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FIVE OAKS

CENTRE



INDEPENDENCE TRAINING

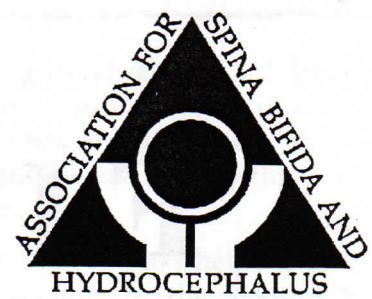
Short courses for individual development
from Childhood to Adulthood



Five Oaks is a unique residential training centre for young people with spina bifida and/or hydrocephalus. It is owned and managed by the Association for Spina Bifida and Hydrocephalus (ASBAH).

*Five Oaks Centre, Ben Rhydding Drive, Ilkley, West Yorkshire, LS29 8BD
Telephone 0943-603013 / 0943-609468 / 0943-602743. ASBAH is a registered charity.*

Structured Courses help fulfil potential



ASBAH is concerned that a large number of children, adolescents and young adults with spina bifida and/or hydrocephalus have difficulties working towards independent living.

They face numerous problems due to the spina bifida lesion. If hydrocephalus is also present, there may be an overlay of additional psychological difficulties.

Our clients are often inadequately prepared for further education, training, employment and leisure. This is especially true of people with hydrocephalus, who require very structured training to allow them to learn to function to full potential.

With this in mind, ASBAH has designed well-structured residential training programmes at our Five Oaks Centre in West Yorkshire. The programmes offer close observation and supervision, and a constructive and comprehensive report, together with recommendations for progression towards independent living. The centre has an EC HELIOS award for independence training.

Why do these young people have special problems?

The many physical limitations resulting from the spina bifida, such as incontinence and restricted mobility, may well have limited a young person's experience of everyday activities.

However, research has shown that hydrocephalus may also cause additional problems affecting the learning of new skills. As this generation of young people has grown up, we have a much greater awareness of how hydrocephalus can adversely affect initiative, organisation and sequencing. Students need help with problem-solving, perceptual difficulties, and lack of motor co-ordination and orientation. There are also problems with general motivation, speed of performance and transferring what has been learnt in one environment to somewhere else.

In the classroom, systematic teaching of basic skills has shown encouraging results and the same approach is necessary with practical tasks.

We take it for granted that children will easily learn to wash and

dress themselves and help with household activities, by watching and working with other members of the family. However, people with spina bifida and/or hydrocephalus, and their associated learning difficulties, need structured, step-by-step teaching and considerable time to practise such apparently simple things as fastening straps on calipers, tying shoelaces, handling knives and scissors and so on.

Many young people may also find it difficult to plan ahead or to know how to set about organising their personal routine and, here again, a structured approach is helpful.

Training for parents with a disabled baby or child

Training in independence should begin in the home and from a very early age. Parents are not always sure of the best ways of teaching their own children, and are often not given enough help or advice.

Five Oaks, therefore, offers a short course when they may come with their son or daughter, to be helped to develop knowledge appropriate to the age of the baby/child on

how to increase skills.

A programme is written for each individual family and may include helping a new parent come to terms with the birth and care of a new baby, knowledge of the specifics of the disability and advice on what to do to help a young child become more independent.

It would be unrealistic to expect a toddler or young child to be immediately receptive to new ways of doing tasks when they are in unfamiliar surroundings. This course, therefore, offers a chance for mum or dad to learn new skills and become the 'trainers' in the home.

Mini-Independence Training Course

This course is offered to small groups of students ranging from nine to 15 years, matched where possible according to levels of maturity. Each group is made up of four girls or four boys and, at present, two courses are held in the Spring and two in Autumn.

Students are often nominated by their schools, therapists or social workers.

The course for this age group is very structured - aimed at developing personal care routines (including management of urinary and bowel incontinence), bathing, dressing, wheelchair transfers, and wheelchair proficiency and stamina.

There are simple talks on their disabilities - 'What is spina bifida?', 'What is hydrocephalus?', 'What is incontinence?' - together with very simplified explanations of how the body works and how their disabilities affect them.

The young students compile an exercise book with short simple text to remind them of the talks when they are at home. They learn about a well-balanced diet and how to plan a simple meal, to shop and to cook, together with safe ways to make hot drinks, cook beans and so on.

■ *A 10-year-old came up with this brief description of the course:*

"When we arrived at Five Oaks, we had a 'getting to know you' sessions and were told what was going to happen. The next day we started a personal care programme in which we were taught to take care of our bodies and, in the afternoon, we learned how to manage our wheelchairs: I enjoyed this because I like to do wheelies.

One day we went shopping in Ilkley. We bought sausages, beans and brown bread which we had to cook for tea ourselves. We went to a restaurant for tea on another evening.

At the end of the course, we talked about our achievements during the week. I learned a lot on the course and, although it was tiring, I enjoyed it."

Parents are invited to collect their child on the last day to discuss progress. A detailed report is written with recommendations for future action and ASBAH may liaise with school staff, social workers, careers officers, medical consultants etc before and after the course. In some areas, where ASBAH has its own fieldworker, ASBAH staff keep in touch with the family afterwards.

■ *'Home-based' students*

Children and young adults who are at residential schools and/or colleges sometimes have no home to return to in the holidays. They can find support and friendship at Five Oaks.

We give them encouragement, practical support and some of the fulfilment that home should provide and, if they want, a point of contact during term time.



Although no formal training programme is established, we try to widen their physical and intellectual horizons.

■ *Individual courses for students over 16*

Individual training courses can be planned round the needs and requirements of the individual and the sponsoring authority. These courses usually cover five days but they can be extended to a maximum of four weeks.

Elements which can be structured into individual programmes include the development of:

- a good personal care routine;
- skills to manage urinary and bowel incontinence;
- transfer skills in and out of the bath;
- an effective washing routine;
- the ability to dress themselves, offering equipment to assist if necessary;

- skills to transfer in and out of the wheelchair;
- wheelchair proficiency, maintenance and road safety;
- the understanding of a well-balanced diet;
- shopping skills, preparing and cooking meals;
- basic budgeting skills;
- dealing with personal laundry;
- personal tidiness and room care.

Priority is given to individual performance and abilities in personal care. Students will be made aware of exactly what needs to be achieved, even if physically they are unable to do the routine themselves. Sometimes, to be able to tell other people what needs to be done is as important as being able to do it themselves.

Students have a chance to discuss their own disabilities, and to explore the implications for themselves.

■ *Continued on page 4*

Need an assessment?

Local authorities are invited to discuss the assessment of children with spina bifida and hydrocephalus with our own specialist staff at Five Oaks. Our skills can assist Local Education Authorities and Social Services Departments in making their assessment of children in need.

Engaged couples and partnerships

We offer a period at Five Oaks which can include training in any of the area listed under Individual Independence Training, but with the emphasis on mutual support. Once each partner has been able to identify their own strengths and weaknesses, they can often bring complementary skills to the relationship.

This course is offered for five days (Monday to Friday) but a longer stay can be negotiated if appropriate. A session with a counsellor skilled in imparting knowledge of sexual awareness can be included at an additional cost -if negotiated in advance.

Disabled Mothers and their Baby/Child

The need for training in this area is very important. We can offer an initial short stay to observe and highlight areas which help and advice may be required.

Quite often, young people with spina bifida have never cared for babies before. They may have seen their brothers, sisters and peers with babies.

They may have held a baby but it is unlikely that they will have experienced what it is like to care for a baby for an hour, never mind 24 hours.

Because of specific learning difficulties and the physical limitations

of being in wheelchair, it is important to prepare carefully during pregnancy and after the birth to help the parent(s) enjoy this part of their lives.

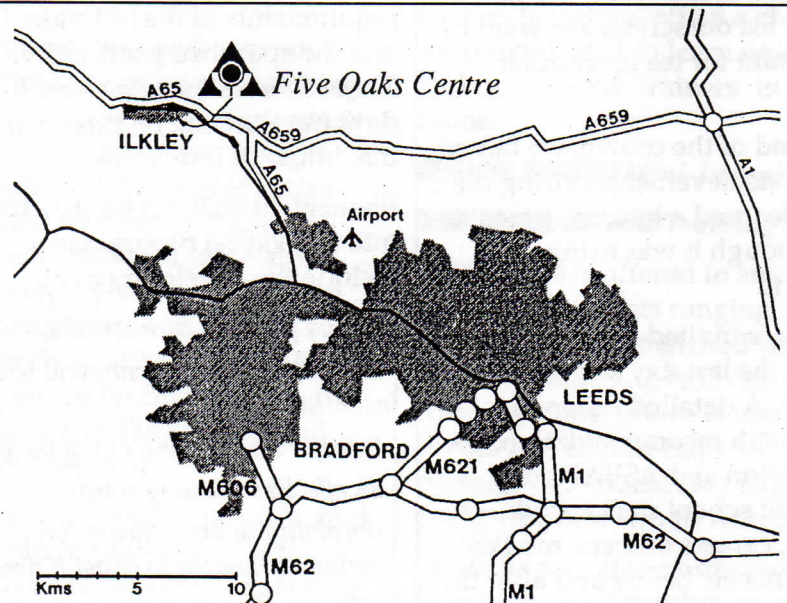
A stay at Five Oaks helps to focus their attention on the needs of the baby and to receive information about useful equipment and adaptations.

At the end of the stay, a detailed report includes observations on how the client has coped and lists equipment the parent(s) may find useful. This report is usually prepared for the sponsoring authority, but we also regularly prepare reports for solicitors where a court hearing has been arranged.

Funding

The stays outlined in this brochure are based round a nightly rate, which increases annually. Students need to bring some spending money and travel arrangements are organised by the sponsoring agent.

Places can be offered as soon as the financial arrangements are in place. An invoice will be sent to the sponsoring authority at the end of the month in which the short course has been completed.



Five Oaks has good road and rail links and is within easy reach of Leeds and the M1 and M62 motorways, Leeds and Ilkley British Rail with Leeds -Bradford Airport nearby.

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