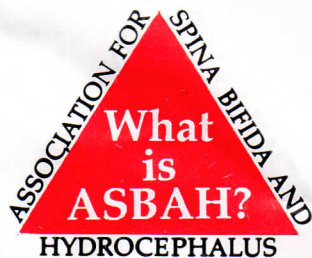


ASSOCIATION FOR
SPINA BIFIDA AND
HYDROCEPHALUS

ASBAH

How we're helping to
get more out of life



▲ ASBAH is a registered charity formed in 1966, to help children and adults with spina bifida and/or hydrocephalus. More than 95% of our work is financed by voluntary contributions.

Because it is a modern, professional and energetic force, ASBAH can help people to overcome the handicaps they face and lead fulfilled, independent and enjoyable lives.

▲ ASBAH is dedicated to achieving equality of treatment for everyone. It is breaking down barriers in areas of life such as education, employment and housing.

It campaigns, educates and informs society about the great potential of disabled people, not just about the problems.

It also presses for improvements in services, influencing legislation, sponsoring research and creating a new awareness amongst the public.

▲ Today, ASBAH is respected throughout the United Kingdom and worldwide, having played a significant role in the founding of the International Federation for Hydrocephalus and Spina Bifida.

▲ The national organisation works from purpose-built offices in Peterborough, which provide a central location and avoid the high property and staff costs in London.

▲ There are also about 80 autonomous local Associations throughout England, Wales and Northern Ireland, many of which are run by parents and young people with spina bifida or hydrocephalus. Most are affiliated to ASBAH and all receive advice and support.

Local Associations work in different ways. Some have started accommodation schemes for young adults; some have holiday accommodation; some support local workers; others function as smaller groups or concentrate on fund-raising.

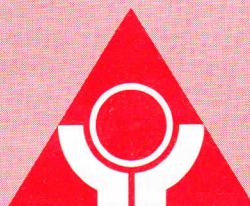
What are the conditions?



SPINA BIFIDA

occurs very early in pregnancy—within the first 25 days. It is a fault in the development of the spinal column, when one or more of the bones of the spine (vertebrae) fail to close properly, leaving a gap.

This means the vitally important spinal cord and nerves are likely to be damaged, often resulting in paralysis below the level of the fault. Walking may be difficult or even impossible. There may also be the problem of incontinence. Later in life, the spine may curve or twist.



HYDROCEPHALUS

is caused by an imbalance between the production and absorption of Cerebro-spinal fluid (CSF) which results in the swelling of the ventricles (cavities) in the brain. An obvious outward sign can be the accelerated growth of the head. The pressure caused by this blockage has to be speedily relieved in order to minimise any damage. This is usually done by the insertion of a valve which drains the excess fluid into the abdominal or heart cavities.

More than 85% of people with spina bifida may also have hydrocephalus but it is also a condition which can occur independently. Because of advances in surgical and medical techniques, many more babies born with the disabilities have survived and taken their place in society. Today, there are more than 15,000 people—children, young people and adults—who, with support, can live fulfilled, independent and enjoyable lives.

ASBAH exists to provide that support.



Giving support and friendship

ASBAH has a team of professional, trained fieldworkers who know the particular problems relating to spina bifida and/or hydrocephalus. Working closely with specialist advisors at the national office, they support parents, families and individuals with advice and practical help. The team covers the majority of England, Wales and Northern Ireland and we are working to increase the number of fieldworkers so reducing the geographical area which they each cover.



Helping with daily living

ASBAH's team of Disabled Living Advisors gives advice on all practical difficulties of living with a disability. The range of potential problems is huge, so the range of expertise within the organisation must reflect it.

Questions about incontinence, mobility, clothing, equipment and treatment are dealt with daily. The advisors also travel round the country sharing in study days which are attended by parents and professionals as well as people with the disabilities.



Helping with education, training and employment.

ASBAH offers advice and help for children at school and to young people going on to further education, training or job hunting.

There are specific and, in the case of hydrocephalus, often hidden difficulties with learning and memory, partial and perceptual problems and poor concentration. These can hinder progress if teachers, employers and colleagues are unaware of them.

ASBAH can provide information to explain the problems and arrange visits by staff to schools, colleges and places of work to discuss specific difficulties. We help some young people to find work by sponsoring them through the Sheltered Placement Scheme or through a work experience programme at the central office. We also help by giving advice and information about the different sorts of employment possible and pointing out the possibilities of rewarding and interesting pursuits which may be available for young people not able to find work.



Helping with Independence Training Courses

ASBAH pioneered the establishment of Independence Training Courses in 1977. Since that time, they have become an important part of the Training Programme, giving young people the opportunity to acquire daily living skills and to learn more about themselves and their disabilities. With help and support from ASBAH, other organisations such as schools and day centres have been able to introduce similar Independence Training Courses into their programmes.



Five Oaks—a unique, positive environment

Set in some of the country's most breathtaking countryside, FIVE OAKS, ASBAH's residential centre in Ilkley, provides accommodation, specialist care and support for young people who attend Independence Training Courses, Activity and Leisure Holidays and Vocational Training.

Five Oaks also offers respite and emergency care to help in a family crisis or when parents wish to go away on a short holiday alone, safe in the knowledge that their child is being cared for and will also enjoy a useful and stimulating break.

A new housing scheme within the Five Oaks complex gives young people the opportunity to live with help and supervision in specially designed flatlets. Here they can, if they wish, undertake studies at local colleges whilst having the opportunity to expand their horizons and develop their domestic skills.

The scheme also has purpose-built individual or shared flats, providing an ideal environment for people who are ready to live independently.

Five Oaks is an ideal place to experience at first hand how ASBAH is helping people to get more out of life.



Helping with housing

Many disabled people are prevented from leading an independent life because of poor housing choice. Housing that is wheel-chair accessible is often difficult to find.

As well as the opportunities at Five Oaks and one or two other locations, ASBAH gives advice and information on other housing options available and works with local authorities and Housing Associations to encourage and support the setting up of new schemes.



Helping with services to young people

ASBAH believes that the provision of support especially tailored to the needs of young people is very important. So, as well as providing the services listed above, there is a constant review of all the things young people with the disabilities need. A regular newsletter is produced and events and courses are organised. These include Mobility Weeks, Driving and Fashion Courses and social opportunities.

A Counselling service is available to both young people and their parents to help with the problems

of growing-up and developing personal relationships. This can be a difficult time for everyone, and there are added problems if you are disabled, especially if nobody recognises your growing sexual awareness.



Helping with information

In addition to the specialist advice and information offered by the various departments within ASBAH, a general Information Service on all aspects of disability is also available.

Publications play a major part in this and Information Sheets are available which give further details on most of the topics covered in this introductory leaflet. LINK, the ASBAH magazine, is produced bi-monthly and there is a range of other booklets about the disabilities and allied topics. A full list is available from the central office.



Helping financially

Coping with disability can be very stressful, worrying and tiring. It is also very expensive. ASBAH directs people to appropriate sources of help and can sometimes give direct financial support through grants for special need such as hospital visiting, equipment, holidays and, sadly, sometimes with funeral costs.



Helping research—and how you can help ASBAH

Research is being conducted into the nature, causes, prevention and treatment of spina bifida and hydrocephalus.

Such fundamental work remains vitally important. Screening techniques can help to an extent but babies are still being born with spina bifida and/or hydrocephalus. ASBAH needs help to help them and to support the research which can improve the quality of life for disabled people, discover more about the disabilities and, perhaps, finally eliminate them.

There is never enough money available to fund all the research projects ASBAH would wish to support. If you would like to help or require further information—please contact ASBAH at the Peterborough address below.

If you would like to make a donation now, please enclose your cheque made payable to ASBAH and send it to the address below, indicating one or any of the following areas of ASBAH's work where you would like the money invested:

- ▲ Fieldwork Support Service,
- ▲ Disabled Living Advisory Service
- ▲ Education, Training and
Employment Service
- ▲ Independence Training Courses
- ▲ Five Oaks
- ▲ Housing
- ▲ Counselling
- ▲ Information Service
- ▲ Research



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