

Association for Spina Bifida and Hydrocephalus/ASBAH

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Link

Association for Spina Bifida and Hydrocephalus (ASBAH)

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ASBAH Publications

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Cheques payable to "ASBAH"

Young People with Spina Bifida and/or Hydrocephalus — Learning and Development (1985) <i>Leonie Holgate</i>	£1.60
The Handwriting of Spina Bifida Children (1979) <i>Joan Cambridge, E. M. Anderson</i>	£1.60
Spina Bifida and You — A Guide for Young People (1985).....	£3.50
Sex for Young People with Spina Bifida or Cerebral Palsy (1984).....	£1.75
Children with Spina Bifida and/or Hydrocephalus at School.....	£2.50
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General leaflet.....	5p
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Five Oaks leaflet.....	Free

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VISUAL AIDS

Slide sets and notes (12 slides) Living with Spina Bifida £8.62 inc. VAT
Video — Training video on Hydrocephalus (May 1987).
Contact Information dept. for details of hire or purchase.

MAGAZINES

LIFT — for members of young ASBAH (LIFT).....Free
Causeway — for contributors to ASBAH's work.....Free

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Editor's Note

New look LINK

Thank you to the few of you who bothered to write in with your ideas for a new look magazine. I am sorry that not more people responded, but I think this reluctance to write is typical of many other journals, and not just LINK. It certainly does make life difficult for the Editor who needs to get regular feedback from readers.

One of the most frustrating aspects of being Editor is to hear by chance - perhaps at a local association meeting - that a particular article did annoy you or strike a chord in some way. How many other readers, I wonder, felt the same way? Why don't people WRITE IN and share their annoyance or feelings - it would make for a much more interesting and representative publication.

However, it isn't a problem that will affect me for much longer. I have decided after nearly 17 years of editing LINK that it is time for a change and so the next issue - March/April will be my last. But your suggestions will not be lost without trace and will be passed on to the new Editor when he or she is appointed. Meanwhile why don't you make my last issue a bumper one and send in a letter!

Research

One of the requests was for more news of ASBAH's work, particularly in the area of research. So in this issue we are pleased to publish a list of ASBAH sponsored research projects.

Problems

And I'm pleased to say that one or two more problems to be answered have come in (see page 9). Please send in some more for the March issue of LINK

Sue Gearing, Editor

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FRONT COVER

Athletic, Mark Tong, 19, of Morpeth in Northumberland in his Olympic outfit. Mark who has spina bifida was a member of the British Basketball team which came eleventh in the recent Paralympics in Korea. Mark said that the trip to Seoul will never be forgotten, particularly the opening parade attended by thousands of people.

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Link

is published by ASBAH (the Association for Spina Bifida and Hydrocephalus).

Contributions to LINK by way of letters, news photographs, articles and opinions are warmly welcomed. The closing date for the March issue is February 20. Send to the Editor, Mrs Sue Gearing, at London office.

Letters



Joe and his mother.

Photo: David Lawrence

Meeting Joe

I would very much like to tell readers about a new venture that I have become involved in. It started when a friend of mine, Jane Drury, asked me to take my two year old son, Joe, into the school where she teaches, to talk to her tutor group about Joe, as they were doing a project on handicaps.

Some of the children had been sent into town in wheelchairs or with blindfolds and ear plugs, so they could find out how difficult it is to have a handicap. The children had also been asked to set out questions to ask me, so they had already given some thought to the problems.

The children - all 14 year olds - asked about how my marriage was affected, how my older children were affected, how I felt when Joe was born with spina bifida and did I ever wish he was dead. I answered as honestly and as openly as I could. I showed them all of Joe's apparatus - the chariot, the swivel walker, balancing board and also showed them pictures of his lesion before it was removed. Joe was quite shy but did relax a bit and walked in his walker after being 'bribed' with polo mints supplied by one of the children.

Jane asked the children, in another

lesson, to write down their response to our visit in the form of four questions:

Was it helpful to be visited by a disabled person and having someone talk about it? What did you learn? What did you want to find out? Did you enjoy it and would you like other people to visit?

Most of the children said they thought Joe would look ugly or disfigured and were surprised that he looked 'normal' and that he could do as many things as any two year old.

They all found it helpful, as most of them knew nothing about spina bifida or hydrocephalus and had never met a handicapped person before. They said they learned a lot especially from his apparatus, as again they hadn't seen it before, nor knew what it was for. They mainly wanted to know how different Joe was from other people, and a lot of them said they would like to see more people with different handicaps.

I have been to talk to another group and have been invited back again. Naturally there is a limit to how long I can keep taking Joe to do this. There will come a time when he realises that he is different and it will have to be his choice, and I will respect his decision.

For the children who have met Joe, it has been a valuable opportunity to ask the questions that they probably felt they couldn't ask anyone else, and so have a greater insight and, hopefully, more compassion for disabled people.

I feel that a lot of confusion has been removed and barriers have been broken down. We all know that fear and ignorance cause hurt and even anger, so if more people could talk in schools to children, it could help to break down barriers.

On a personal note I was greatly rewarded as I have always felt that there was a purpose to all the suffering that I've been through.

**Mrs Mary Myers,
Newmarket, Suffolk.**

EDITOR'S NOTE: What do other readers think of going to talk to schools as Mary Myers and Joe did?



Carsten

A host family for Carsten?

Through our membership of the Association for Spina Bifida and Hydrocephalus in Germany, we received LINK and your address.

We are seeking a family in London able to host our son Carsten, 16 years old (190 cm tall) from March 22 to April 5, 1989. Carsten was born with meningomyelocele and underwent an operation for hydrocephalus immediately after. Despite the rather successful operation, Carsten continues to be burdened with a bladder problem. We are, therefore, looking for a family with understanding of his handicap.

Our son is able to walk and ride a bicycle like any healthy boy his age. (It is virtually impossible to see that he has a handicap. He is in the 9th grade in secondary school and has been studying Latin for four years, English for two, and has recently begun studying French. Carsten is a nature enthusiast and a music lover.

Now, a few words about our family. We have a 17 year old daughter who also attends secondary school. We live in the outskirts of Munster in an old, rustic farmhouse which we have restored ourselves.

In the event that a family interested in hosting our son is found, we would be more than happy, in exchange, to host a child (adolescent) during the Summer holidays!

With the hope that we hear from you soon.

**Mathilde Grahn,
Raringheide 120,
440 Munster, W. Germany.**

LETTERS continued

Is there anyone like me?

I have recently been told I have spina bifida occulta - about eight months ago. I am 33 years old and as you can imagine I found it very hard to come to terms with at first, but I have done so with the help of my family and Mrs Jean Black, fieldworker for ASBAH.

I was wondering if anyone else has had the same experience as myself. I am not feeling sorry for myself because there are people worse off who to me are just great the way they cope from day to day. I think they and their families deserve medals.

Keep up the good work Link!

Christine Riley,
Wythenshawe, Manchester.

ASBAH NEWS

DENISE DUNNING

Unfortunately ASBAH has had to say goodbye this January to Denise who has been with the Association for nearly seven years, and for the last five years has so ably carried out the job of Education, Training and Employment Co-ordinator. Denise's husband is being relocated out of England which would make it impossible for Denise to carry on her job.

"I have learned a lot while working at ASBAH particularly from the young people with spina bifida and/or hydrocephalus with whom I have come in contact. I will really miss them and their families so many of whom I have come to know over the years" she said.

CLARE MICHELMORE

Readers will be delighted to hear that Clare, Disabled Living Advisory Manager for ASBAH, gave birth to a baby daughter, Helen Amy, on Christmas Day.

Mobility Week

In May 1988, ASBAH held a Mobility Weekend for 14 year olds and over on the theme of Mobility. The weekend showed that there was a great need for training people with disabilities on the subject of mobility.

Therefore, to answer that need, ASBAH is running a Mobility Week from July 3-8, 1989 at the Ludwig Guttman Sports Centre at Stoke Mandeville, Aylesbury, Bucks for 9-14 year olds.

The week will start on Monday morning and finish on the following Saturday morning. We have chosen the first week in July as it is after school exams but before the holiday when people may be away with parents. We are hoping that up to 100 young people will come.

The week will not just aim at wheelchair mobility, but will also include other subjects such as: incontinence



management, personal care, self awareness, fashion, make-up and much more. We do aim by covering such a variety of topics and by offering personal attention to start to equip these children for life in its widest sense.

The cost of the week is £75 and will cover full board and lodging.

There will also be exhibition stands, sporting and social events, and time to talk things through with someone who is there to listen and to offer help.

The week is primarily aimed at preparing young people for life, but it is hoped that it will be full of fun and excitement.

If you are interested in sending your child, or if you know of someone who would like to go, and you would like further information please contact either John Naude or Ian Laker, Disabled Living Advisors at ASBAH's London office.



ASBAH news continued

WELCOME TO.....

CHARLES SPOTTISWOODE Services Manager

ASBAH is delighted to have filled this position which has been vacant for some time. Mr Spottiswoode has been involved in working for various charities for ten years, notably with the Cystic Fibrosis Research Trust of which he was Director, and most recently with the Royal Surgical Aid Society. His earlier career was with the Royal Engineers, where he served for 26 years.

He is married with three daughters and has a personal interest in the problems of handicap because his middle daughter is brain damaged after a virus infection shortly after birth.

SUE FENTON

Education training and Employment Co-ordinator

Mrs Fenton took over from Denise Dunning at the beginning of the Year. A teacher by profession, she has taught children with spina bifida as well as children and young people of different ages. She also has a great deal of expertise on training and development and curriculum design.

As Mrs Fenton, who is married with two daughters, lives in Peterborough she will be 'on the spot' when ASBAH moves there. She is very keen on outdoor pursuits such as canoeing, rock-climbing and walking - Five Oaks will, no doubt, be seeing a lot of her!

Local Association **Round-up**

Somerset Shaun visits Norway

A recent trip to Norway for scout, Shaun Neill, 18, a member of Somerset ASBAH, has clearly made a big impression - not only on him, but probably also on the able-bodied scouts with whom he travelled!

He recounts that they lifted him on a two hour walk up to a glacier-Svarisan Glacier - where they were able to enjoy the wonderful scenery and the blue ice flows.

The scouts left Taunton and flew from Gatwick to Bergen, where they stayed in the local scout hut. They then crossed Norway by train to Mo-I-Rana staying in a school there.

They crossed the Arctic Circle, saw the Saltrehem river and went to a youth hostel in Fauske. One day they were able to cross the border into Sweden, and other excursions included a visit to a scout hut in the mountains and a tour of a steel works.



West Yorkshire A special moment

(Above) A moment that Joy and Brian Ellison of Sowerby Bridge, Halifax, say they will never forget: their eldest son Adrian is getting into his own personalised transport for the first time.

The Nissan Prairie chosen by the Ellisons had been adapted to carry telescopic ramps by Motability Services of Batley, Yorkshire.

"When we were searching for an ideal vehicle to transport Adrian we approached our local Nissan dealer

Which? reports on the needs of the disabled

Which? consumer report is extending its test programme to highlight features particularly helpful to people with disabilities. The issue of January 5 included a report on washing machines, 15 of which have been specially assed by the Handicapped Persons Research Unit. Which? is extending its assessments to cover a whole range of products and it intends to tell manufacturers how they might be able to improve their products to benefit disabled users. The magazine is keen to get views from readers on how useful this information is to them - letters to RICA, 2 Marylebone Road, London NW1 4DX.

Kent Dramatic help

(Right) A happy occasion for Kent local Association, the presentation of a £1,500 cheque to them from Kent Countryside Productions. The cheque was received on behalf of KASBAH by Lady Swinten (centre). With her from left to right are Mrs Pat Edser, ASBAH fieldworker, Les Shaw, Director of KCP, Heather McCleod, Kent ASBAH Secretary, and Debbie Fearnhill who played Puck in the drama company's production of *Midsummer Night's Dream*.



KCP was formed in 1981 and each year presents a play, the profits of which go to charity. A cast of 30 actors and 50 production crew all gave

their time free.

Kent ASBAH is at the 'thinking stage' of setting up a 16-plus clinic and if this does get off the ground, the money from KCP will be put towards it.

In view of the special needs of children with spina bifida and/or hydrocephalus, KCP has kindly agreed to present the proceeds from their 1989 production to Kent ASBAH.

who demonstrated the low boot load height that the Prairie offered, and also discussed the financial implications of the ramp adaptations." The Sales Manager explained to them that when the vehicle is adapted to carry a disabled person, the purchaser isn't liable for VAT.

The Leeds & Bradford Association provided the 'icing on the cake' by raising money to help the Ellison's with this transport for Adrian. They feel they have the ideal vehicle now, bypassing 'the stress and strain' they previously felt when embarking and

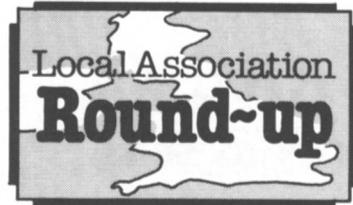
disembarking on car journeys with Adrian. They have sent their special thanks to the Nissan dealer, to Ros Scott, ASBAH's fieldworker and to Austin Crowther of Calderdale local Association.

40% COMPUTER DISCOUNT
IBM has announced this huge discount for disabled people on its personal System 2 computers. More details from: IBM Centre for People with Disabilities. Tel: 0800 269545.



Worcestershire Youth at the helm

(Above) Four young members of Worcestershire Association's Committee. From left to right: Ann-Marie Bourne, Tracy Coates, Beverley Cotter and Drusilla Henley. Tracy led the way by joining the committee about a year ago and the other three followed suit a few months later. It's an active Association so there's a lot to keep them busy and they are representing many young people with spina bifida and/or hydrocephalus. The youngest member of the Association is 14! At present the girls are taking an interest in helping to equip a new kitchen at the Association's Venture Centre in Stourport on Severn.



Midland and Somerset Coupon collectors

The Midland Association and Somerset Association are grateful to receive 'money-off' coupons, and also Green Shield and other stamps.

They collect any type of coupon or stamp, including petrol coupons and Co-op stamps, which clutter up one's purse or drawer. If you have any of these or would be kind enough to cut them out of magazines and papers the Associations would be very grateful.

Send to the Midland Association: Mrs D. Britt, 14 Court Road, Sparkhill, Birmingham II; or Somerset: Mr and Mrs P. Lillywhite, 15 Springmead, Chard, Somerset TA20 2EW.

NEWS FROM NORTHERN IRELAND

SHARING EXPERIENCES

Stephen Kenny from Ballymena wrote to LINK about a recent Northern Ireland Association Seminar 'Sharing Experiences' at the Share Centre in County Fermanagh. Here are extracts from his report.

"Although I had not intended taking part, I soon found myself preparing a talk on 'Employment Opportunities' which lasted eight minutes. Not being accustomed to public speaking, my first reaction was one of fear - fear for two main reasons. Firstly I pictured myself in front of people (the type who can't smile in case their face cracks), and secondly, would I be good enough? After many hours at my typewriter, the finished article was completed and everything was ready".

A special bus took Stephen to the Share Centre and he arrived there about 5 pm. The first evening was one of getting to know each other and settling in.

"A lot of tired sleepy people appeared for breakfast on Saturday

morning," said Stephen, and the seminar started on the topic of Further Education with the participation of the headmaster of Omagh Technical College. The theme centred upon students with disabilities taking up further education and the obvious problems of access.

The second session was the one that concerned Stephen. "I took a personal look at employment opportunities..while Laura McCartney looked at employment from a general point of view". Like the other sessions, this ended in discussion.

The third session was with Ian Laker, one of ASBAH's Disabled Living Advisers from London, and Collette Rushe, Industrial Therapy Organiser from Northern Ireland. Ian challenged everyone, no matter what their disability, to take up sport in one form or another, or to get involved with something worthwhile and enjoyable. After a tea break the delegates were split up into various groups for an activity session - make up, sailing or archery. Stephen tried his hand at the latter.

At the end of the first day, everyone went to a disco in a local hotel, specially organised for the occasion. "I think the highlight of the weekend for me was what I can only describe as a tremendous sight and that was everybody, although they were in wheelchairs, getting themselves on the floor and dancing around to the music - everyone that was except me, but Janet Davidson, (ASBAH's Fieldworker in Northern Ireland) persuaded me to join in. That night everyone slept like logs."

Independence and acceptance were on the agenda for the next morning with one of the speakers, Miss Monica Wilson, talking about her life as a disabled person and as a student at Coleraine University.

The fourth session was group discussion on personal relationships with everyone divided into three separate groups to make them more of a manageable size.

During the final session Ian Laker gave a short talk on LIFT.

CURRENT RESEARCH SUPPORTED BY ASBAH

Dr Jean Bowyer, The Brompton Hospital, London
A Study of the Cardiopulmonary Function of Children with Ventricular Atrial Shunts

This is a project designed to study why children who have ventricular atrial shunts - shunts which drain the cerebrospinal fluid away from the brain into the heart, as opposed to the abdominal cavity - seem to be subject to impaired cardiopulmonary function. The obvious hope is that, once a link has been firmly established, the degree of risk can be assessed and treatments amended/adjusted. Project cost to ASBAH: £6,000. Completion: early in 1989.

Dr Patricia Collins, The University of Southampton, Faculty of Medicine
An Investigation into the Morphological Characteristics of the Ependyma in Normal and Hydrocephalic States

Dr Collins is looking at the damage found in hydrocephalus to the ependymal layer of the brain (the delicate layer of cells which guards the blood/brain barrier) and how this damage might be slowed or possibly reversed. People with hydrocephalus exhibit particular problems in behaviour, memory, spatial awareness, ability to cope with stress etc., and the damage to the ependyma may have a bearing on these. An ability to slow (or repair) the damage could significantly reduce the problems. Project cost to ASBAH: £28,000. Completion: January 1991.

Professor C. Rodeck and Dr Gudrun Moore, The University of London, Institute of Obstetrics and Gynaecology
Genetic Linkage in Families with X-linked Spina Bifida and Related Neural Tube Defects

Professor Rodeck and Dr Moore are studying an extended Islandic family showing an x-linked inherited form of spina bifida. The purpose of this research is to pin point a certain chromosome and to map its development. As spina bifida is a multifactorial disability - the researchers hope that their work will help isolate the various genetic/inherited factors. Cost to ASBAH: £33,000. Completion: 1991.

Doctors Margaret Borzyskowski, Brian Neville, Timothy Cox, Gerald McEnery, Guy's Hospital (Newcomen Centre), London SE1
Assessment of Spinal Cord Lesions in Children with Spina Bifida using Magnetic Resonance Imaging (MRI)

MRI is usually only employed once problems and severe

deterioration have been noted. It is, therefore, often difficult to correlate the findings of MRI with the neurological signs. The team at Guy's feels it is essential to assess children, whether or not they are exhibiting problems, so that realistic and reliable judgements and comparisons can be made, and often unnecessary surgical intervention can be avoided. Project cost to ASBAH: £2,000. Completion: July/August 1990.

Barbara Simms, Banstead Place, Mobility Centre, Banstead, Surrey
The Car use of Young Drivers with Spina Bifida and Hydrocephalus

It is known that young people with spina bifida and hydrocephalus have difficulties with driving, and although some will pass their driving test and get a car, these difficulties can persist beyond success in the driving test. Difficulties particularly in map reading/route finding can severely limit a young persons ability to use a car. This project aims to follow up a group of young people who have passed their driving test and to identify the problems faced by them - so that appropriate support and training can be offered in the future. Project cost to ASBAH: £6,000. Completion: April 1991.

Professor Michael Laurence and Dr Sara Elder, University of Wales, Institute of Medical Genetics, Cardiff
The Effect of Support Given to Couples who have had a Mid Trimester Termination for Fetal Malformation

A study of termination for fetal abnormality in the late 1970's showed that this was often followed by an acute grief reaction similar to that of neonatal death, but that few couples received support or understanding. A policy of support was introduced in South Wales which seemed to help. The aim of this study is to assess the actual effect of this support in enabling couples to overcome their grief effectively and quickly. The aim is to produce models for good practice.

Victor Boston FRCS, The Royal Belfast Hospital for Sick Children; David F. M. Thomas, St James University Hospital, Leeds
Treatment for the Neuropathic Bladder

ASBAH has funded the purchase of bladder function testing equipment at both these centres to help identify the best way of treating young people with impaired bladder function, which can lead to life threatening infections and illnesses. Project cost to ASBAH: £15,500 as a capital sum.

Dr Martin Bax, The Westminster Children's Hospital, London
A Study of Adolescents with Spina Bifida and Hydrocephalus

Many of these young people seem to have very poor self image and as a result very little social contact. Dr Bax and

Continued on next page

RESEARCH continued

his team have studied many of the effects of disability on young adults. A recent study also funded partly by ASBAH, studied health and social needs and uncovered huge gaps in provision. This study, entirely funded by ASBAH, is highlighting enormous difficulties and identifying areas where ASBAH must expand services. Project cost to ASBAH: £65,000. Completion: Summer 1989.

Projects supported by ASBAH and which have been recently completed are:-

Doctors Brown/Maxwell -
A Study of Cerebrospinal Fluid Flow under Normal and Hydrocephalic Conditions.

Dr Goodall
A Study on the Effect on Parents of Babies Deemed Unsuitable for Surgery and a Comparison between Home and Hospital Care.

● *Press Gang* is a new 12 part ITV serial, featuring Billy Homer a disabled youngster who becomes involved in the production of a young people's newspaper. It started Monday January 16, 4.45-5.15 pm

Problem share letter

I am writing to comment on an item in your Problem Share column. I feel that the advice given to the reader who 'can't turn round sufficiently to wipe my bottom' was inadequate.

The suggestion of using a mirror to 'get a better view' did not tackle the problem of inability to reach. There are several different types of bottom wipers on the market and if the reader would like further details, perhaps you could put them in touch with our centre.

Diana Williamson, Dip.C.O.T.
City of Birmingham Social Services Dept., The Disabled Living Centre, 260 Broad Street, Birmingham B1 2HF. Tel: 021 643 0980

? Problem share

The new LINK column where you can air your problems. If ASBAH can't find the solution, maybe other readers can. It's YOUR space so please do write in .

.....
? I am 20 years old and about to move into my own flat. I understood that I could get a Community Care Grant to help me set up my new home, but have been told that I am not entitled to this because I have about £1,000 in the bank. I have been saving this for a long time because I knew when I moved into my own place I would have to have a reliable car and wanted to put a good deposit down. I said to them that Mobility Allowance savings don't count, but they said they do.

A Unfortunately "they" are right. Since the new regulations came into force in April, any savings above £500 preclude you from a Community Care Grant, even if they are from your Mobility Allowance.

It is true that until April Mobility Allowance Savings were not regarded as capital, but the changes in the Social Security system brought Mobility Allowance savings into the net.

? I want to learn to balance on my back wheels. How should I go about it?

A The first thing to do is to have a settee or bed behind you (against the back wheels) to practise against so should you fall, you fall on to a soft surface. Tip the wheelchair back by pushing the wheels and leaning back at the same time. You will discover that if you pull the back wheels backwards it brings the front down, and if you push, it brings the front up. What you need to be practising is to stay up for as long as you want to, without either falling forwards or backwards and so that you feel confident.

Once you can do that, the next thing to do is to try and push yourself around whilst remaining on two wheels. It's quite handy to have someone behind you to start off with until you feel confident.

The next step is to push yourself on four wheels and then to push hard and try and tip yourself upon two wheels and stay rolling on the back wheels. Once you've perfected that, life will become so much more 'independent'; such things as kerbs will not seem a problem any more.

It is true that some wheelchairs are difficult to balance because of the weight and axle position, but if you persevere it will be worth it. It won't happen in a day. All of the above takes lots of practice.

? Is there an easy to read inexpensive range of reference books about equipment etc. for disabled people ?

A Yes. The Muscular Dystrophy Group of Great Britain has a set recommended by one of our Fieldworkers. Eight booklets cover all aspects of equipment from seating and mobility to adaptations and bathroom equipment. It was published in 1982 but is still relevant. (The set is in fact being revised). Price: only £2 including p and p. Send cheque payable to 'University of Newcastle upon Tyne' to Mrs Irene Simms, Muscular Dystrophy Unit, General Hospital, Westgate Road, Newcastle upon Tyne NE4 6BE.



A change for the better!

Next time you're travelling across London and need to get from one Main Line terminal to another, try Carelink. It's an hourly door-to-door bus service between stations with cheerful little red and yellow buses. They're wheelchair-accessible and they've got friendly, patient drivers.

Carelink is especially for people who find ordinary buses or the Underground difficult to manage (you might be carrying luggage, for example). And at Victoria and Euston, Carelink becomes an air link, meeting up with the frequent Airbus services to and from Heathrow. These buses, too, are now wheelchair-accessible.

For more information about these and other special facilities on London's buses, Underground and Docklands Light Railway, call London Transport's Unit for Disabled Passengers on 01-222 5600 Or write to the Unit at 55 Broadway, London SW1H 0BD.



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- Advice for senior citizens
- Advice for disabled people
- Energy saving tips
- Practical help with energy saving from your local NEA project
- Information for the caring professions about British Gas services for those in need

Name: Mr/Mrs/Miss/Ms

Address:

Postcode

British Gas

Best wishes from Abbey National.



ABBEY NATIONAL BUILDING SOCIETY.
ABBEY HOUSE, BAKER STREET, LONDON NW1 6XL

The most recent NAIDEX broke all records when it was held last Autumn at Alexandra Palace. It was also the largest to date with a record number of exhibitors and exhibition space.

But what is it like to visit this vast exhibition if you are disabled? Is it really worth going, or is it just a very tiring and bewildering experience as some exhibitions can be? One of ASBAH's Disabled Living Advisers, John Naude, paid his first visit in October, and here reports from a newcomer's point-of-view:

A first view of NAIDEX

NAIDEX '89. What does it mean? Well those of you who like me had no idea of what NAIDEX stands for - it's the National Aids for the Disabled Exhibition.

On arrival you receive a brochure which will list all the exhibitors and what their stand number is. I found it a great help to go through the brochure first and pick out which stands I wanted to visit - over a cup of coffee, of course. The actual size of the exhibition is so enormous I couldn't possibly have gone to all the stands without running out of time.

I found the exhibition very good in general. You are able to talk to the professionals for as long as you need and they are prepared to answer as many awkward and simple questions as you can ask, and if they can't, then they take your name and address to write to you.

While I was there I was able to speak to a couple of parents and ask them what they thought of the exhibition. Like me they felt it was well worth coming to see what equipment is available.

I came away with a pile of leaflets to browse through at leisure and to remind me of what I had seen - or what I had missed as the case may be!

CORRECTION

We apologise that in the last LINK in the article 'Dial-a-Chemist' about Healthlink we missed the last digit off the telephone number. Healthlink is at 2 Windlesham Road, Shoreham by Sea, West Sussex, BN4 5AE. The telephone number is: 0273 455878.

Treatment of shunt infections in hydrocephalus

Hydrocephalus shunt infections are potentially serious and should be treated promptly. The symptoms differ with the type of shunt used.

In ventriculo-atrial shunts (which go into the heart), the infection causes septicaemia due to organisms from the shunt being discharged into the bloodstream. In ventriculo-peritoneal shunts (into the stomach), the organisms are discharged into the peritoneal (abdominal) cavity and cause inflammation - peritonitis - and sometimes abscesses. In both types of shunt there is often infection in the ventricles of the brain or ventriculitis. In ventriculo-peritoneal, but not usually in ventriculo-atrial shunts, infection causes blockage at the bottom end of the shunt.

In true shunt infections the organisms live inside the shunt tubing causing colonisation. Infection can also occur around the outside giving rise to abscesses in the skin.

Despite all this, some patients do not appear to be very ill and in such cases, especially if the shunt is working well, there is a temptation to try to clear the infection with antibiotics without shunt revision. However, with few exceptions this approach is unsuccessful, although the patient's condition might improve temporarily. The best chance of successful treatment is given when the infected shunt is removed. Occasionally, if the infection is confined to the shunt and does not involve the ventricles in the brain, the infected shunt can be removed and a new shunt can be inserted at the same operation, although the risk of re-infection of the new shunt is high.

In most cases, therefore, the patient has a period without a shunt while the infection in the body is being treated. As such, some form of treatment will often still be needed for the hydrocephalus. In some cases, especially in babies, fluid can be withdrawn from the ventricular system either by direct tapping of the ventricles through the soft fontanelle or using a reservoir specially inserted under the scalp. The removal of fluid is done at intervals when the pressure has built up to a point where relief is needed. More constant control is achieved by the use of an external ventricular drain (EVD) which drains fluid from the cerebral ventricles externally into a bag. Secondary infection is a danger with these systems, especially if they are not managed carefully or if they are left in for longer than ten days or so.

When the commonest type of bacterium is responsible for the infection, treatment can now be carried out swiftly and almost always successfully. Using this method, the infected shunt is removed and an EVD is inserted. A highly active antibiotic, Vancomycin, is injected directly into the cerebral ventricles once each day for up to ten days, and another appropriate antibiotic is given by intravenous drip. After this time the infection should have been completely eradicated and re-shunting can be carried out immediately without the risk of re-infection of the new system. The relatively short course of treatment also means that the EVD is in use for only about seven to ten days, so minimising the risk of secondary infection.

Unfortunately, not all infections are treated so successfully. Some are due to different 'gram-negative' bacteria and these are more difficult to eradicate, though a suitable antibiotic and plan of treatment can often be found.

Dr Roger Bayston,

Senior Lecturer in Bacteriology, Institute of Child Health, and Bacteriologist, National Hospital for Nervous Diseases, London.

holidays



Even if your idea of a good holiday isn't lazing beneath the palms like the holiday-maker left, there are plenty of other options. Most successful holidays take quite a lot of thought and planning. These pages of LINK have a few helpful suggestions and ideas to point you in the right direction. There will be more next issue.

Photo Nancy Roach

Good advice

The most helpful books of all are 'Holidays in the British Isles 1989: a guide for disabled people' available from W.H.Smith at £3 or from RADAR (see below) at £4.50 to include p & p, and its overseas equivalent - publication 'Holidays and Travel Abroad for Disabled People' available for £2 from W. H. Smith or for £3 from RADAR.

They are invaluable reference books with useful contact addresses, advice and tips on all aspects of arranging a holiday.

RADAR also publishes free fact sheets taken from the above books, on: Useful Addresses and Publications, Sport and Outdoor Activity Holidays, Holiday Insurance Cover, Holiday Finance, Planning and Booking, Escort Taxi and Private Ambulances, Holiday Accommodation with Nursing Care, Holiday Accommodation for Elderly people, Holiday Accommodation for Groups, Holiday Accommodation for Children and Young People, and a new one on Volunteers for Holidays (giving a list of organisations which run holidays for disabled people and need volunteers).

RADAR (the Royal Association for Disability and Rehabilitation) is at 25 Mortimer Street, London WIN 8AB. Tel: 01 637 5400.

Accommodation list

Several disability organisations own accessible and adapted holiday accommodation that they rent to members and non-members. Details of these holidays can be obtained from RADAR (address above).

Don't forget many local ASBAH's have holiday chalets or bungalows in beautiful areas all round the country, available at very reasonable prices. Some of these appear on the inside back cover of LINK, or alternatively contact ASBAH's London office (Pat Corns).

Equipment loan

The Red Cross has a network of Medical Loan Depots which can lend equipment, including wheelchairs. The cost varies between depots.

To find out the address and telephone number of your most convenient depot contact: British Red Cross London Branch, Reception, 3 Grosvenor Crescent, London SW1. Tel: 01 235 3241.

Help abroad

Anyone who is very severely disabled and simply cannot find assistance or transport abroad may be able to get some help from the Red Cross. Given plenty of notice, it may be possible for the Red Cross to arrange transport at both ends of a journey abroad and to borrow equipment from an overseas Red Cross Society.

Contact British Red Cross Society, International Welfare Department, 9 Grosvenor Crescent, London SW1. Tel: 01 235 5454.

Holiday Care Service

This useful information service offers advice to individuals on their particular holiday needs. It has a list of various kinds of holiday accommodation in different areas, can sometimes help with transport, and also runs a holiday helpers scheme which puts people needing a helper in order to take a holiday independently in touch with suitable volunteers. The Holiday Care Service takes account of the age, experience and interests of both. The information service is free. Arrangements for paying for the helper's accommodation and travel must be agreed between the two people concerned.

The address is Holiday Care Service, 2 Old Bank Chambers, Station Road, Horley, Surrey RH6 9HW. Tel: 0293 774535. The Helpers Scheme telephone no. is: 0293 775137.

Camping

For information and advice on camping and campsites in Britain and Europe suitable for people with disabilities contact: Camping for the Disabled, 20 Burton Close, Dawley, Telford, Shropshire. Tel: 074377 489, or 0952 507653 (evenings and weekends).

continued on next page



holidays

Personal account:

On a slow boat to Milton Keynes

I have just returned from a holiday on the Grand Union Canal on a narrow boat which was specially converted to take wheelchairs - one of four run by the same group.

At first look, it seemed very big, but when we got down below it was not quite so big, as it had to be home for nine people for a week.

The route we chose was Hemel Hempstead to Milton Keynes. All was going well until the first set of lock gates. Then hard work began for the staff from the hostel as there were about 40 locks, and that was just one way. The whole thing is repeated on the way back! We didn't set off every morning until about 10 am, which in September is possibly a bit late as it gets dark early in the evening and the boat had a top speed of 4 m.p.h., so we did not get to Milton Keynes as planned.

On the journey down the canal the views were very good and there were plenty of places to eat and drink but not always with easy access for wheelchairs, so we saw quite a lot of pub gardens. Most of the time we ate on the boat partly because of this, but when you moored up it was not always easy to find a shop for food supplies.

Come the Wednesday we had to make our way back to Hemel Hempstead. We had a problem with the engine,

but it was quickly resolved and things went smoothly after that. We had a very enjoyable holiday.

From David Stacey, 28, from Taunton, a member of Somerset ASBAH

He went on the holiday with other people from the residential hostel where he lives.

□ Canal holidays

For details of David's boat ('Sheldrake') and three others (one of which has a wide beam and is extra suitable for wheelchairs) contact: Reach Out for Kids, Diocesan Education Centre, Hallgrove, Welwyn Garden City, AL7 4PJ. Tel: 0707 335968.

There are two other places where you can also hire narrowboats accessible to wheelchairs: Staffordshire Narrowboats Ltd., Equity House, 42 Central square, Wembley, HA9 7AT. Tel: 01 903 2081. They have a boat 'Doubloon' based in Staffordshire.

The Spinal Injuries Association, 76 St James's Lane, London N10 3DF. Tel: 01 444 212. They have two boats: 'Kingfishers I and II', in Rugby and Monmouthshire.

□ ASBAH

Don't forget that ASBAH's London office (Pat Corns) has a wealth of information, advice and useful addresses about planning, booking, financing your holiday as well as addresses of particular types of holiday. Contact Pat and she will do her best to help.

Below is a list of the activity programme which ASBAH will be running this year at its activities centre in the beautiful Yorkshire moors, Five Oaks at Ilkley. Many readers will, no doubt, have already enjoyed one of these courses.

NINE good reasons for going to FIVE OAKS this Spring Activity programme 1988

- | | |
|---|---|
| ★ 1 Independence Course.....February 13-17 | ★ 6 Holiday Week.....March 25-April 1 |
| ★ 2 Indoor Activities Week.....February 19-25 | ★ 7 Fashion Course.....April 2-8 |
| ★ 3 Driving Assessments.....March 6-10 | ★ 8 Daytripper Week.....April 16-22 |
| ★ 4 Independence Course.....March 13-17 | ★ 9 Independence Course.....April 24-28 |
| ★ 5 Holiday Week..... March 18-25 | |

continued on next page

holidays



Norman splices the main brace

Crewing a tall ship - some people's idea of hell - but for Norman Cooper, 16, from Cardiff it was a dream come true.

Thanks to British Telecom in South Wales, Norman who has spina bifida, spent 10 days as one of the 50 or so able-bodied and disabled crew of Lord Nelson, the Jubilee Sailing Trust's ship on a cruise from Swansea to Glasgow via Ireland.

He described the adventure as "absolutely brilliant. Being in a wheelchair didn't affect my holiday at all. Working with the crew, I spent a lot of my time turning the ship by pulling the sail ropes. The only thing I really couldn't do was climb the mast - which I didn't fancy anyway! I enjoyed every minute and would love to go again if I get the chance".

If you'd like to splice the main brace for your holiday write off for more information about the Jubilee Sailing Trust cruises: to the Trust at Test Road, East Docks, Southampton SO9 1GG. Tel: 0703 631395.

Photo: courtesy of British Telecom's magazine for disabled customers 'Dovetail'.

Volunteers wanted

Quaker International Social Project welcomes disabled people as volunteers on various projects in Britain and Northern Ireland. Experienced volunteers may be able to take part in exchanges with volunteers on schemes abroad.

Contact: Quaker International Social Project, Friends House, Euston Road, London NW1 2BJ. Tel: 01 387 3601.

Caravan site in Wales

Tyddyn Sander Caravan Site is a small, newly developed coastal caravan site on the Llyn peninsula in North Wales. All facilities are accessible to disabled visitors.

Brochure and further details from: Mrs Sarah Williams, Tyddyn Sander Caravan Site, Tudweiliog, Pwllheli, Gwynedd LL53 8PB. Tel: 0758 87420.

River cruise

Varioustrips on the River Stour in Kent can be arranged aboard the purpose-built Reneroy IV which has room for ten wheelchair passengers. The boat is based at the Grove Ferry Inn, just off the A28 between Canterbury and Thanet. Advance booking for groups is advisable.

More information from: Reneroy IV Services, the Boat House, Grove Ferry Road, Upstreet, Canterbury, Kent CT3 4BP. Tel: 0227 86345.

Trying intermittent catheterisation for myself

a personal view

by

Jamie Gilham,
Disabled Living Advisor, ASBAH

I have used a penile sheath and leg bag for many years quite successfully.

In fact, the only problems I had were when there was a faulty batch or if I had left the sheath on for too long.

After I joined ASBAH last year, I found out about self intermittent catheterisation. On first hearing and reading about it, I was a bit sceptical as I thought it would hurt (I'm a devout coward when it comes to pain) and I also believed that every time I drank, it would go straight through me, as I wasn't sure that my bladder muscle would be strong enough to stop any urine escaping.

After all this, I was still prepared to try it, as so many people seemed to have had success with this system of continence management.

I went to the urologist at my hospital and he seemed to be quite happy with the idea. I had just had an IVP a few weeks earlier, so he didn't see much point in doing any further tests.

I made an appointment to see an incontinence nurse for the following week. She showed me how to insert the catheter, and to my surprise, it didn't hurt, although I did feel it passing up my urethra and through the sphincter muscle. I was warned beforehand that some blood might get passed along with the urine for the first few days, but I was not to worry unless a lot was passed or if it didn't subside.

The first couple of days I spent building the time up between visits to the toilet. Within a week I was able to stay dry for three hours.

This was during annual leave when I wasn't driving around so much and I wasn't doing any sport or drinking sufficient amounts to keep away those dreaded infections.

The fun started in the second week when I returned to work and to sport. When I was in the office it wasn't too bad, but I was spending 20 minutes in the toilet every two and a half hours, because we are such manic tea drinkers and my bladder couldn't hold for any longer time.

The worst times were when I was driving around or playing basketball, as there aren't that many accessible toilets by the roadside when you need them. Unfortunately, being in a wheelchair often means that whatever you do you will exert some pressure on your stomach muscles. This is especially true of basketball or getting a wheelchair in and out of your car.

On these occasions, even if I had emptied my bladder a few minutes previously, I would still be soaked. I use my car every day and play basketball three times a week on average, so you can imagine how annoying this became.

I went back to the urologist and told him the problems I was having, so he prescribed me some drugs to take,

but unfortunately, the drugs he offered me were on the banned substances list for sports as they were muscle stimulants.

I am now back using a penile sheath and leg bag, and I feel much more at ease as I don't have to be so time conscious.

Please note, I am not trying to put anybody off this system. I am merely trying to point out the pitfalls so that if any of you are thinking about changing to this system you will have some idea of what to avoid, or questions to ask your urologist or incontinence nurse.

If you have any questions or you would like some advice on any incontinence matter or other subject of daily living, please do not hesitate to contact the Disabled Living Advisory Department.

Good luck!

BRISTOL WORKSHOP CLOSES

After running a workshop for young people for five years, Bristol local Association has reluctantly decided to close it. The high running costs were out of proportion to the small number of young people employed.

The workshop, in the capable hands of Liz Luckwell, produced a range of craft items such as rag rugs, t-shirts and cards, but although these were sold, the workshop still ran at a huge loss.

The young people have been or are being placed in employment elsewhere.

Access in Israel

A new edition of this popular guide to the Holy Land for travellers with disabilities has recently been published by Pauline Hephastost Survey Projects. Available, price £3, from the Publications Department, RADAR, 25 Mortimer Street, London W1N 8AB.



Hairwashing from a wheelchair can be a problem. This hairwash stand, from the Keep Able mail order catalogue, has been designed with this in mind.

Normally the basin is positioned over the washbasin to allow the suds to drain away, but if this is inconvenient, there is an optional collecting tub (as shown in the photo). The stand is adjustable for height.

This is just one of a range of personal care products which aim to make life easier and provide solutions to awkward problems and which have been introduced in the Keep Able mail order catalogue.

Price - basin and stand: £54.60; collecting tub: £13.45; postage and packing: £2.85. from Keep Able, Fleming Close, Park Farm, Wellingborough, Northants NN8 3UF. Tel: 0933 679426

Tapping into specialist advice

Plumbing Services for the Disabled Community (PSD) is a service available to all those who provide housing facilities for the disabled community. The firm, based in Eltham, London can offer help with plumbing and sanitation installations, building access, cost consultancy, drainage engineering, electrical engineering, fire protection, heating, ventilation, refrigeration and air conditioning.

PSD says it is not only concerned with large scale institutional projects but also with "all types of problems, large or small".

For more details contact PSD, 202 Footscray Road, Eltham, London SE9 2EL. Tel: 01 859 41867.

The same firm has also set up Plumbing Help Line, a free telephone consultancy service available to all who have technical queries with plumbing. Tel: 01 468 7767.

Fashioned for comfort

Artimaze has announced the launch of a specially designed range of fashion and leisurewear under the Eez-E-Wear label, particularly for people with disabilities and clothing problems.

The clothes are for ladies and men and all are available in five sizes and three colourways and made of easy care fabric (15% polyester, 40% cotton and 45% acrylic) fleecy lined, and machine washable (40 degrees) and non iron.

There are three types of unisex tops which mix and match with either the pants or culotte skirts. Many of the garments have striped ribs.

Style 1 has a ribbed centre panel in the back and front allowing extra stretch for additional comfort or to deal with spinal problems. A long vertical zip with easy pull loop aids adjustment by the wearer. This style features deep raglan sleeves as a fashion note.

Style 2 has shoulder zips to allow the garment to be slipped over the head easily, and angled pockets make it easy to get your hand in, even when seated in a wheelchair.

A diagonal zip for the neck opening is a feature of Style 3. This makes it particularly suitable for stroke patients, and again there are easily accessible pockets in the deep raglan sleeves.

All three tops have ribbed sleeves with velcro fastenings, and an extra long back gives additional warmth and comfort avoiding that 'cold gap' in the middle.

The culotte skirt has many design features to ease dressing and to give extra modesty as well as warmth such as extra strong loops inside the elasticated waistband, front and back panels which cover the matching culottes and velcro fastenings.

The leisure trousers for men have an extra high back to eliminate gaping when seated in a wheelchair. It also features an elasticated waist with concealed pull on loops for comfort and easy dressing, knee level pockets with velcro fixings for increased comfort, easy access and security, and an extra deep fly with velcro studs to the crotch. The trousers are generously cut in the seat, yet fit snugly in the front to prevent bunching when seated, giving the effect of a well cut pair of trousers.

The unisex leisure pants have many of the features of the trousers (but without the fly) as well as ribbed ankle cuffs with velcro fixings to allow maximum openings for stiff joints.

In addition to this range, there is a really stylish ladies' cape/jacket for warmth and good looks. It comes with a hood and spare, detachable sleeves so that even when a wheelchair decides to dirty your sleeves, you can always look smart and clean. A similar version is available for men, without a hood, beautifully styled in grey melton fabric.

Prices are about £25 per item, except for the capes made of tweed and easy care fabric which cost about £50 each.

For further details and a comprehensive catalogue and price list contact Artimaze Ltd (Eez-E-Wear Division), Dept 1L, c/o 6 Lechmere Road, Willesden, London NW2 5BU. Tel: 01 459 7053.

Reading Matter

Scoliosis -

**an information booklet
Published by the Scoliosis
Association (UK)**

Scoliosis is the disorder of the spine in which the spine curves sideways and becomes twisted, pulling the ribcage round to form an often unsightly prominence on the back. It is a condition which children with spina bifida can develop. This book has been written for patients, their families and others who have contact with the children. It emphasises the importance of early diagnosis so that a child's curvature can be monitored and treated if it shows signs of deterioration. There are sections describing the disorder, its possible causes, treatments, school screening, and clothing to wear under a brace.

The publisher of this book, the Scoliosis Association is an independent organisation with about 1,300 members, mostly people with scoliosis and their families.

Price £3.95 plus 30p postage and packaging from the Scoliosis Association (UK), 380-384 Harrow Road, London W9 2HU. Tel: 01 289 5652.

Our Special Children

A practical guide to stoma care in babies and young children published by CliniMed on behalf of the National Advisory Service for Parents of Children with a Stoma (NASPCS).

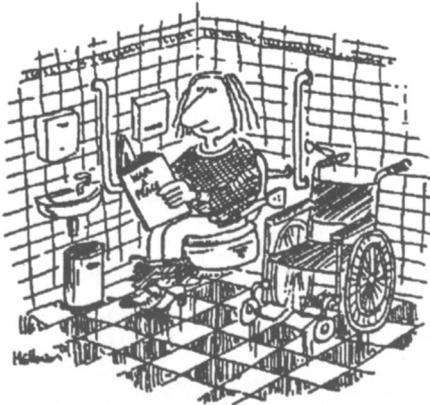
There is little written information and practical advice available on stoma care for children and this little booklet, therefore, meets a real need.

It has been produced by CliniMed, suppliers of the Biotrol stoma care range, on behalf of the support group of NASPCS. It was compiled by the founder of NASPCS, Sue Bird, and is

based on the experiences of many families, the problems they have faced, and the solutions they have found.

It is well illustrated and gives clear and simple information on stoma care for babies and children. Sue Bird was helped by Helen Johnson, Stoma Care Nurse at St Mark's Hospital, London who comments "The booklet can act as a reinforcement of information and advice given which is sometimes forgotten or misinterpreted during the stressful period of hospitalisation.."

The booklet is free from CliniMed Limited, Cavell House, Amersham Hill, High Wycombe, Bucks HP13 6NZ. Tel: 0494 444027.



Good Loo Design Guide

**By Stephen Thorpe B Arch
Published by Centre on Environment for the Handicapped**

Why do architects design 'conveniences' that are inconvenient for disabled people? Why is it, despite the quantities of technical design guidance, that so much WC provision for disabled people is poorly designed or even unusable?

The answer, CEH believes, is the lack of forthright, unembarrassed and factual information on how people with disabilities actually use a unisex or other loo. Without this, designers are interpreting technical guidance with imperfect or no knowledge as to what it is for. With the aid of annotated drawings, photographs and text the CEH guide will illuminate their task.

Price £5 including postage and packing from CEH, 35 Great Smith Street, London SW1P 3BJ.

Footwear for Swollen Feet

**Published by the Disabled
Living Foundation**

Finding the appropriate footwear if you have swollen feet, whether temporary or permanent can be very difficult. The leaflet describes the various types of footwear now available, which can be grouped into three categories -temporary, rehabilitation and bespoke. It also covers adaptations to shoes and hosiery. Details of sources of supply are included in this useful leaflet.

Price: 80p from The Clothing Adviser, Disabled Living Foundation, 380/384 Harrow Road, London W9 2HU. Tel: 01 289 6111.

Orders totalling less than £1 are free if accompanied by a stamped addressed envelope (although donations are welcomed).

After Attenborough - Arts & Disabled People

**From the Carnegie Council
Published by Bedford Square
Press**

This is a comprehensive review of how government, arts councils and other arts bodies have responded to the recommendations of the Attenborough Report 'Arts & Disabled People' (1985). The Carnegie Council was set up to further the aims and follow up the Attenborough Report recommendations and guard against 'pigeon-holing' of the report.

After Attenborough documents a number of significant advances locally and nationally as well as the failure of many government departments to take action. Overall it provides a clear picture of the difficulties facing those organisations and people who in the words of Sir Richard Attenborough hope to 'transform the lives of disabled people and to enrich the world of art itself by their greater involvement'.

Price £5.95 from bookshops, or from Harper & Row Distributors Ltd., Estover Road, Plymouth PL6 7PZ (include an extra 75p for postage and packing).



CORRECTION

Left: The correct photographs of a new wheelchair with a difference, the Fenolyte.

It is an alternative to the normal folding chair and is made of 90% plastic, is comfortable, light-weight and in the inexpensive price range.

LINK's printers by mistake chose the wrong photograph to illustrate the Fenolyte in the last issue. Our apologies

Details of chair from Lieuse Technology Ltd., 6 Hornton Place, London W8 4LZ. Tel: 01 938 1762.

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- free first year AA membership

LK3

Please send details of the NIPPI

Please arrange a demonstration without obligation

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Address

.....Post code.....



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Proprietor: Maureen A. Nuttall. SRN RSCN QN



The Running Costs of a Car

One of ASBAH's Disabled Living Advisers with a special interest in mobility, Mrs Leonie Holgate always concerned about the realities of owning one's own car has sent this list of running costs produced by the AA.

She says by way of explanation: "I do not think it is always realised how expensive it is to run a car. Of course, if someone receives Mobility Allowance, the car licencing fee is waived, and if someone leases a car through Motability they can omit servicing charges and the cost of the first new set of tyres. Insurance premiums are also favourable with this scheme and membership of the AA is included in the rental payment. This will help to reduce the running costs per mile, but adaptation costs would have to be met.

NB: These figures from the AA do take absolutely everything into account. Some organisations feel that they are on the high side, but at least they convey the fact that it's expensive to run your own car.

TOTAL OF STANDING AND RUNNING COSTS (IN PENCE) BASED ON ANNUAL MILEAGE OF:

Miles	Engine capacity (cc)				
	Up to 1000	1001-1400	1401-2000	2001-3000	3000-4500
5,000	35.572	43.486	51.994	89.642	115.083
10,000	23.194	27.684	32.858	54.745	69.644
15,000	20.013	23.716	28.097	46.375	58.879
20,000	19.122	22.708	26.931	44.639	56.784
25,000	18.587	22.103	26.232	43.597	55.527
30,000	17.299	20.399	24.146	39.638	50.306

'With a Helping Hand...'

TEACHING PACK

Queen Elizabeth's Foundation for the Disabled, Leatherhead has produced a 40 page self-teaching pack for carers intended to be a basic guide to understanding and managing teenagers with spina bifida.

It includes information on learning difficulties, a detailed self-care programme, useful addresses and a bibliography.

The compiler, Victoria Houlton-Hester has been

on the staff of Banstead Place for over 10 years and has had experience of teaching large numbers of students with spina bifida and/or hydrocephalus.

The pack costs £3 including postage and packing.

Also available is a supplementary pack of illustrative material - a set of overhead projector transparencies, an album of 10 photos on showering and the ap-

Sensible Health Care for Teenagers with Spina Bifida

plication of urinary appliances, with instruction text, and a recorded tape of daily bathing programme. These packs are available as boxed sets at £30 including postage and packing.

For further information on *With a Helping Hand* contact Queen Elizabeth's Foundation for the Disabled, Leatherhead, Surrey KT22 0BN. Tel: 0372 842204

New club for those seeking work

A job club for disabled people has been opened in Kent by the Director of Kent's Social Services, Norman Warner. The Bal-four Job Club in Findsbury, near Rochester, is believed to be the first of its kind to help disabled people find employment. It can also help those with some learning difficulties.

For details contact Kerry Sparkes, the Job Club Leader, Unit 11, Medway Enterprise Centre, Enterprise Close, Medway City Estate, Findsbury, Rochester, Kent. Tel: 0634 293001.

CARE PARENTS

Does your youngster enjoy making new friends? Do you occasionally appreciate a break from the extra care that your child with spina bifida and/or hydrocephalus needs?

Barnardo's in County Durham run a scheme which aims to make these things possible by linking children with families known as 'care parents'. The children have a wide variety of special needs from mild learning difficulties to profound handicaps and are aged from a few months to 21 years.

The time spent with care parents is flexible - perhaps just an evening a week, or a weekend, or a week or two. The two families involved make the arrangements to suit their needs. As the families get to know each other everyone relaxes and looks forward to the short periods of respite care.

For more information please contact:

Tessa Sampson,
Project Leader,
Durham Shared Care,
Maiden Law Hospital,
Lanchester, Co. Durham
DH70QN. Tel: 0207 520502.

SUNNY TENERIFE; Los Cristianos

As featured on TV and radio, the beautiful 'Mar y Sol Health and Fitness Resort'. Purpose-built, totally wheelchair-accessible. Swimming pools, sports facilities. Apartments for rent or ownership. Flights can be arranged too. "Brilliant..amazing" says BBC TV's *The Travel Show*. Come and see for yourself.

Video (£10 refundable deposit), brochure: Lynne James, 7 Overpool Road, Ellesmere Port L66 1JW. Tel: 051 339 5316.

YOU MIGHT LIKE TO PASS THESE FORMS ON TO A FRIEND OR LOCAL FIRM

To: Association for Spina Bifida and Hydrocephalus

22 Upper Woburn Place
London WC1H 0EP

Please tick as appropriate

- I enclose _____ as my donation to the work of **ASBAH**.
- I should like to give _____ as my donation to the work of **ASBAH**. Please debit my ACCESS/BARCLAYCARD, Number _____ with this amount.
- I enclose a Banker's Order in favour of **ASBAH**.
- I enclose a covenant in favour of **ASBAH**.
- I should like details of the Deposited Covenant Scheme[•]
- I should like to remember **ASBAH** in my will. (An approved form of wording is given below).
- I should like to organise a local fund-raising event for **ASBAH**. Please send me suggestions and support material.
- Tick this box if a receipt is not required.

[•]*The donation of a lump sum on which we can recover the tax.*

Signed _____

Name _____

Address _____

Suggested Will Codicil

"I bequeath to the Association for Spina Bifida and Hydrocephalus the sum of £..... free of duty to be applied for the purposes of the Association, and I declare that the receipt of the TREASURER or other proper officer for the time being of such Association shall be sufficient discharge for the same."

Form of Covenant

Association for Spina Bifida and Hydrocephalus (Limited by Guarantee)

I
(Block letters and full names please)

of
(Home Address)

HEREBY COVENANT with the Honorary Treasurer of the Association for Spina Bifida and Hydrocephalus, 22 Upper Woburn Place, London WC1H0EP, that for a period of four years from this date (A).

.....
or during my lifetime, whichever period shall be shorter, I will pay annually to the said ASSOCIATION such a sum as will, after deduction of tax at the Basic Rate for the time being in force, leave in the hands of the ASSOCIATION

the net sum of £ (.....)

such sum to be paid from my General Fund of Taxed Income, so that I shall receive no personal benefit in either of the said periods from the above-mentioned sum, or any part thereof.

IN WITNESS whereof I hereunto set my hand and seal this

(B) day of 19.....
Please note that the date at (A) should be later than the date at (B)

SIGNED, SEALED AND DELIVERED

by the said..... 
(Signature of Subscriber)

in the presence of *Signature*

Address

Occupation

BANKERS ORDER

To the Manager Bank

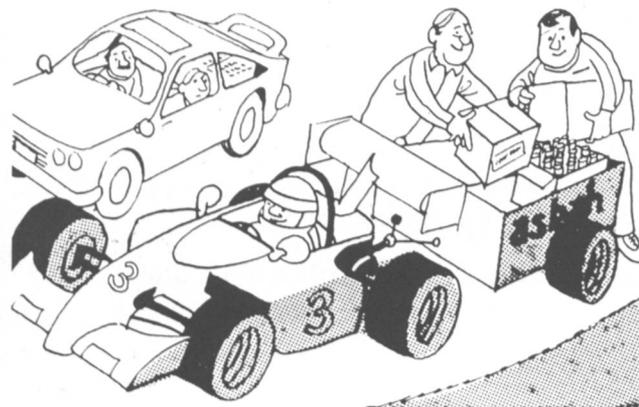
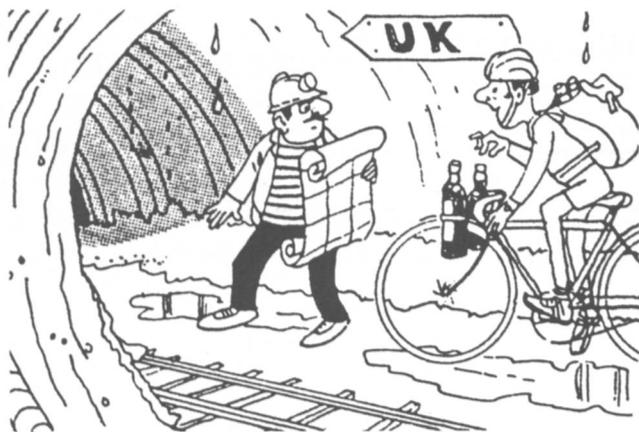
..... Branch

Please pay National Westminster Bank Plc, Tavistock Square, London WC1,
Code No. 60-80-07, for the credit of ASBAH, A/C No. 36254444 on the

..... day of the sum of £ (in
words) charging such payment to my account with you,
and continue to pay this amount annually on the same date in each of the
following 3 years, making 4 payments in all.

Name..... Signed.....

APPEALS NEWS



Strike blow for Beaujolais Rally

The rally got underway at one minute past midnight on November 17 with 144 competitors, each trying to record as low a mileage as possible from the vineyard at Lacenas to Calais harbour.

However, there was a slight hiccup to the challenge as Calais port workers were on strike which meant all entrants were diverted to Zeebrugge, and this led to an extra four hours travel time. As a result no competitor was able to get to the finish and champagne breakfast at Margate.

The winner was Mr M. Allen - 393 miles, with Mr M. Evans second (402 miles) and Mr J. Brown third (413 miles). Cyril Levy who drove the ASBAH car loaned by Vauxhall Motors finished a creditable 18th with 449 miles on the clock. All entrants raised money for charities in the UK, including ASBAH.

A dozen of the best

The third ASBAH Wimbledon Greyhound Meeting takes place on February 21 and once again promises to be a popular event.

There will be 12 races, each sponsored by a company, with six dogs to a race. Every dog has a 'nominator' at £15 a go.



(Above) Northern Ireland Fieldworker, June Kerr (left) receives a cheque for ASBAH's work from Chris Wallace (right holding his baby Kirsty who has spina bifida) and Pat Token. This was part of the money raised from a sponsored marathon in which the two energetic men took part. Our thanks to them for their help.

The talking never stops

The Conversationalist of the Year takes place on May 13/14 at the Glaziers Hall. Once again ASBAH hopes for a good response. Let us know if you'd like to enter.

ASBAH is urgently looking for sponsors for this popular event. Last year Dewhurst the master butcher and LBC did the honours, but have declined this time around although LBC will still be helping with publicity.

And the chatting is now being extended to schoolchildren. A first ever SCHOOLS CHATATHON, sponsored by the Montessorri St Nicholas teacher training college, will take place in July for secondary schools in the country. Please get in touch with Stewart Morrison at ASBAH's London Office in Appeals if you'd like more information on either event.

Kart Day is great fun

Chris Ball from Harlow in Kart no. 7 had a terrific meeting at the Fun Kart Day in aid of ASBAH at Brands Hatch in November. He took first place in the final, with Dave Houghton, from Stockport, second, and Rick Kirby from Canada in third place. Each helped raise £7,500 for ASBAH and all three won a magnum of Beaujolais for their stirring efforts on a damp, cold November Friday.

Altogether 72 competitors began their day at 8.30 am and by 10, having gone through the tuition of gears etc., there was a series of heats culminating in two semis and a grand final on the Brands Club circuit of 1.2 miles.

ASBAH sends its thanks to everyone who took part and contributed in any way to this fun day. Particular thanks go to Jeff Crookbain for supplying his Superkarts, along with his team and expertise. Catering in difficult conditions was provided on a generous scale by Joan Chapman, ASBAH's Appeals Administrator and a team of helpers.

Advertising

FOR THE USE OF LOCAL ASSOCIATIONS AND OTHER READERS

Rates: £3 for 30 words max; £4.25 for 30-45 words;
£5.50 for 45-60 words.

Cheque or postal order payable to 'ASBAH'

Adverts for the next LINK (March/April) should be in by
February 20. Send to: The Editor, Mrs Sue Gearing,
The Gables, Long Lane, Wrington, Avon, BS18 7NE.
Tel: 0934 862279

HOLIDAY ACCOMMODATION

BORTH, Nr Aberystwyth. 6-berth de luxe holiday home. Licensed site. Suitable for wheelchair users who live independently. Details: Mrs J. Carter, 1 Meadow Road, Craven Arms, Shropshire.

ISLE OF WIGHT. Very well equipped chalet with easy wheelchair access at **Brambles Chine, Freshwater.** Sleeps 6. Indoor heated pool, club, shop. Details: Ring or write: Mrs S. Gully, Old Princelett, Apse Heath, Sandown, Isle of Wight. Tel: 0983 863354

SELSEY, Sussex. Six berth purpose built fully equipped mobile home. Ramp access. Site near sea. Pool, club, etc. Details: Mrs C. Bugden, 27 The Grove, Sholing, Southampton SO2 9LT. Tel: 0703 444921.

WINTERTON ON SEA, Great Yarmouth, Norfolk. Six berth chalet bungalow, well equipped and on pleasant site with all amenities. Cooker, fridge, colour TV, toilet and bathroom. Heated indoor pool, shop, bar with live music, children's play areas. Cycle hire. Take-away food and snack bar. Details: Tel: Mr R. Morris, 0494 32184.

RYE HARBOUR, Sussex. Fully equipped mobile home, adapted for wheelchair users. Sleeps 4. Clubhouse on site. Details: Mr P. Borthwick, 170 Hollington Old Lane, St Leonards, East Sussex. Tel: 0424 51145.

WESTWARD HO!, North Devon. Holiday chalet. Sleeps 6. Excellent club. Swimming pool and shop on site. Near sandy beach. S.a.e. to Mr Oakley, 12 Farleigh Road, Perton, Wolverhampton. Tel: 751484.

SELSEY, Sussex. Five berth mobile home, purpose-built for wheelchair users. Fully equipped including colour TV and telephone. Licensed site near sea. Pool. Many tourist attractions in surrounding area. Details: Mrs B. Nunn, 13 Grafton Gardens, Lancing, West Sussex, BN15 95P. Tel: 0903 763473.

LOOE, Cornwall. Fully equipped, self-catering two bedroom 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.

MOLD, Clwyd, North Wales

Luxury detached bungalow set among magnificent pines in the heart of Clwyd, yet minutes from the market town of Mold.

Specially adapted for wheelchairs. Two bathrooms. Sleeps 4/5.

Prices £170 per week (discounts).

Brochure: Lynne Dowling, 23 Gleneagles Road, Gt Sutton, South Wirral L66 4NF. Tel: 051 339 5316).

Holiday in a historic Welsh Long House

At Dolgellau, Gwynedd, there is an old Welsh long house with a range of all-the-year-round holiday accommodation for groups or families, and is accessible for holiday-makers in wheelchairs. It is beautifully situated in the grounds of a tiny residential special school, Ysgol Hengwrt. Self-catering or fully inclusive holidays are available.

Hengwrt is situated in an unrivalled natural setting, flanked on one side by its own old woodland and on the other by undulating fields with spectacular views down the Mawddach estuary towards Cardigan Bay. It is near local attractions such as mountain walks, towns, beaches and not too distant holiday resorts.

If required, advice and help will be given to organise day outings to places of interest - from pony trekking to visits to a puppet theatre or sea zoo.

For a brochure and booking details contact Mr P. S. Hett, headmaster, Ysgol Hengwrt, Barmouth Road, Dolgellau, Gwynedd, LL40 2SS. Tel: 0341 422597.

FOR SALE

Carter electric wheelchair with kerb climbers. Recently serviced with new batteries. Good condition. £500
Stannah Stairlift left hand, straight track, 13 stairs. Serviced regularly. Good condition. £850.

For both, telephone: Brighton (0273) 693327.

HOUSE FOR SALE

A semi-detached 4 bedroom house at St Paul's Cray, near Orpington Kent is for sale and has been extended and adapted to accommodate someone in a wheelchair. It has ramps to front and rear and a downstairs bedroom, and a bathroom with a large low level shower and a special toilet with rail. The whole of the ground floor is adapted with wide doorways and, low light switches. The house has an attached garage and private front driveway providing off-street parking, as well as a rear garden. Price: £115,000 freehold.

The present owner is moving abroad and would like the house to go to a family with someone who is disabled.
Details Mrs R. J. Kirby, 11 Blythe Hill, St Pauls Cray, Orpington, Kent BR5 2RP. Tel: 01 302 0644.

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