Link

The magazine for people with
Spina Bifida and/or Hydrocephalus

ASSOCIATION FOR SPINA BIFIDA AND HYDROCEPHALUS

February/March 1993
Issue No 144 Price 80p

LIFESKILLS DEVELOPMENT COURSE

18 - 23 July, 1993
at Beaumont College
of Further Education, Lancaster

A unique residential course for young people (11-15 years) with spina bifida, designed to improve:

- ▲ personal independence
- ▲ mobility skills
- ▲ creative use of leisure time
- ▲ sense of self-awareness
- ▲ awareness of relationships with others

For more details and an application form, contact
Lynn Thomas
ASBAH House
42 Park Road
Peterborough PE1 2UQ
Tel: 0733 555988

ASBAH is indebted to the Association for Wheelchair Children for supporting this course, but it is necessary to make a minimal charge of £95 (including £25 non-refundable deposit)

A meeting with the minister

ASBAH has raised key issues confronting people with spina bifida and/or hydrocephalus with the Minister for Health, Dr Brian Mawhinney. The Minister visited our National Centre in December.

Topics raised included: the shortage of therapy in school, patchy provision of well-designed wheelchairs, fears for the future of specialised training facilities following a funding change, and the potential for lapses in co-ordination when community health care and acute care are run by different NHS trusts.

ASBAH stressed that there was too little therapy available to children in schools, at a time when a holistic approach to educational and physical development would help produce confident and independent young adults.

Dr Mawhinney said improvement would result from spreading good practice rather than attempting to direct health authorities.

Dr Mawhinney appeared to accept that the provision of well-designed, modern wheelchairs, to boost the capacity for independent living, had been patchy since the wheelchair service had been delegated to District Health Authorities. In many cases, ASBAH argued, unsuitable wheelchairs were being supplied. The Minister asked to be supplied with details of areas of serious deficiency.

ASBAH expressed concern that national centres of expertise like Five Oaks, which have been partially funded by DSS payments, might be at risk when funding passes to local authorities in April. Dr Mawhinney said that most money being passed to local authorities had to be spent in the voluntary and private sectors. ASBAH should market its services to local authorities to take advantage of this. The Minister invited ASBAH to contact the head of the Government's Community Care Support Force on specific issues.

ASBAH was also concerned that, with the setting up of NHS Trusts, the essential co-operation and co-ordination between acute hospital services and community health services may be damaged. Department policy was for trusts to provide either acute or community services, but not both. Dr Mawhinney said he expected good communication between trusts and that government policy was to place more emphasis on primary care services, such as GPs, child development centres and community health services.

Representing ASBAH were chairman Patrick Daunt, vice-chairman Austin Crowther, medical advisory committee member Carole Sobkowiak and executive director Andrew Russell.

Afterwards, Mr Russell said: "The meeting opened up several useful avenues for us to press for improvements we know to be necessary. We shall continue to keep Government informed of our views. I am meeting the head of the Department's Community Care Support Force in early February, and I have arranged to attend the Parliamentary All-Party Disablement group, to put ASBAH's views on therapy and wheelchairs."

Contents

On the cover: Robert Murphy enjoys a view to a thrill as he takes part in an abseiling expedition from our Five Oaks Centre in Yorkshire. See page 10.

Government accepts advice on folic acid

ASBAH has every reason to be proud of the Department of Health's decision, announced just before Christmas, to urge all women planning a pregnancy to make sure they have enough folic acid in their diet.

Our campaigning and approval of the form of the study were instrumental in the setting up of the Medical Research Council's Vitamin Study, which 18 months ago proved that folic acid added to the diet had a 72% effect in preventing the reoccurrence of neural tube defects in pregnancy.

Now the Department of Health has gone an important step further to promote the vital importance of folic acid in all pregnancies - by stressing that folic acid will help prevent neural tube defects like spina bifida and anencephaly happening in the first place.

It has accepted the advice of an expert working group, established after the publication of the MRC results, which confirmed that daily 5mg capsules of folic acid should continue to be made available on prescription to all women at risk when they are trying to have a baby and into the first 12 weeks of pregnancy.

In a new shift in direction, the Department also urged all women wanting a baby to eat folate-rich foods and in addition to take daily 0.4mg supplements of folic acid, as soon as preparations containing this dosage can be got into chemists' shops for general retail sale.

The reasons for the over ten-fold difference in dosages are complex but relate, in essence, to the maximum dosage where no major adverse reactions have been reported and the minimum which is thought to be any use in prevention. The dosages, however, are not cast in tablets of stone; they will be varied if future research shows they need adjustment.

Executive director Andrew Russell welcomed Government promises to spread the word about folic acid more widely through a public education campaign and to attempt to monitor NTD occurrences more fully, by counting terminations of pregnancies.

"We know that about 400 babies are born each year with spina bifida and related disabilities in England, Wales and Northern Ireland. But that figure does not give the true incidence because information is missing," said Mr Russell.

"Until we know how many hundreds more pregnancies are terminated every year as well as recordable miscarriages, we can only guess at the real extent of the stress and trauma faced by families and the real prevalence."

Dressing up for ASBAH

Peterborough's Soke Round Tablers, who carried out a fancy dress collection for ASBAH in the city's Queensgate shopping centre, handed over an £850 cheque from the results, at ASBAH House, just before Christmas.

Pictured receiving the cheque are (from the right of the picture) Andrew Russell, Helen Stevenson and Donna Drew.

Promise of better treatment in Northern Ireland

Hospital managers have promised to improve facilities for children with spina bifida needing paediatric orthopaedic surgery at the Royal Belfast Hospital for Sick Children - following ASBAH's complaint of a "lamentable" breakdown in service.

Regional co-ordinator Meta Harvey and Jimmy Rippey, secretary of Northern Ireland ASBAH, pursued the complaints at a meeting with administrators at the end of last year. They are still waiting to hear how the situation will improve, and when.

Information sheets revised

ASBAH has revised two of its fact sheets - Number 6 dealing with vaccinations, and Number 7 about statementing for special educational needs.

The vaccinations sheet updates ASBAH's advice about MMR II vaccination (for measles, mumps and rubella) and welcomes the Hib vaccination (for type B bacterial meningitis) which has been available only since October last year.

Peter Walker, who has recently had his hours as education adviser at National Office increased to full-time, has updated our sheet on educational statementing and increased its content.

These information sheets are available, on request, from the Information department at ASBAH House.

New South East Region office opens

ASBAH's new South East Region Office is now open in Barnet. The office is manned by regional co-ordinator Gina Broughton and the new secretary Denise Taylor who are awaiting the appointment of a full-time disabled living adviser, to join them in the near future.

Jo Rees, fieldworker for North London, will also make the office her base.

ASBAH South East Region, 123 East Barnet Road, New Barnet, Hertfordshire EN4 8RF. Telephone: 081 449 0475.

New continence charity

The Continence Foundation - launched in November last year - aims to bring together professional, consumer and research activities relating to bladder and bowel control. Their first publication is a 'Continence Resource Pack' for Primary Health Care Teams.

The Association for Continence Advice, of which ASBAH is a member, is amongst those organisations which have become affliated to the Continence Foundation.

Essay award

An international honour has come to Carole Sobkowiak, a member of our medical advisory committee.

Miss Sobkowiak won the 1992 Casey Holter Essay Prize, awarded by the Society for Research into Hydrocephalus and Spina Bifida. Her essay title was 'Effect of Hydrocephalus on Neuronal Migration and Maturation'.

It was the first time in seven years that the award panel has been presented with an essay good enough to merit the prize.

The prize is awarded in memory of the son of John Holter, the American inventor of the first Silastic valve which in 1956 paved the way for successful shunting of many thousands of patients with hydrocephalus.

Miss Sobkowiak, superintendent physiotherapist at Darlington Memorial Hospital, has a long and distinguished record of support and advice for ASBAH.

Her visit to the pioneering conductive education institute in Hungary in 1988, on behalf of ASBAH, resulted in the association receiving a comprehensive overview of Peto's work in relation to children with spina bifida and hydrocephalus.

Write on

The written work of two teenage schoolgirls has improved dramatically since they were given word processors. Both Janet Charlesworth and Georgina Cash, who have difficulties with handwriting, are delighted with their new machines.

The word processors where donated by Sharp UK.

Mr Norman Bethell from Sharp UK presents Jean Black with a word processor.

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Allergic to latex?

In America, latex allergy has raised cause for concern in hospitals, where this material is widely used in the operating theatre, for example, latex surgical gloves.

Children with spina bifida could be at risk of developing the allergy as they often face many operations where they will come into contact with latex. This fact was reported by the Baltimore correspondent for The Economist - in the science and technology column of the magazine: "Children with spina bifida... face as many as 20 corrective operations before reaching adulthood, so they come into contact with all sorts of medical apparatus that contains latex. And for people predisposed to latex sensitivity, the more frequent and prolonged their exposure the worse the reaction can become." In the USA, staff caring for children with spina bifida take precautions to prevent them becoming sensitised to latex.

The US experience is similar to that described by Professor Barry Shandler (Professor of Paediatric Surgery at the Hospital for Sick Children, Canada).

ASBAH continence adviser Mary White, who visited the USA last year, came across this problem in her discussions with medics. At the Children's Hospital in Boston, Massachusetts, a surgeon reported on one of the earliest proven cases of latex allergy and at the Shriners Hospital in Houston, Texas, they also expressed concern about this problem.

At the Houston Center for Incontinence and Bladder Disease, the medical director told Mary White he thinks that in Britain perhaps we do not recognise latex allergy as the cause of the reactions of some children undergoing surgery and, instead, cite anaesthetics as the cause.

On her return to Britain Mrs White informed all paediatric consultants, engaged in the urological and surgical treatment of children with spina bifida, of the American experience.

One of the areas under investigation in the USA is manufacturing. Mary White was asked to supply several pairs of UK surgical gloves to Dr Rudi at Houston University Hospital. These will be compared with American gloves and the results shared with us.

Obituaries

Dr Brian Tew *BA (Phil), BA (Psych), PhD, Dip Ed Psych, F B Psych S*

Dr Brian Tew died at home on Thursday 14 January, having borne with great and characteristic fortitude the effects of a brain tumour since the middle of last year.

Brian will be known to many either as a source of advice or as an informative yet amusing lecturer. He has also been of immense help to children with hydrocephalus and spina bifida and their families over the years and many have cause to be grateful for his efforts on their behalf.

Brian Tew was born in 1937 and after initially deciding to leave school at the earliest opportunity he later returned to this studies. He had a variety of spare-time jobs while at university and was a very active student. He was also extremely hardworking and by the time he took up a Lectureship in Education at Cardiff University he was well qualified for the post. He later achieved his doctorate. He has also been a very active member of the Society for Research into Hydrocephalus and Spina Bifida, his illness last year causing him to miss his first meeting since he joined in 1974. Since 1985 Brian has been one of the Society's Publications Secretaries, first with Professor Guiney of Dublin and then with Miss Bannister of Manchester, and as expected he excelled in this remarkably difficult job. He and Miss Bannister were also joint editors of a textbook on hydrocephalus and spina bifida, published last year. Through his academic work, his publications and his involvement in scientific meetings, Dr Tew has left an indelible mark on the field of psychology related to hydrocephalus and spina bifida. He will be remembered for this, but also for his wit and good company, by his colleagues both here and round the world. He is survived by his wife Jessie, whom he met while at school, and three grown-up children. *Dr Roger Bayston.*

Steve Robinson

Steve Robinson was a member of Lincoln and Mid Lincs ASBAH from childhood. He was known by all the members and had served on the committee. Described by the association's secretary, Mrs Malson, as a "tireless worker, who is missed by everyone", Steve was a popular local figure.

He was an active fundraiser not only for his local association but also Lincoln Dial-A-Ride, where he worked, and for Birchwood Health Centre. His tricycle marathon in the summer of 1991 was featured in LINK magazine - only two weeks after having his appendix removed, Steve rode 18 miles to raise money for Birchwood Health Centre as a thank you for all the treatment and help he had received from them over the years.

Steve, who had spina bifida and hydrocephalus, died suddenly in November, he was 22 years old.

We send our deepest sympathy to his parents, sister and brothers.

NEWS IN BRIEF

A good year for Tanni

Tanni Grey won four gold medals at the paralympics in Barcelona, won the London ladies' wheelchair marathon and was named as one of Britain's people of the Year - quite a year for the 23-year-old athlete who has spina bifida. And to add to her triumphs she has been made an MBE in the New Year's Honours List. Our congratulations to Tanni and here's to another successful year in '93.

Wheelchair trousers

The 'Special Collection' spring and summer catalogue from J D Williams is now available. Wheelchair trousers, which are cut higher at the back and lower at the front, are one of the items in the catalogue - they come in beige for men, from £26.99, and blue for ladies, from £25.99.

The catalogue also marks 'easy dressing' features of other clothes (such as long front-fastening zips) and contains a small section on useful gadgets.

The Special Collection, J D Williams,
Daie Street Mail Order Group of
Companies, PO Box 123, Manchester
M1 8BH. Telephone: 061 228 0626.

Mail order questionnaire

If you would be interested in shopping by post from a major mail order catalogue but feel they do not cater for special needs, or you have tried mail order shopping, please fill in our questionnaire on page 20 of this issue.

Penfriends

Michael (right) is a 14-year-old, French school boy who would like to write to an English boy.

Tracey is 22-years-old and has hydrocephalus alone. She would like to hear from anyone aged 18-30. Tracey is a fan of Aussie soap operas and rock music.

Jason, from Stratford, East London, is 27-years-old and would like to hear from anyone aged 20-30. He also has hydrocephalus alone and is interested in pop music (Michael Jackson and Whitney Houston are two of his favourites), football and comedy TV programmes.

If you would like to contact any of these penpals, send your letters to LINK and we'll pass them on.

Driving Holidays at Banstead

Banstead Mobility Centre are holding two driving holidays: from 10-15 May and 9-14 August. The holidays are designed for young learner drivers with a disability. Each course includes 10 hours in-car tuition in an adapted car. For further details contact:

Barbara Simms, Banstead Mobility Centre, Damson Way, Orchard Hill, Queen Mary's Avenue, Carshalton, Surrey SM5 4NR. Telephone: 081 770 1151.

Pressing for better services for the over 19s

Action 19 Plus is an alliance of voluntary organisations, including ASBAH, which has produced an information pack for people aged 19+, with physical, sensory and learning disabilities, and their parents, to help them get more from statutory services.

The group has been formed to challenge the low status and low priority given to disabled people. Workshops have also been designed for disabled adults, carers, enablers and all those concerned with the quality of services available to disabled people. The Workshops take participants through the wide range of actions they can take to apply pressure and get results.

The next Action 19 Plus workshop for parents and service users is on 20 February in Bristol with other days planned in Calderdale (27 March); Cardiff (3 April) and in Newcastle, Portsmouth and Clacton (dates to be announced).

To get a copy of the information pack, and details of future workshops contact: *Action 19 Plus,, 148-150 Curtain Road, London EC2A 3AR. Telephone: 081 550 5466.*

Lyke wake walk

Readers who would like to take part in the exhausting, 42-mile Lyke Wake Walk across Yorkshire moorland on 29 May should contact Tony Britton at ASBAH House. The driving force for the expedition - responsible for liaison with the 'Chief Dirger' who invented the walk, and the logistical backup - is Kevin Daily, of Ely, Cambs, whose daughter Joanne has spina bifida. The walk will be an ASBAH fundraiser.

Did you go to special school?

If so, Simone Aspis would like to hear from you, as she is writing a book about the kind of education being offered by special schools. *Phone Simone on 081 459 5717.*

Improving handskills in our children

Mary Barton reviews some research into sensory hand function and relates it to her work with children at Five Oaks.

For those readers who remember the early years, when there was an increase in the survival rate of babies with spina bifida and the associated hydrocephalus, you may well recall the optimistic forecast of that time. This equated the condition with spinal injury and thus concluded that those with spina bifida and hydrocephalus would grow up to be employed on the strength of their language abilities and unaffected hands - the effects of hydrocephalus had not been taken into account.

Since those days our knowledge has grown and much has now been written about the "hidden learning difficulties" which may be experienced by those with hydrocephalus. *(a,b)*

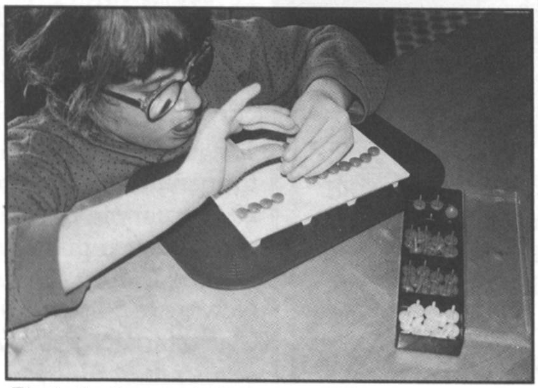


Fig 1: Student aged 13 years- unable to turn a peg around using the fingers of one hand - has to use both hands. Note the extra movements include the tongue

There have also been various studies on hand skills and articles written on the delayed myelination of the nervous system. *(c,d)* Carole Sobkowiak combined these in her article Hydrocephalus and upper limb control in LINK June 1992.

The results of a study carried out in Australia were published In the British Journal of Occupational Therapy in the autumn of 1991 in an article by Ann M Hamilton. This research included sensory tests of joint and position sense; two point discrimination; localisation of tactile stimuli; stereognosis (the ability to name objects their size and texture when held unseen in the hand) and graphaesthesia (the ability to name a figure or shape unseen when drawn on an outstretched palm).

The results of this study indicated that there was a significant deficit in these sensory areas in the spina bifida group. And that: "such widespread sensory abnormality can be expected to have effects both on the current level of hand function and on the subsequent development of movement patterns and hand skills". *(f)*

Reports from Five Oaks

Perhaps the most common comment, written in reports following a short independence training course at Five Oaks is: "immature hand movements and poor finger dexterity, leading to poor and clumsy handskills". This conclusion has been made following careful observation of the student's performance in personal care, daily living activities and more specific tasks - such as the use of a pegboard. (*fig 1*) For example it is not uncommon to note the inability of a 13-year-old or even 16+ aged students to grasp and rotate the forearm when wringing out a flannel/sponge. The action appears similar to the immature movement of a 5-7-year-old, before they have developed the ability to easily supinate (turn the forearm upward).

Fig 2: Student aged 11 years using top opening tin opener. In spite of some immaturity of the hands, she can produce a tripod grip and indicates her ability to understand direction of movement.

Supination of the forearm is a more mature movement and until this has developed, other daily living activities cannot be

Fig 3: Compare 13-year-old student's attempt to open a tin with that of fig 2. Exaggerated arm movement and inability to localise movement to wrist alone. Possibly a difficulty in body scheme.

performed with ease. Using an ordinary tin opener, not only requires skills of perception to place it correctly on the lip of the tin, but to turn the key some supination is used. However, when a top opening tin opener is used *(figs 2 & 3)* the key is turned with the hand/forearm in pronation and the screw movement is achieved using a smaller wrist movement. For those who cannot achieve this movement, but can manage perceptually to place the tin opener, an electric or battery type may be more appropriate.

Early training

Researchers have identified abnormal body scheme amongst some of the spina bifida group, which may be part of the reason for the poor hand function with such daily living tasks as using scissors, undoing and doing up buttons, writing and using a knife and fork. *(fig 4)*

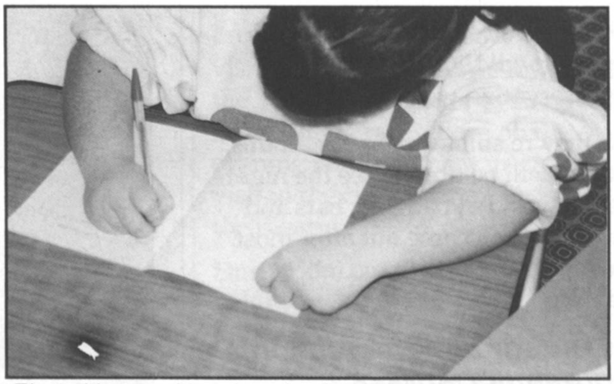


Fig 4: 11-year-old student showing persistant mirror movement which usually disappears at about 5/7 years of age

Ann Hamilton stressed the importance of early training to help develop the ability to discriminate sensory information in order to help develop body scheme.

In the past there was the danger that the development of hand skills was being neglected due to the emphasis placed on "walking". Not only did this consume the therapist's and parents' time, but the fact that the child lost out on hand experiences, whilst they supported themselves on their walking aids, was neglected. This makes it even more important that there is plenty of sensory input through play with textured materials (finger painting, sand and water play etc). Also toys and games which encourage play between two hands (use of balls, stickle bricks, popoids and larger toys) and finer finger movements (finger puppets, duplo, pegboards etc).

From my previous experience, working with the pre-school child and the work at Five Oaks with students on the short courses, I have seen the importance for early sensory stimulation to encourage development of the hands. Paediatric therapists should be involved with babies with spina bifida and/or hydrocephalus, as early as possible to work with them and to advise their parents on appropriate hand play *(g)*. Throughout the child's development the movements and sensory development of the hands should be observed and compared with the general physical and mental development. When necessary the advice of an occupational therapist should be sought in order to help the child achieve the best possible hand function for their future.

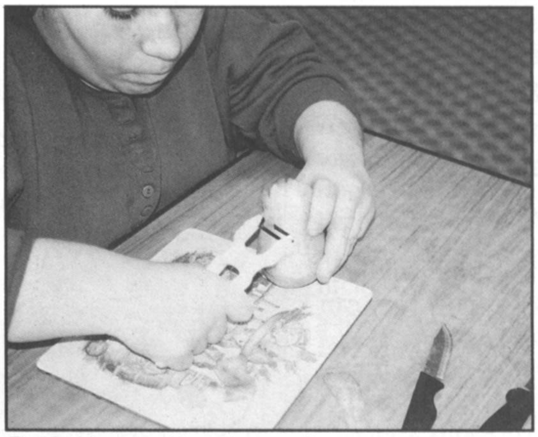


Fig 6: 11-year-old student peeling a pear using a two sided peeler. This makes for easier manipulation and only requires one direction movement - a downward stroke.

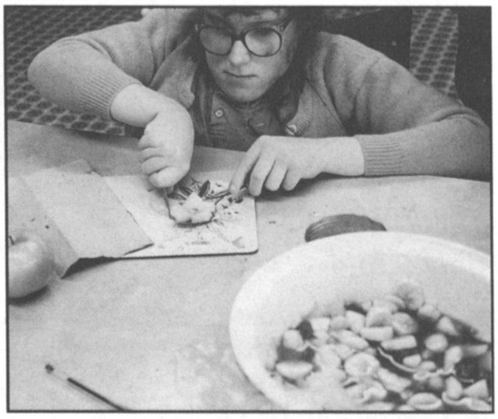


Fig 5: 13-year-old student showing pronation and deviation of right hand whilst cutting fruit. (student writes with her left hand)

References

(a) Young People with Spina Bifida and/ or Hydrocephalus - Learning and Development. Leonie Holgate MCSP SRP.

(b) Hydrocephalus ASBAH Fact Sheet no 2.

(c) Myelination as an Expression of the Functional Maturity of the Brain - Developmental Medicine and Child Neurology 1991.

(d) Handskills in children with spina bifida LINK no 55

(e) Hydrocephalus and upper limb control, Carole Sobkowiak, LINK no 140

(f) Sensory hand function of the child with Spina Bifida Myelomeningecele, Ann M Hamilton, British Journal of Occupational Therapy, September 1991.

(g) Development of upper limb and hand function found in the development progress of infants and young children by Mary Sheridan, published by HMSO.

Also summarised in "I can use my hands", produced by Play Matters National Toy and Leisure Libraries Association, 68 Churchway, London NW1 1LT.

Mary Barton is a disabled living adviser at our independence training centre, Five Oaks, in Yorkshire

Something for everyone

You can be as lazy or energetic as you like on a Five Oaks holiday. For 1993, ASBAH's independence training centre in Yorkshire offers everything from fishing to fashion, wildlife watching to waterskiing and learning to drive a car to learning to be a DJ. Now all you have to do is make your choice. Whatever you choose, you can relax confident in the knowledge that the experienced support team provide 24-hour cover to ensure assistance is there when you need it.

Fishing Weekend

July 2 to 4

At Ilkley Lagoon, the fishing weekend will teach the skills of coarse fishing. Many large fish live in the lagoon and students will be able to pit their wits against carp, tench, perch and chubb. With luck, there should be at least once big catch (tales about "the one that got away" are not allowed), but dinner will be provided - even if they don't catch a bite.

D J Course

December 1 to 5

This course gives the opportunity to find out all about live broadcasting. Whether fans of Radio 1 or Classic FM, students will learn about the use of sound equipment and how to go about putting together a live show.

There will be visits to radio stations to get some handy hints from the professionals. This expert advice will be put to good use on the Saturday night when students host their own disco.

Wildlife Week

June 19 to 26

If people enjoy watching wildlife programmes on TV, now they can see some of Britain's most beautiful animals and birds for real. During the week, they will be on safari in the Yorkshire Dales, Lake District and along the coast.

Patience will be needed to spot a herd of deer on a remote hillside, but it's worth the wait. With luck, there might also be a golden eagle or other bird of prey soaring overhead or swooping down to catch its dinner.

At the coast, there will be chances to spot seals and visit bird sanctuaries, nature reserves and a gannetry with noisy nesting sea birds. By the end of the week, students will not only know more about the way in which animals live, but also about how we can protect wildlife by countryside conservation work.

If they're still awake after all this, there will be time to see the night-time world of badgers, bats and owls, which come out after most wildlife watchers have fallen asleep.

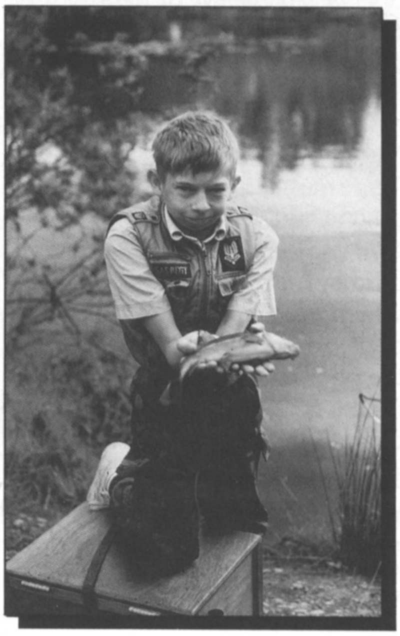
Outdoor and Recreational Pursuits Courses

July 17 to 24

July 24 to 31

September 4 to 11

These courses are led by some very experienced instructors who are skilled at teaching a variety of exciting sports and interests.



Watersports to be tried include sailing, canoeing, waterskiing, swimming and canal boating. For those who would like to take to the skies, how about having a go at the microlight flying or gliding - simply breath-taking!

If, on the other hand, Five Oaks visitors prefer dry land, they could try abseiling down the Cow and Calf Rock at Ilkley, caving, skiing, orienteering, racket/ball

sports, ice-skating, fencing or archery. Students might also like to combine some of these activities with the gentler but fascinating pursuits of arts and crafts, photography or film-making.

Our instructors will help you learn something new and challenging. Learning a new skill can give a great deal of fun and satisfaction, as well as the confidence to perhaps take up a new sport or hobby.

Driving Courses

March 14 to 20

September 26 to October 2

The Driving Courses are taught by instructors who know all about the needs of disabled drivers. They are skilled at teaching young people with spina bifida and/or hydrocephalus, so learner drivers will receive expert tuition and advice.

There will be driving lessons twice a day. First of all, however, students will be taught off the road - so they can learn the basics safely away from other traffic. They will be taught how to judge space, good road positioning, decision-making and reaction times. These are all essential for safe driving. Our instructors will watch how well students perform, and give helpful advice on how to improve and develop road skills.

When not driving, L-drivers will be given help and advice about the Highway Code, road safety, car maintenance, the cost of running a car and the legal aspects of driving. Special advice for people with disabilities will also be given, including how to get the best driving tuition, suitable adaptations and car controls, getting a wheelchair in and out of the car safely, and Motability.

At the end of the week, a personal progress report will be discussed individually with each student, giving handy tips on what aspects of driving needs to be looked at next.

Day Tripper Weeks

March 21 to 27

June 6 to 12

Day Tripper Weeks let Five Oaks guests choose from a wide range of trips out and activities, to give a wonderful variety of days out.

Perhaps they would like a trip out to the coast, or a spot of bird and animal watching. Or perhaps bump into friends on the dodgems at Lightwater Valley Theme Park, learn to ski, or test their skills at tenpin bowling.

Enjoy a canal boat cruise, visit some of the historic towns of the Yorkshire Dales or even have a flutter at the races. For your evening entertainment, perhaps a visit to the cinema or an outing to the theatre.

During the Day Tripper Week, what you do is really up to you, and we can guarantee that you will have plenty of fun.

Winter Wildlife Course

November 25 to 30

Does the idea of coming for a winter holiday to Britain sound bird-brained?

Well, that's exactly what many birds which live in colder countries do!

After their exhausting journeys, some up to thousands of miles, they make their winter homes on lakes and reservoirs all over the country.

We shall see that some of these exciting winter visitors are quite shy, whereas others live in huge flocks. During this long weekend, we will be watching them from the secrecy of specially-built hides, in a number of different reserves and bird sanctuaries.

As well as spotting some rare visiting birds, we should also see flocks of swans, geese, graceful herons, teal, oyster catchers and brightly coloured shovelers. With luck, we might spot a bird of prey such as a barn owl, or peregrine falcon. With knowledgeable guides on hand, this long weekend is an ideal opportunity to see some of Britain's most exciting winter wildlife.

Activity Holiday Weeks

Throughout the Year

Why not get away from it all with a Five Oaks Activity Holiday Week?

During the school holidays, we have an exciting variety of things for you to do.

Perhaps you want to relax among the peace and beautiful surroundings of Five Oaks itself, or maybe you would prefer an action-packed week of day trips out, sports, outdoor pursuits and other recreational activities.

We offer weeks for children and weeks for adults, so there is something to suit everyone on an Activity Holiday Weeks at Five Oaks.

Fashion Course

April 25 to May 1

International Fashion

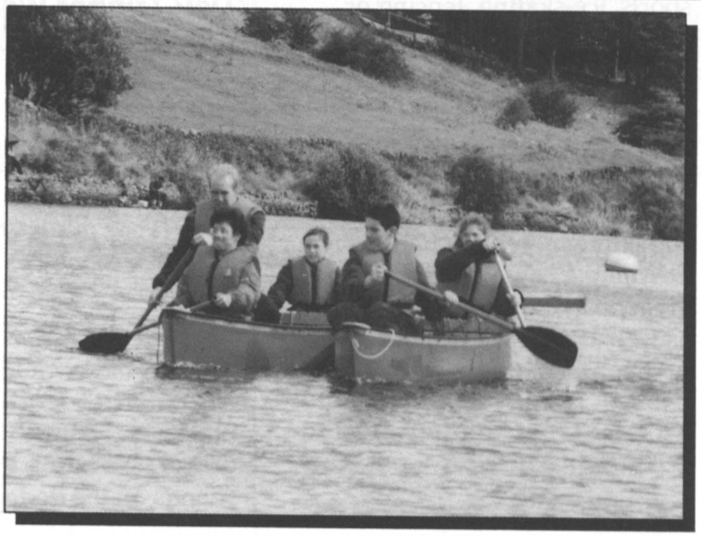
October 10 to 17

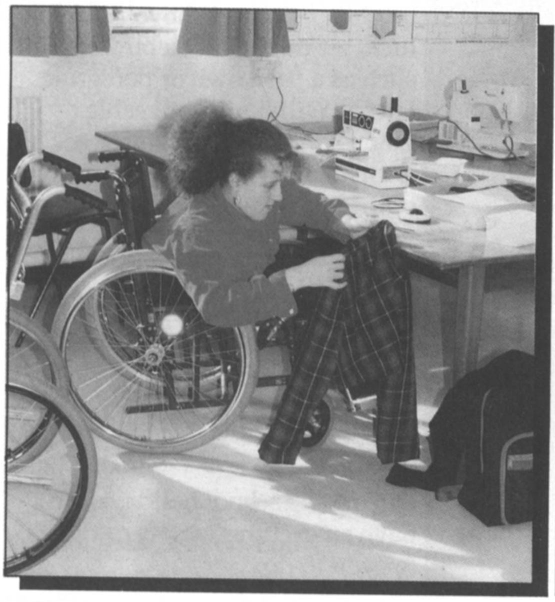
Our Fashion Courses are run with the expert help of Fashion Services for People with Disabilities, and will cover all aspects of clothes design - from choosing the right material to making the finished, stylish outfit.

During the week, you will be shown how to design a basic pattern that is tailor-made for you and your lifestyle. This pattern can be used time and again to make flattering clothes and you will have the added satisfaction of knowing that you made them yourself.

During the week, trips out are arranged and evening events organised so that you will have a lot of fun, as well as learning the practical side of the world of fashion.

During the International Fashion Course, you will be joined by young people from other countries and the week will also include a fun weekend of sightseeing in London.





Five Oaks Centre

Course and Holiday Fees April 1993 - March 1994

DJ Course *(4 nights)*	**£140.00**
Day Tripper Week *(6 nights)*	**£210.00**
Driving Course *(6 nights)*	
- March	**£265.00**
- September	**£285.00**
(plus the cost of driving lessons)	**£130.00**
Fashion Course *(6 nights)*	**£210.00**
International Fashion Course *(7 nights)* (including a weekend in London)	**£300.00**
Fishing Weekend *(2 nights)*	**£70.00**
Activity Holiday/Respite Care *(per week)*	**£368.69**
Outdoor and Recreational Pursuits *(7 nights)*	
July 17 - 24	**£280.00**
July 24 - 31	**£368.69**
September 4 - 11	**£280.00**
Wildlife Week *(7 nights)*	**£245.00**
Winter Wildlife Course *(5 nights)*	**£175.00**

Advice about funding your stay is available from the Five Oaks Centre on request.

Five Oaks Centre, Ben Rhydding Drive, Ilkley,
West Yorkshire. LS29 8BD Tel: 0943 - 603013

Your Voice - Your ASBAH

Alan Twyford, an ASBAH member from Surrey, attended the latest meeting of the steering group of young adults with spina bifida and/or hydrocephalus who are looking at ways in which disabled members of ASBAH can have more input into the Association.

The meeting was held at ASBAH House on 9 January and further progress was made.

Introductions were made by Tony Britton, ASBAH publicity manager, who asked the group to discuss their aims and objectives and then report back to executive director Andrew Russell at 2pm, when he would also be able to answer any questions. Tony then left the group to its deliberations.

A brief résumé of progress so far, was given and then thought was turned to future priorities and issues to be tackled. Note had already been taken that budget constraints prevented any expansion of services and it would be sensible for the group to move forward cautiously to be really effective.

One major point which emerged was that the group wanted to be seen as an official working group of ASBAH and not, as had been the case with some other charities, a divisive splinter group.

A further priority was that members of the group should be able to nominate young people with spina bifida and/or hydrocephalus who they would like to be co-opted on to the Executive Committee, from its next meeting in April. Were this to be done the group would then meet with its nominees prior to Executive meetings to support those members and help clarify issues to be raised by them.

Local ASBAH associations and their recruitment of people with spina bifida and /or hydrocephalus were discussed. Though these groups are autonomous, we felt that they should be urged to welcome disabled members on to their committees. Members of the steering group would, wherever possible, provide support to disabled members locally.

Following from this, the steering group felt they would like to examine the documentation used for nominations to the Executive Committee to ensure that disabled people really feel welcome to be nominated.

Steering group members were pleased that Andrew Russell was able to give very positive responses to the points outlined above. ASBAH's chairman will be consulted about co-option of steering group members to the Executive Committee.

A further meeting was arranged for 17 April when members will be able to determine the group's nominations to the Executive Committee and to continue its work. We would like to encourage any adult (16+) LINK readers with the disablities to join the steering group. Send your name to Tony Britton at ASBAH who will send papers to you.

Letters—Letters—Letters—Letters

Access to the AGM

I am concerned about arrangements for the recent AGM.

One of my fellow committee members wrote to ASBAH to express concerns about parking and access to the venue, she being a wheelchair user. The reply received was dismissive of her concern and at variance to the attitudes which I would hope all senior ASBAH staff would exhibit in dealing with members' concerns.

In his letter to my colleague, Mr Knightbridge said (1) "wheelchair accessibility is most important" - agreed, but then point (3) says "the venue must be reached reasonably easily by those using public transport (the vast majority of attendees)."

Two things occur to me. In Point 1, wheelchair access is regarded as most important. If that is so, it must also be accepted that adequate parking, an equal part of access, is of equal importance and this was certainly not the case. Also, if we cannot gave really accessible venues for large numbers of our wheelchair-using members, all you will get is those who can use public transport.

It is strange that ASBAH is not more aware of suitable venues - hospitals and college lecture halls might be possibilities.

T J Denyer, Committee member, Kent ASBAH

Mr Knightbridge replies: Parking and access for meetings in London is always a big problem. Having used the National Children's Bureau in the past, with no insurmountable problems, we had no hesitation in using it again. The 1993 AGM will be held in Peterborough, and we believe parking will be less of a problem here.

Editor's note: Pressure on space prevented us from publishing Mr Denyer's letter in full, and we had to omit comments about the 'Your Voice' meetings, attitudes towards the AGM and the availability of documents for 'last minute' attendees at the AGM.

Letters for publication are welcome but we do reserve the right to edit them. The best advice, as always, is keep 'em short!

An ACE way to *independence*

Jane Williams, ASBAH continence adviser, explains how Bowel Washouts can be used to acheive independence in continence management.

Some people with spina bifida suffer from constipation which does not respond to a regime of high fibre diet, suppositories, medication and exercises to promote daily emptying of the bowels.

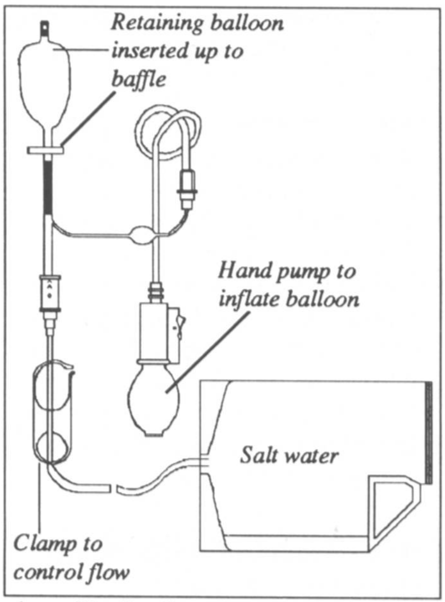
The bowel has the ability to stretch and accommodate large quantities of faeces. The more it stretches, the more difficult it is to empty. This causes the faeces to remain in the large bowel for long periods, during which time water is removed from the faeces, giving hard, dry stools. This makes it even more difficult to empty the bowels. When every effort has been made to retrain the bowel, without success, high bowel washouts may offer a solution.

The rectal washout involves running a specified amount of normal saline into the rectum via a special catheter. There are several options to be considered when choosing a catheter.

The Canadian, Toronto or Cardiomed catheter which was specifically designed for this task, is not available on prescription and costs about £100. Some hospitals will purchase the catheter for patients but this is not always possible.

Stoma washout kits are perfectly adequate for some people and these kits are available on prescription.

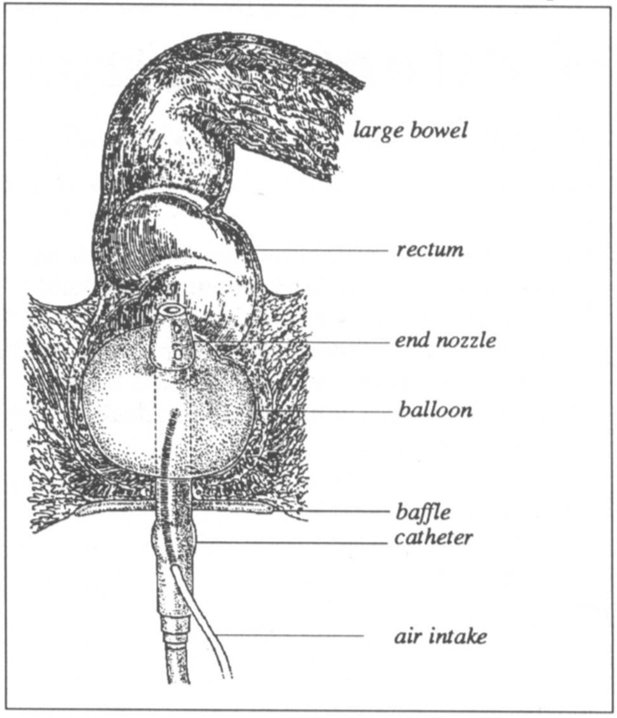
Large Foley catheters may also be used and are readily available.



above: The Cardiomed Enema Continence catheter

The Canadian and Foley catheters have retaining balloons. The bag of saline (20ml per kilo of body weight), which is warm tap water with salt added at one teaspoon per pint, is positioned four feet above the toilet, giving force to the water flow. Once the solution is put in, the catheter is removed and the contents of the bowel, plus the saline, empty into the toilet. The procedure requires a certain amount of agility, good balance and several pairs of hands! Once accustomed to the procedure, some people can manage independently.

If the washout system works well for you, but does not give you full independence, you may be interested in the ACE surgical procedure which was developed to aid independence. The appendix is removed from the large bowel, with its own blood supply, and inserted into the first part of the large bowel, so as to form a flap valve. The other end is brought out onto the front of the abdomen to form a stoma which looks rather like a belly button. It is not like a conventional stoma. (NB different surgeons use different techniques and, therefore, the appearance of the stoma varies). This gives a catheterisable channel through which a soft catheter is passed and either saline, at a rate of 20ml per



above: Cross section of lower bowel showing Cardiomed inserted kilo of body weight, or a phosphate enema, or a combination of both, is passed. Again, the fluid is put in under pressure (ie from a height of four feet) whilst sitting on the toilet. The contents of the bowel is evacuated into the toilet. The stoma is a continent stoma, so when the catheter is removed there is no leakage.

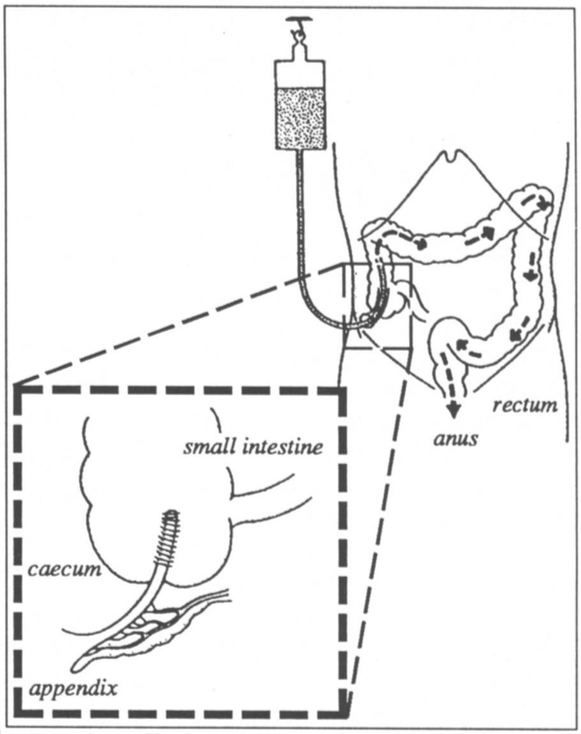
Both methods should take about half an hour, every other day. Some people have to do it more often, some less. If left too long between washouts there may be problems with constipation.

When changing to either of these methods the bowel needs to be empty before starting the programme. If hard stools remain in the bowel there can be many problems. For people with spina bifida this can take a week of strong laxatives and/or enemas with possible 'accidents' and it can be a difficult period.

The surgery involved for the ACE is not major. There will be a small scar around the stoma and another 4-5 inch one across the lower abdomen, usually in a natural crease. As with any bowel surgery there is nothing to eat before and after the operation. Only clear fluids are given post-operatively until they are sure the intestines are working. The first washout will be approximately a week later, (this varies between hospitals) through a catheter which was inserted at the operation. There may not be a good result with the first washout. This catheter usually remains in place for a few days, until the stoma is healed. Different surgeons have different regimes. It may be necessary to begin to take Lactulose and continue that to keep the stools soft - this may discontinue later.

Depending on the hospital, discharge can be 48 hours after the operation, returning after one week for the first washout. There is a period after this, when the system needs to 'settle down' and changing the amount/type of fluid is necessary to find the best method for that person. For some, things seem to work out quickly but for others perseverance is necessary. There may be times when things do not go to plan (for example, with tummy upsets and the use of antibiotics) but there may be ways to overcome these problems.

Several ACE operations have now been performed - mainly at the Hospital for Sick Children, Great Ormond Street and at Southampton. At a recent meeting about the procedure at Great Ormond Street, it was generally thought to be a very successful operation. However, as with all surgical procedures, it is not without its problems. Some of the following points were raised.



above: The antegrade continence enema (ACE)

Patient selection

The child or adult themselves must want to use this method of continence management and be prepared to work hard to achieve success. They should have tried all the simpler methods first. Therefore this procedure is not likely to be offered to very young children.

Complications

Stenosis - (narrowing) of the stoma has been a problem but techniques are improving. It is thought that catheterising the stoma daily (even if washouts are not done daily) will help to stop this.

Other surgical complications - such as adhesions (tissue 'sticking' to the tissue where it should not) and infections.

Phosphate Toxicity - at the meeting, one case of phosphate toxicity was mentioned. the child had been given a phosphate enema which was not expelled and another was given, which was also retained. This allowed absorption into the blood stream and the child became very ill. The phosphate enema is thought to be safe as long as it is not retained for long periods.

The complication rate is quite low and re-operation has solved the difficulties. There are a couple of people to-date who have decided not to continue doing the washouts.

On the positive side, many of the children gained increased confidence, improved lifestyle and were able to do many activities that had not been possible previously, such as swimming.

Most health authorities have a continence adviser working in the community. Your local continence adviser may be able to advise you on the best method of bowel management for you and may well be able to obtain the necessary equipment and provide, or arrange for instruction.

If you require further advice, please contact Jane Williams or Mary White, ASBAH Continence Advisory Service.

Complementary therapy

It was described as a "passing fashion" by the BMA in 1986 but alternative medicine has increased its advocates in recent years and the BMA are now looking at the subject again. But do alternative therapies have any place in the treatment of problems associated with spina bifida. In a very personal account, Pam Williams, mother of seven-year-old Sarah, tells us how she believes it has helped her daughter.

"It all started in November 1990. I looked across the table and there, sitting next to my young son was a MONSTER - not a big hairy green one blowing fire, but a six-year-old, brown-haired, freckle-faced girl. A child who screamed from morning till night, hit us with her crutches, made claws with her hands, as if to scratch our eyes out and greeted us each morning with a screamed 'Shut up' when we cheerily said 'good morning'.

She hated us and we, in turn, couldn't wait to escape from her.

My husband dreaded coming home from work at night and I dreaded collecting her from school, knowing full well that she would scream at me and hit me all the way home, no matter what I did.

What had happened to our beautiful, freckle-faced, delightful, charming, precious joy? Our Sarah has spina bifida and hydrocephalus. We had given her so much stimulation, stability, security, dedication and genuinely unselfish love that there just had to be something wrong.

Around this time, Sarah was suffering agonising bowel pains in the middle of the night. We sat awake for hours, regularly, trying to soothe her. Calpol had no effect. Nothing seemed to help. Drugs from the GP had no effect. It was then I began to wonder if the drug Oxybutinin, which she had been taking for several months, was having some effect on her personality. The GP promised to write off for information about it and by the time that information arrived I was absolutely convinced that Oxybutinin was not only causing the pains, it was causing behaviour changes. She was obsessive about my attention and she resisted going to school. Her squint had become worse (she was prescribed glasses). She was weak, constipated, had a skin rash, suffered from severe headaches, loss of appetite and looked tired continually - even on holiday. Her skin was breaking down in her creases.

It had all happened over a period of several months, I believe oxybutinin had had a cumulative effect and I was beginning to put the picture together. All of these months Sarah had suffered, in fact, the whole family had suffered. Getting through the day was something like torture. Once I realised it had to be the oxybutinin, I phoned Sarah's consultant at the hospital - a wonderful lady for whom I have great respect. She said that I should stop giving Sarah oxybutinin completely. I told her about the other symptoms and she suggested that we come to the hospital for a CT scan to make sure the shunt was working and she offered to get a clinical psychologist to see Sarah about her behaviour.

Then the information about oxybutinin arrived from the GP. It confirmed everything we had experienced and I decided there had to be an alternative.

I am one of those mothers who, when I am worried about my child for some reason, gets on the phone and calls anyone and everyone who might be able to give me information or help in any way. And, true to form, I did just that.

From many years of reading I had decided that homeopathy might just have something to offer a person with spina bifida - I didn't know exactly what, but at this stage, I was concerned that Sarah should get over the effects of oxybutinin and I though homeopathy might be the answer. Eventually, I found a homeopath who is a qualified doctor and a consultant at the Royal Homeopathic Hospital. She also has a private clinic and was recommended by a friend. I plucked up my courage and phoned. That evening I was well on the way to finding a solution to my feelings of desperation and panic and the guilt of not realising sooner, the cause of my daughter's plight.

About the same time we went to our usual hospital for Sarah to be checked over. The rash was diagnosed as ringworm. But the headaches caused them to shrug their shoulders as the CT scan was normal. Make no mistake, the consultants are people for whom I have great respect and who have, quite literally, saved Sarah's life. But they don't know everything.

About two days after stopping the oxbutinin I looked across the table and there, once again, was my beautiful, brown haired, freckle-faced little girl. I could have cried with relief, her whole demeanour had changed.

A few days later, we went to see the homeopath. I explained all that had gone before and then she began to ask some questions about Sarah - unusual questions like: "What kind of food does she like to eat? Did she have a difficult birth? Does she sleep on her side or her tummy?". The homeopath looked at the colour of Sarah's hair, eyes and skin and asked about her personality and whether she was shy etc. The whole appointment took an hour. She concluded that this was " a difficult one" but said she would have a a try. She prescribed a remedy and told me exactly how to give it.

It must be said that homeopathic remedies are completely safe but it is essential that you follow the directions carefully. Homeopathic remedies taste nice and are even very easy to give to a baby. Sarah took the remedy as directed with nothing to eat or drink (except water) for twenty minutes before and after. We sat back and waited, not knowing what to expect and not expecting anything. Within a fortnight Sarah was showing signs that the treatment was working - we were astonished! Not only was she able to wear just a pad (as she had done when on oxybutinin), her anus had tightened and closed a bit - a bonus. The remedy was now to be administered one tablet per month, instead of one tablet several times a day as it had been with the oxybutinin.

The homeopath also did some cranial osteopathy with Sarah. Within two sessions the headaches disappeared. The glasses were no longer needed. Here were some minor miracles! We were cautiously excited.

With some further and different treatments, Sarah's skin improved: no more breakdown of skin tissue, no more athlete's foot. She was no longer agitated and squirming.

At this time, Sarah's left foot was twisting in again, after two tendon releases and a further operation which resulted in the surgeons taking her shin bones apart and putting them back together. I couldn't bear the thought of more surgery and the months of recovery, both physically and emotionally, for Sarah. So I started my own brand of foot massage. I was determined to stop her foot getting worse and happened to mention this to the homeopath. She recommended that Sarah see a lady who does holistic foot massage and healing. I was *very* sceptical and rather reluctant to part with any more money. It took me a long time to come around to the idea but eventually, in desperation, I phoned Monica. She was very kind and told us to come that afternoon. She showed me exactly what to do. I was to carry on the work at home (without making it a burden) and she would see Sarah once a fortnight.

Now, a year later, we still go once a fortnight and I still do this massage on Sarah's feet every evening for 20 to 30 minutes as we chat or listen to tapes, or she reads to me. It is a part of our normal routine. We both enjoy that time together. What benefits have we seen? Sarah's feet have changed from hard lumps, like blocks of wood, with hard claws for toes, to softer, movable, recognisable feet, with good colour, much better circulation and far fewer sores. The bruises she does get heal much faster. She is walking much better and actually has much more feeling in her legs and feet. The leg which was bent by the surgery is much straighter. Her feet are much warmer and have life in them. I am cautiously optimistic for the future and even the orthopaedic surgeon has said we don't have to go back for a year.

I have a friend who is an aromatherapist. One day I asked her about oils for scars, having heard that vitamin E was supposed to be good for them. Belinda made a recipe for me of anti-scar oils which was to be put on every day for a year, at least. I put them on Sarah's very nasty scars (she has lots of scars from surgery) every night after the holistic foot massage. So far, after about 10 months we have seen quite a remarkable change in her scars. The very ketoid one on her upper thigh is now quite flat and the ugly redness is nearly gone. The other scars on various parts of her body are softening and smoothing out and some are becoming quite faint. It is early days yet but we are hopeful.

A few months ago, the homeopath suggested that Sarah's hips might be straighter (She had surgery on a dislocated hip when a baby) and that the "energy flow" wasn't very good through the hip area. She suggested that we stop coming to her for a few months and go instead to Deidre, the osteopath, to see what she could do to help improve Sarah's bladder.

Deidre was another lovely lady. She did the osteopathy treatment on Sarah. After one treatment we saw very marked changes in Sarah's feet. After five treatments we have seen that Sarah's hips are now level. She is able to stand and sit and swim straighter. We have also found that, after several hospital tests, that the reflux to Sarah's kidneys has gone from Grade III reflux to Grade I. I call that at least a minor miracle!

Throughout all of these alternative therapies I have kept Sarah's hospital consultants fully informed. They have, in most cases, positively encouraged me, though some have been sceptical.

These alternative treatments are very gentle and Sarah has never been hauled about or yanked, or hurt in any way. Each of the alternative therapists said that they would try three treatments and if

Continued on Page 18

these didn't work then we would stop. Fortunately, with every treatment we have seen a change - it hasn't always been what I was expecting but it has always been positive.

Homeopathy and Osteopathy are available on the National Health. Unfortunately, there is no accessible place nearby where I can take Sarah. Much of the money I spend on her treatment can be found by cutting a few luxuries off my grocery list.

Alternative treatments have given us hope and we are not finished yet. There is still much more work to do. We are not looking for a cure. We are looking to make the very best of everything that Sarah can do. We can improve the quality of her life and, by improving her life and future, we can improve our own."

Dr Wynne-Simmonds, who treated Sarah, was pleased that she responded so well but told us that as treatment is specific to the individual she could not give any general advice on treatment for other children with similar problems.

Similarly, ASBAH is unable to recommend any particular alternative therapies and reminds readers that this is one person's experience. We would stress that anyone considering the uses of alternative therapies should contact their GP first. The Royal Homeopathic Hospital is a National Health hospital and patients can be referred there by their GP in the usual way. There are also NH homeopathic hospitals in Liverpool and Glasgow. It should be noted, however, that there is likely to be a long waiting list for treatment on the National Health.

It is important to keep your consultant fully informed of any other treatment you are receiving, as Sarah's mother did.

Useful addresses

Royal London Homeopathic Hospital,
Great Ormond Street,
Bloomsbury,
London, WC1N 3HR.

Homeopathy Department,
Mossley Hill Hospital,
Park Avenue,
Liverpool L18 8BU.

Glasgow Homeopathic Hospital,
1000 Great Western Road,
Glasgow G12 0NR.

Manchester Homeopathic Clinic,
telephone: 061 273 2446.

British Homeopathy Association,
27a Devonshire Street,
London W1N 1RJ.
Telephone: 071 935 2163.

Society of Homeopaths,
2 Artizan Road,
Northampton NN1 4HU.
Telephone: 0604 21400.

A list of GPs who are homeopaths is available from the
Faculty of Homeopathy,
Powis Place,
Great Ormond Street,
London WC1.

General Council and Register of Osteopaths,
56 London Street,
Reading RG1 4SQ.
Tel: 0734 576585.

British Chiropractic Association,
29 Whitley Street,
Reading RG2 OEG.
Telephone: 0734 757557.

Brothers and Sisters

In a future issue of LINK, we are hoping to carry a feature on the effect a disabled child in the family has on their brothers and sisters. We would be pleased to receive input on this subject from LINK readers. We would like to hear from parents - and how they have overcome any difficulties this has presented - and we would also like to hear the views of the brothers and sisters of the disabled child. It would be helpful to have the ages of children but no names or identifying information will be given in the article.

Please contact Gill Winfield, LINK editor, if you would like to give your views on this subject.

Moving heaven and earth

Determined to make their hotel fully accessible for wheelchair users, Julia and Roger Percival moved 4,500 tons of soil to enable a ramp to be built at the entrance of the **Pheasant Hotel in Norfolk.** Their efforts were rewarded when Judith Chalmers presented them with first prize in the Holiday Care Awards, in the 20 bedrooms and over category.

Other awards were as follows:

Cheshunt Marriott Hotel in Hertfordshire and The Lodge on the Loch, Inverness-shire *(both highly commended).*

Bryn Meirion Guesthouse in Anglesey *(winner of the under 20 bedrooms category).*

Corndene in Shropshire (a guesthouse) and Woodlands Country Hotel in Carlisle *(both highly commended).*

Ghyll Cottages, North Yorkshire *(winner of the self-catering category).*

Calvert Trust Kielder, Northumberland (an activity centre) and Penrose Burden Cottages, Cornwall *(both highly commended).*

For more details of the award winning holiday accommodation contact the: *Holiday Care Service, 2 Old Bank Chambers, Station Road, Horley, Sureey RH6 9HW. Telephone: 0293 774535.*

Station to station

London Transport's fully-accessible inter-station bus service has been revamped to include four new stops, following requests from passengers.

Using new full accessible midibuses, they will provide an hourly service linking these central London main line stations:

Paddington, Marylebone, Euston, St Pancras, King's Cross, Liverpool Street, Fenchurch Street, London Bridge, Waterloo, Victoria, Victoria Coach Station and returning to Paddington. Fares are £1 for any journey but there is a 50p reduction: for children aged 5-15 years or for holders of London Boroughs' Edlerly or Disabled People's Travel Permits and holders of British Rail Disabled Railcards.

Steven Norris, Minister for Transport in London (right), launches the new Stationlink service watched by Andrew Braddock, head of London Transport's Unit for Disabled Passengers

Timetable leaflets for the service are available from British Rail outlets or the Unit for Disabled Passengers, London Transport, 55 Broadway, London SW1H OBD. Telephone 071 222 5600.

UK holiday advice

A wide range of information on British holidays is given in the latest edition of "Holidays in the British Isles: a Guide for Disabled People". RADAR has been publishing this guide to holidays for almost 20 years. It contains detailed entries for over 1000 places where disabled people can stay in all parts of Britain and Eire. Hotels, holiday parks, activity holidays, self-catering and camping, along with centres providing specialist care are among those in the guide.

Copies are available from: *RADAR, 25 Mortimer Street, London W1N 8AB. Price £5, including postage.*

ASBAH member helps with guide

Steve Cooper and support worker Mark Best, who are residents at ASBAH's independence training centre, Five Oaks, took part in the preparation of a new access guide. It covers towns in the Ilkley district in Yorkshire.

The guide includes everything from restaurants and pubs to shopping and places of interest and even accessible telephones.

It would prove a valuable travelling companion to those visiting Five Oaks as well as a handy guide for residents and tourists in this attractive area.

Available from: Ilkley District Access for the Disabled Group, 1 Queen's Drive Lane, Ilkley, West Yorkshire LS29 9QS. £1.50

Prizes offered for mobility ideas

Nominations are now being accepted for the 1993 Ratcliff Mobility Awards. The main prizewinner will receive a silver medal, certificate and cheque for £1,000, with the runner-up receiving £500.

The awards are open to any individual, group or organisation, who:

*has invented or improved an item of equipment to assist the mobility of disabled people

*operates a new or improved service for people with a mobility disability

*has made a major commitment to increasing public awareness of the mobility needs of disabled people.

Nominations for the award may be made by the entrant or by a third party. In either case the nomination should be seconded by an independent person who is familiar with the equipment, service or individual.

Last year, awards or commendations were given to a wide variety of entries, from wheelchair tables and sit easy frames to a specially converted railway carriage and a "streetwise campaign" which was designed to make pavements safer for everyone.

This year it could be someone you know.

Further details and nomination forms from: *Sally Gething, Ratcliff Tail Lifts Ltd, Bessemer Road, Welwyn Garden City, Herts AL7 1ET. Telephone: 0707 325571.*

All entries must be received by Ratcliff, no later than 15 April 1993.

Benefit Changes

Some of the benefit rate changes from April 1993, are given below. For a full list contact your local DSS office or CAB (Citizens Advice Bureau).

	Old Rates 1992	New Rates 1993
ATTENDANCE ALLOWANCE		
Higher rate	43.35	44.90
Lower rate	28.95	30.00
DISABILITY LIVING ALLOWANCE		
Care Component		
Highest	43.35	44.90
Middle	28.95	30.00
Lowest	11.55	11.95
Mobility Component		
Higher	30.30	31.40
Lower	11.55	11.95
INVALIDITY BENEFIT		
Invalidity pension	54.15	56.10
Invalidity allowance		
Higher rate	11.55	11.95
Middle rate	7.20	7.50
Lower rate	3.60	3.75

	Old Rates 1992	New Rates 1993
INCOME SUPPORT		
Personal allowance		
Single under 18		
- usual rate	25.55	26.45
18 - 24	33.60	34.80
25+	42.45	44.00
Couple both under 18	50.60	52.40
One or both over 18	66.60	69.00
Dependent children		
Under 11	14.55	15.05
11 to 15	21.40	22.15
16 to 17	25.55	26.45
18	33.60	34.80
Premiums		
Disability		
Single	17.80	18.45
Couple	25.55	26.45
Severe disability		
Single	32.55	33.70
Couple (one qualifies)	32.55	33.70
Couple (both qualify)	65.10	67.40
Disabled child	17.80	18.45

Shopping by post

FREEMANS, the mail order catalogue company, has agreed to investigate the possibility of making its catalogue more relevant to disabled customers. This could take the form of marking certain items as being particularly suitable for disabled customers - for example easy-to-wear clothing - or including a special section in the main catalogue, of items for disabled people.

But, before they decide how far to develop this idea, they do need to know that there is a demand for mail order from disabled customers.

This is where YOU come in. Please answer these few questions on mail order shopping and return the form to the LINK editor by the end of March.

✂- -

SHOPPING BY POST QUESTIONNAIRE

Do you use any mail order catalogue now? YES/NO

If so, which one? ____________________

Does it include all the things you want in it? YES/NO

What else would you like to see in a mail order catalogue? ____________________

____

If you do **not** use a catalogue at the moment, would you do so if it included a section specifically for disabled customers or marked suitable items in the main catalogue? YES/NO

Please add any further comments below:

____

____

____

Reviews

Teaching the Student with Spina Bifida

Edited by Fern L Rowley-Kelly MSW, LSW, and Donald H Reigel MD. Published by Paul Brookes Publishing - . Baltimore, London, Toronto, Sydney. 1993. £27.50.

This book does not dwell on the medical aspects of spina bifida, other than outline what they are. It does, however, give an extremely good account of the learning, social and behavioural development of young people with this disability. The way in which parents, teachers, and peers can grow with these young people and develop a deeper understanding of their needs and aspirations is handled sensitively and realistically.

Strategies are offered and also many practical guidelines for use in the classroom and at home. Emphasis is placed on co-operative programmes for the school and home.

It is not the sort of book to read at a sitting but it is a superb reference book when dealing with a problem; to use for identifying, clarifying and suggesting ways of dealing with the difficulty.

Any school integrating a child with spina bifida and hydrocephalus should have this in their library for constant reference. It might also be something that Local Associations might consider buying to loan to parents, and/or interested professionals, as it is quite pricey for individual purchase. It should certainly be recommended reading for teacher-training courses and would encourage an easier passage for some of our young people through the education system. There is a most informative chapter on conducting psychological assessments which should be compulsory reading for educational psychologists.

The only two areas which were not well developed were wheelchair competence - the emphasis being more on an outside operator, at least for curbs, and sexuality which was dealt with rather summarily, with dubious optimism. However, there was so much that was really good that this should not deter anyone from using this book. *Leonie Holgate, (ASBAH disabled living adviser).*

From Me... To You

Anne Whaite and Judy Ellis. Jessica Kingsley Publishers, 1987. £10.50

Reviewed by an ASBAH member who is the mother of a child with spina bifida.

This Australian book, identifies the issues faced by parents of disabled children. The ethos of the book seems to be that "people, no matter what degree of disability they have, should be able to live in an ordinary environment with the level of support they require as individuals".

I appreciated the honest and practical views parents expressed about their feleings of how this works in practice; be it at home, school or the place where the disabled person works.

The book discusses what to do when it is first discovered that a child is disabled and how to begin an early education programme.

There is a chapter on how to approach professionals; keeping in mind that they do need to provide a worthwhile service but some relationships with them will be stronger than others.

An over-riding emphasis of the book is that the most effective source of information, be it on education, family matters or respite care - which are dealt with in separate chapters, is the parents of other children with disabilities. They can be the strategic resource, support and initiators of change.

I have found this book fascinating to read; not one to be skimmed over quickly but one to go back to when specific questions arise. In several chapters there are suggested questions to ask the professionals which could be invaluable in intimidating situations.

Most of the services and financial benefits mentioned have their equivalents in England. However, a short, up-to-date, "where to find help when..." might have been beneficial to make it more user friendly.

Working Towards Independence

A practical guide to Teaching People with Learning Disabilities

by Janet Carr and Suzanne Collins. Jessica Kingsley Publishers, 1992. £14.95

This book is both a theoretical and practical manual. In part one some of the known problem areas experienced by some students with spina bifida and hydrocephalus are outlined and general principles of the behavioural approach and coping with unwanted behaviour are discussed. Part two concentrates on practical aspects such as personal hygiene, home management etc.

The book is a useful teaching, reference and practical guide for those who work to develop life skills with children and young people.

E M Barton (ASBAH Disabled Living Adviser, Five Oaks)

Council Tax

As you are all probably well aware, Poll Tax or Community Charge ends on 31 March 1993. As from 1 April 1993, we have the introduction of Council Tax.

Council Tax is a combination of a property tax and personal tax - ie 50% property, 50% personal. If you are single and living alone you will be eligible for a 25% discount.

Properties have been placed into 8 bands - A to H - at different levels for England, Wales and Scotland. Your property will be set in a band according to its market value.

Arrangements for disabled people

Where a disabled person needs additional space to accommodate wheelchairs or requires an extra bathroom, kitchen or other room, the property will be billed as it if were a band lower than the actual value.

A disabled person who lives alone is entitled to the same 25% discount as any other person living alone.

A 25% discount will also be available for a household where a disabled person on higher rate Attendance Allowance lives with a full-time carer (*unless* he or she is the spouse or partner of the disabled person and/or the parent of a disabled child under 18 years).

Information

Information lines have now been set up at most Council Offices to offer help and advice. If you do not agree with the banding of your property a formal appeal can be made to the Valuation Office between 1 April 1993 and 30 November 1993.

The amount of Council Tax you will be paying will not be sent out until March 1993. However, forms are being sent out now to register your right to 25% discount and should be completed and returned at the earliest opportunity.

Free booklets, Council Tax: a guide, and Council Tax: Liability, Discounts and Exemptions, in 12 languages, are available from Council Tax Publicity Material, PO Box 506, London SE99 7UY. Further information can be obtained from your local Council Offices, Citizens Advice Bureau, Post Offices and in the national/local press.

✂ -

ATTENDANCE ALLOWANCE QUESTIONNAIRE

We need your help

ASBAH has joined forces with MENCAP to mount a campaign to obtain back payment of attendance allowance, for children under the age of two pre-April 1990

But if we are to press our case
WE MUST HEAR FROM MEMBERS WHO **WERE SUCCESSFUL** IN
OBTAINING BACKDATED ATTENDANCE ALLOWANCE
for under-twos for this period.

Please help by filling in the questionnaire and returning it to Mary Malcolm, by the end of **March 1993**

i)	How many months backdated allowance did your receive?	Months
ii)	When did you receive a result?	Months
iii)	Have you received payment yet?	Yes/No
iv)	Please give date of birth of the claimant	____________________

ALL INFORMATION GIVEN IN THIS QUESTIONNAIRE WILL BE TREATED IN CONFIDENCE

NAME OF CLAIMANT ....

APPOINTEE/PARENT/CARER ....

ADDRESS ....

....

PLEASE RETURN COMPLETED QUESTIONNAIRES TO:

Mary Malcolm, Assistant Fieldwork Manager, ASBAH House, 42 Park Road, Peterborough PE1 2UQ

HOLIDAY ACCOMODATION

When booking, check to make sure the accomodation suits your particular needs

MAR Y SOL - TENERIFE

Lowest ever summer prices, wheelchair accessible apartments, heated pool with hoist, restaurant, poolside bar, equipment hire. Ring today for video and cheapest prices on flights and accommodation. (Tel: 0753 685718) Sue Abbott, 123 Coppermill Road, Wraysbury, Staines, Middx. TW19 5NX.

SELSEY, SUSSEX

Fully-Equipped, six berth mobile home, with colour TV, ramp access, all rooms designed for wheelchair access. Site near sea, heated pool, also clubhouse and small shops. Details:Mrs C.Bugden, 27 The Grove, Sholing, Southampton, SO2 9LT. (Tel: 0703 444921)

ISLE OF WIGHT ASBAH

Completely refurbished, fully equipped, wheelchair accessible 2 bedroom holiday chalet, sleeps 6 + cot. Clubhouse, indoor heated pool, shop, etc. Site overlooks sea. Own transport advisable. Details: Mrs P. Burden, 34 Sherbourne Avenue, Binstead, Ryde, Isle of Wight PO33 3PX. (Tel: 0983 564604)

BLUE ANCHOR, NEAR MINEHEAD

Privately situated self-catering 2 or 3 bedroom bungalows, fully accessible fully equipped with linen, TV, video and games room, laundry, parking, playground. Splendid views of sea. Exmoor, steam railway. Contact: Lorraine or Martyn Baab on Dunster 0643 821200, to discuss your particular needs.

MOONPENNY COTTAGE, LEVISHAM, N. YORKS

Self-catering holiday cottage - sleeps 4. Fully equipped to a very high standard and designed specifically to accomodate the wheelchair user as well as the able-bodied. Large sitting/dining room with open fire, kitchen, shower room, one double bedroom, one twin bedded room. South facing overlooking paddock, valleys and hills beyond. Full details/brochure from Frank and Maggie Ashworth. (Tel: 0751 60311)

LOOE, CORNWALL

Fully equipped, self catering bungalow. Sleeps six, site near sea with easy access to beach, shop and camp facilities. Easily accessible for wheelchairs. Details: Mr P. Cash, (Tel: 0425 72055)

NEW MILTON HAMPSHIRE

Fully equipped, completely wheelchair adapted self catering 2 bedroom chalet. Sleeps six. Excellent all year round site, indoor and outdoor pool and superb facilities. All 100 yards from chalet. Near to New Forest and Bournemouth. Bookings taken to November. Also similar property at Millendreath in Cornwall. For details contact Mr P. Cash (Tel: 0425 72055)

FOR SALE

FLAT

Well maintained, one-bedroom ground floor flat. Wheelchair accessible, wide doors, large kitchen with low worktops. Low bath. Parking space. Small garden. Price £24,950.

Tel: (0733) 236148 (Peterborough)

SERVICES

EPC - Equipment for the Physically Challenged (a company run by the disabled for the disabled. New and second-hand lightweight wheelchairs. Authorised dealers for Action Technology, Quickie and Swede. Home demonstrations, wheelchair insurance, advice. For further information, please ring 0252-547939, or our new office in Coventry, 0203-422327.

LINK Rates

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Air Mail £15.00
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Classified rates: £3 for 30 words max;
£4.25 for 30-45 words;
£5.50 for 45-60 words.
Cheques and postal orders should be made payable to 'ASBAH'.

Small adverts for the next issue of Link (April) should be submitted by Friday,12 March. Please send them to the editor.

Display rates on application, from the publicity manager.

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