well as producing several publications. Fieldworkers throughout the country liaise with local associations and families, advising them on available statutory provision. The Association has a home in Yorkshire which provides holiday care, Individual Independent Living Training Programmes, and Leisure Courses.



Occulta

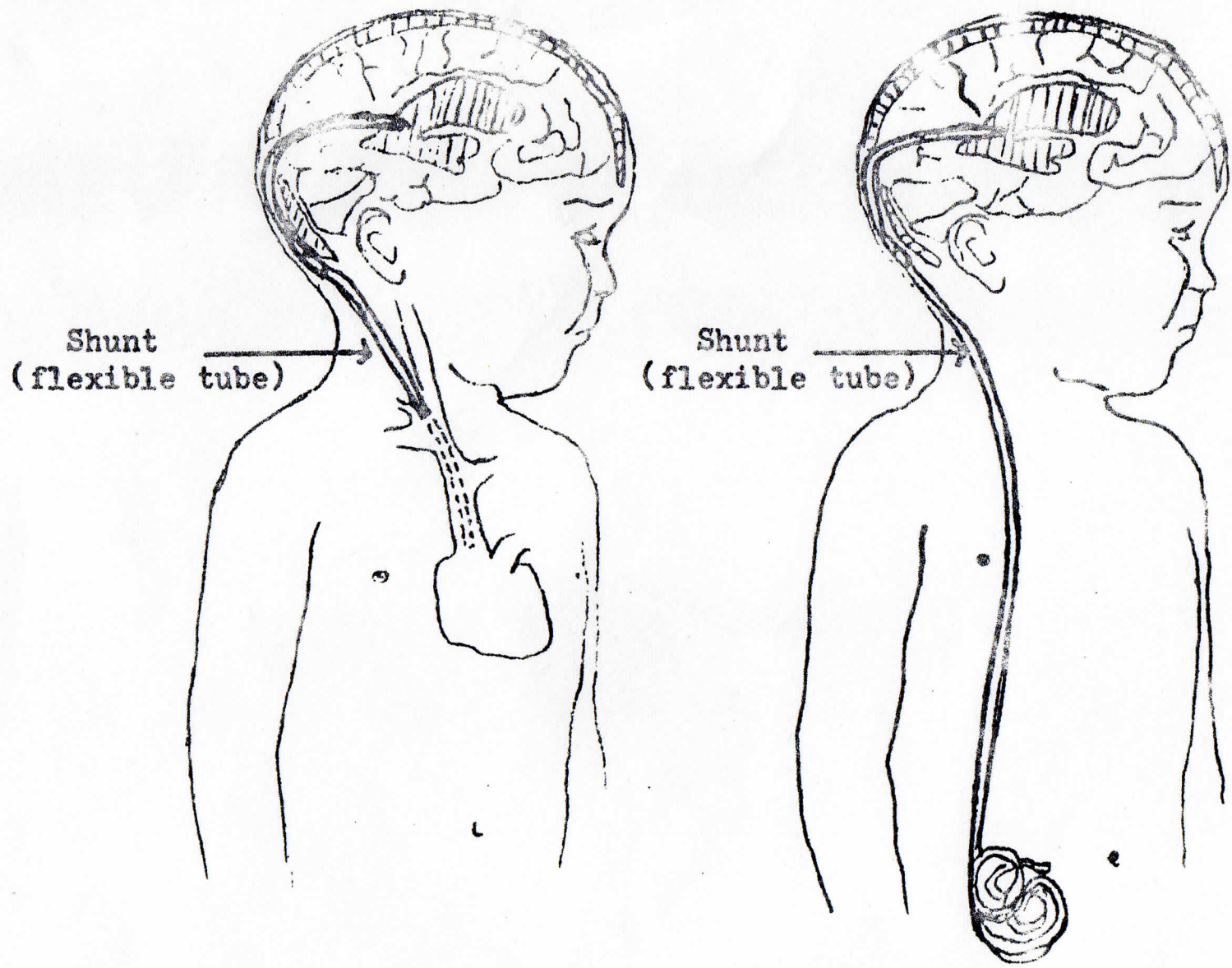


Meningocele



Myelomeningocéle

Spina Bifida 3 Types



Ventriculo-Atrial Shunt

Ventriculo- Peritoneal Shunt

SHUNTING SYSTEMS USED TO CONTROL HYDROCEPHALUS