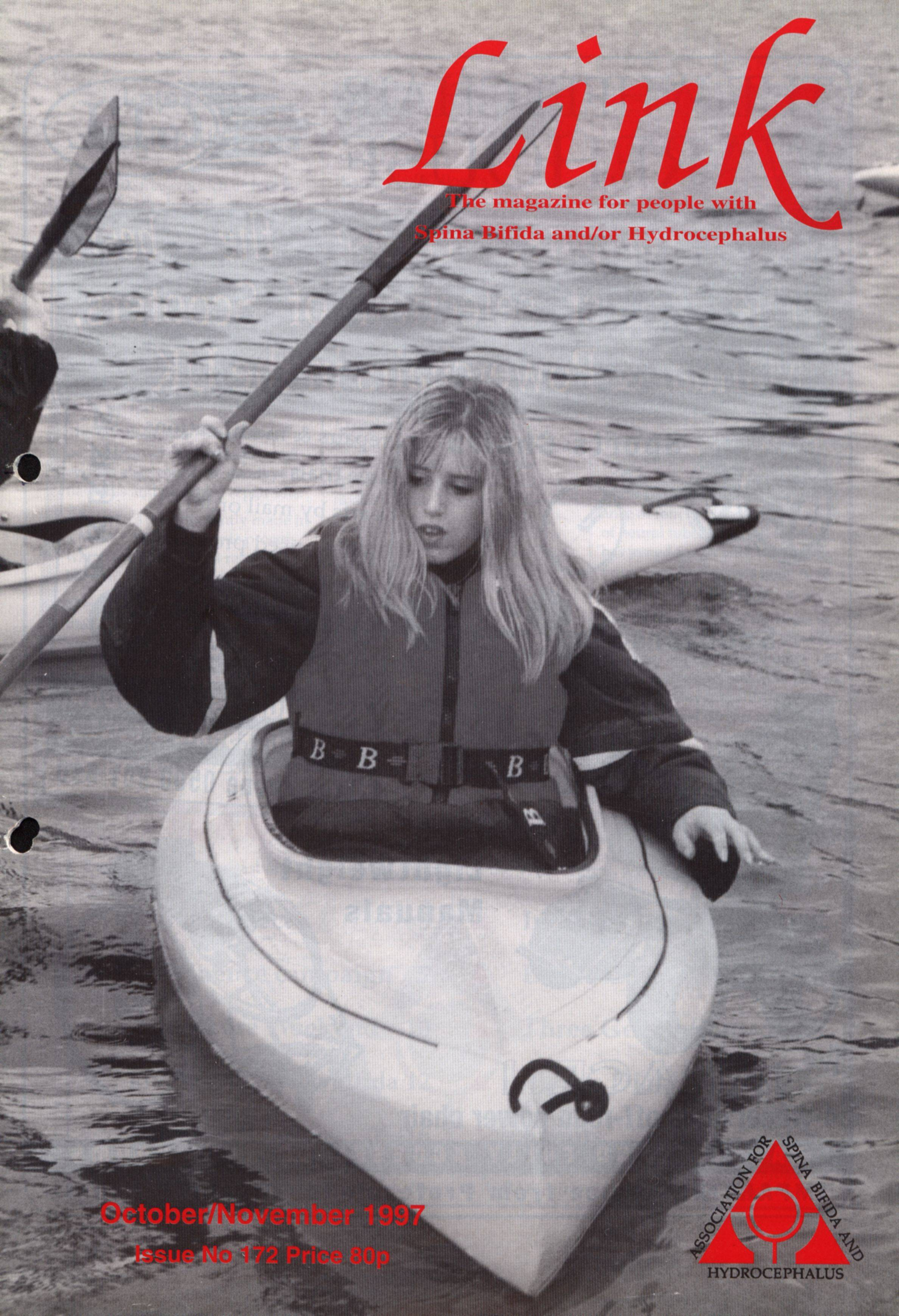
Link

The magazine for people with
Spina Bifida and/or Hydrocephalus



October/November 1997
Issue No 172 Price 80p

ASSOCIATION FOR SPINA BIFIDA AND HYDROCEPHALUS

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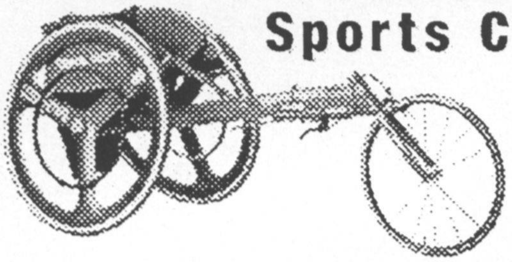

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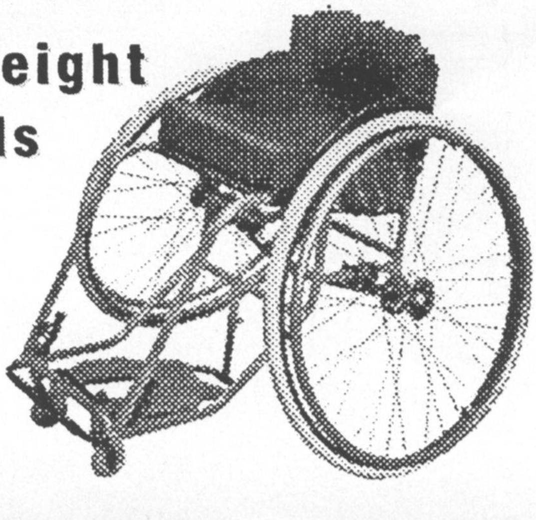

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Full details and prices from: Green Tyre Company plc, Riverside Park Road, Middlesbrough TS2 1UU. Tel: 01642-223322; fax: 01642-223313.

Cereal showpiece

'WAKE up and start the day with a bowlful of Kellogg's breakfast cereal, fortified with folic acid,' was the message of a roadshow which raised funds for ASBAH.

The exciting showpiece, travelling to 22 showgrounds across Britain, aimed to give a fun, educational and interactive approach to learning about healthy eating and the importance of breakfast, through the use of all senses.

Visitors followed *The Kellogg's Experience* from 'grain to box'– feeling the warmth of the sun that grows the grain, smelling the aroma of the ingredients and finally tasting Kellogg's cereal.

Nutritionists were available to offer individual dietary advice, with a special focus on folic acid for women between the ages of 16-45 as a daily requirement.

Visitors could *Bike for Spina Bifida* for three minutes, with Kellogg's giving £1 to ASBAH for every mile clocked up on the cyclo-meter.

And children could bounce around in the Fun Bowl – a large, inflatable bowl filled with pretend cereal – and meet Tony the Tiger.

Denise Taylor from ASBAH SE Region (left) with the cyclometer at The Kellogg's Experience, *Battersea Park, London*

In raising awareness of the importance of folic acid in the prevention of neural tube defects, Kellogg's has joined forces with the Health Education Authority's Folic Acid Campaign and ASBAH.

Reg Fletcher, head of nutrition at Kellogg's, said: "A cereal breakfast provides approximately one quarter of the vitamins and minerals we need to ensure a healthy balanced diet. Breakfast cereals provide an easy vehicle for providing this important vitamin in the diets of women of child-bearing age."

Contents

ASBAH is a registered charity

E-mail: postmaster@asbah.demon.co.uk Find us on the Web – http://www.asbah.demon.co.uk/

***Cover:** Fourteen-year-old Vicky Ramshaw, from County Durham, enjoys the watersports session during an ASBAH Adventure Weekend. See pages 10-11.*

The importance of folic acid still ignored by some doctors

ANECDOTAL evidence from callers to ASBAH suggests that a significant number of doctors are still not alerting women to the role of folic acid supplements in preventing the occurrence of neural tube defects, such as spina bifida and hydrocephalus.

In the worst examples of bad advice, women, who were at high risk of having a child with spina bifida because they had already had one affected pregnancy, were advised that they did not need to take folic acid.

For women whose pregnancies have not been complicated by a neural tube defect, the news is not much better. Recent research carried out by the University of Leeds showed that, although two-thirds of women said their general practitioner had talked to them about folic acid, only 28 per cent had taken a supplement prior to conception.

Women who have already had one pregnancy affected by spina bifida are more likely to have a future spina bifida pregnancy, yet folic acid has been proven to prevent neural tube defects in up to 72 per cent of at-risk pregnancies.

This news was released as ASBAH launched its fourth National Spina Bifida Week (15-21 September 1997), sponsored by Cantassium Micro Folic Acid from Larkhall Green Farm, which aims to create further awareness of the need to take folic acid prior to and during pregnancy and to raise funds for ASBAH initiatives.

Andrew Russell, ASBAH executive director, said: "We are horrified at the low level of awareness despite the Health Education Authority's sterling efforts over the past two years and on-going initiatives by ASBAH to ensure that every woman of a child-bearing age is aware of the benefits of folic acid.

"We are particularly concerned about the attitude of a minority of general practitioners and consultant doctors to folic acid, especially in the case of women who are already at risk of a spina bifida pregnancy and should be prescribed 5mg folic acid for pregnancy. And women generally should be informed that, as soon as they stop using contraception, they should start taking a 400mcg supplement of folic acid – not that folic acid 'is for cranks'."

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- Supported by The Treloar Trust (Registered Charity 307103) which also supports a school for 5 -16 years.

For further information, please contact:
Admissions Secretary 01420 547425

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Since 1993, Computer Sense has been offering a highly-professional sales and advice service to firms which use Apple Macs.

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Meeting place

Would you like the chance to talk to other people with the same disability as yourself?


Jill Barlett


Carolyn Jones

WALES is the focus of a new project for people of any age who want to get together and discuss housing, relationships, budgeting, health – in fact, any subject under the sun which is important to you!

The project is split into two areas – North / Mid Wales, covered by Jill Bartlett; and South / West Wales, covered by Carolyn Jones.

Carolyn and Jill were appointed by ASBAH earlier this year and have so far written to about 200 service users in Wales, asking them what they want from ASBAH, and whether they would like to be more involved in the organisation.

Jill said: "We want to make things better for people aged 16+. We are the service-providers and you are the service-users – so please let us know what you want. "Your experience and knowledge can be very valuable to others, just as their experience might help you, so we are trying to create opportunities for you to meet other young people like yourself."

An example of how young people from Wales can help each other occurred this summer when four young people gave talks at two *Towards Independence* weekends in Plas Menai, North Wales, and the Jane Hodge Hotel, near Cardiff, South Wales, which were organised by ASBAH's START team.

In North Wales, people tend to live far apart, so Jill has got funding for residential weekends. This means overnight stays can be offered to those attending the meetings.

In South East Wales, Carolyn has set up a group which meets monthly. Subjects under discussion have been transport, facilities for disabled drivers and training opportunities. They are now joining with PHAB to start a group in Haverfordwest and Cardigan.


Scene from the Towards Independence *weekend in Plas Menai*

If you wish to be involved in this project in any way, contact:

Jill Bartlett, North/Mid Wales, 01248-671838.

Carolyn Jones, South/West Wales, 01222-450126.

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STAFF NEWS .... STAFF NEWS .... STAFF NEWS ....

- ROMANCE blossomed for Amanda Dowsett, administrative assistant for ASBAH's telesales department, when she began regularly bumping into Chris Sanderson at a leisure club.

Breaking with tradition, Amanda made the first move by asking Chris, who worked at the club, to join her and some friends in town to celebrate her birthday.

"He didn't turn up," Amanda recalls, "but afterwards he left a birthday card at the leisure club's reception with a note asking me out for a drink."

That was seven years ago and the happy pair finally fixed their wedding day for 14 June, with the marriage ceremony taking place at the Holy Trinity Church, Orton Longueville, Peterborough, and the reception at the Woodlands Leis-ure Centre, Castor, near Peterborough.

Amanda and Chris spent their honeymoon in the United States – a week in Orlando and a week in Sarasota.

- ANNA Haigh, secretary for Northern Region and START, has left after 18 months to do a two-year Diploma in Social Work at Leeds Metropolitan University. We wish her well.

Staff changes in Peterborough

THE following staff changes have occurred in ASBAH's services department at National Centre:

- Rosemary Batchelor is now senior adviser – health and policy issues. Her role is to identify and report on issues requiring policy decisions by senior management, maintain up to date information on health matters, represent ASBAH at appropriate meetings and continue the essential telephone support service for individuals, families and professionals, including ASBAH staff.

- Specialist advisers previously managed by Rosemary will now report to services manager Milly Rollinson.

- Paula Thompson, part-time specialist adviser (medical/continence), moves from national to the Eastern Region team.

- Julie Llewelyn, full-time specialist adviser (medical/continence), reverts to working full-time on a national basis instead of sharing her time between national and Eastern Region.

New address for SE Region

- A MOVE to new premises by our South East Region team will enable them to work more effectively and allow complete accessibility to service users.

The new address is: 209 Crescent Road, New Barnet, Herts EN4 8BS.

The two outside telephone lines – 0181-441 9967 and 0181-449 0475 –and the fax number – 0181-440 6168 – remain the same.

South East Region co-ordinator Jo Francis said: "We all have very positive feelings about moving to offices where we'll give a much better service to clients."

With more separate office space, and an extra room for meetings/information library, there will be added confidentiality.

Specialist adviser (medical/continence) Caroline Berkley continues to be based at the regional office, and there is space for area advisers Deryck Brown, who covers parts of North and West London, and Gill Yaz, who covers North East London.

The new regional office is five minutes walk from the old one and has better parking. It is open from 9am-5pm, Monday-Friday.

Fighting on all fronts

OUR continence campaign continues to draw letters and phone calls from service users and parents about inadequate supplies, as well as requests for other information.

We have also received a letter from an NHS trust director who blames growth in demand and pressure on resources for the squeeze on continence supplies – *see page 8*.

So who are we to believe? Who is responsible for the diminishing service and who is in a position to fund the shortfall by giving it higher priority within NHS health care provision?

Our campaign is targetted at both national and local policy makers to achieve maximum effect.

At a national level, ASBAH is highlighting the seriousness of the problem to Department of Health ministers and MPs.

We have explained that without adequate supplies of pads and other equipment, our service users not only suffer indignity but are more at risk from infection which sometimes can be life threatening.

In a letter to Paul Boateng MP, Junior Minister at the Department of Health, ASBAH executive director, Andrew Russell, stated that a more purposeful policy was needed from the NHS to remind trusts that these services are important for disabled people. He also raised the subject in a meeting with the Minister for Employment and Disability Rights, Andrew Smith MP, on 17 September.

At local level, we are urging service users who have experienced declining continence supplies to complain to your NHS trust and to inform your MP.

A sample letter of complaint, which can be adapted to your own circumstances, appears on page 9.

In the next issue, we will be publishing a typical complaints procedure which you can follow if you are not satisfied that the matter is being properly dealt with.

If you need help from ASBAH – either in making a complaint, gaining up-to-date information on the latest products available, or if you require any other information on continence – please contact Julie Llewelyn at national centre.

If you live in East, North or SE England, Wales or Northern Ireland, you can contact your regional specialist adviser (continence) – *see foot of this page for ASBAH regional office telephone numbers.*

Help & Advice

Members seeking help and advice on any matters should make initial contact with ASBAH as follows:

London, Surrey, Kent, West and East Sussex

ASBAH South East, 209 Crescent Road, New Barnet, Herts EN4 8SB.
Tel: (0181) 449 0475. Regional Co-ordinator: Jo Francis.

Lincolnshire, Cambridgeshire, Leicestershire, Nottinghamshire, Northamptonshire, Norfolk, Suffolk, Essex, Hertfordshire, Bedfordshire

ASBAH East, ASBAH House, 42 Park Road, Peterborough PE1 2UQ.
Tel: (01733) 555988. Regional Co-ordinator: Mary Malcolm.

Northern Ireland

ASBAH Northern Ireland, 73 New Row, Coleraine, Northern Ireland
BT52 1EJ. Tel: (01265) 51522 Regional Co-ordinator: Margaret Young.

Northumberland, Durham, Cleveland, North Yorkshire, South Yorkshire, West Yorkshire, Tyne & Wear, Humberside

ASBAH North, 1 The Wells Walk, Ilkley, West Yorkshire LS29 4LH.
Tel/fax: (01943) 609468. Regional Co-ordinator: Joan Pheasant NNC.

Rest of England and Wales

ASBAH National Centre, 42 Park Road, Peterborough PE1 2UQ.
Tel: (01733) 555988. Fax: (01733) 555985.

ASBAH welcomes and appreciates the support of its commercial partners.

***Larkhall Natural Health** gives us 10p from the sale of each container of Cantassium Folic Acid tablets. These can be obtained in chemists and health food shops.*

***AlphaMed Ltd** makes a donation for every prescription order received, as a result of ASBAH's introduction, for continence and medical equipment supplies. Tel services floor, 01733-555988, for introductory Freepost envelope. Prescriptions for drugs or medicines should not be sent to AlphaMed.*

Fighting on all fronts

– news on our continence campaign

Letter from Mrs Angela Bates, Director of Community Nursing, South Lincolnshire Community and Mental Health Services NHS Trust, Orchard House, Rauceby Hospital, Sleaford, Lincs.

IN the June/July issue of *Link*, you raised concerns about the provision of incontinence wear to children in South Lincolnshire, and the effects of the waiting list recently implemented.

The Continence Service is contracted by Lincolnshire Health for the population of South Lincolnshire. Over the past four years, in common with many services across the country, we have been experiencing growth in the number of patients to whom we supply incontinence wear, and increases in costs due to the increasing dependency of patients.

A number of actions have been taken to address this increasing pressure on resources. The Trust has improved the assessment and prescription processes that community nursing staff use. We have appointed a continence adviser to support this work and to develop robust policies to ensure that the effectiveness of the service is improved and maintained.

Each year we have discussed this growing problem with the health authority but they have been unable, due to other major financial problems, to resolve the problem.

This situation is no longer viable, so much so that a long term solution has to be reached. One immediate effect of this has been the change in policy for the provision of incontinence wear for children. This change, from three to five years, brings the Trust into line with the provision of equipment in North Lincolnshire, and indeed a number of health authority areas.

The Trust is presently completing a major clinical audit of patients who receive incontinence wear in order to really understand all the linked dependency issues for patients. Whilst this work is being completed, the health authority decided that rather than remove equipment from groups of patients, ie those suffering from stress, urge etc incontinence, that it would be fairer to implement a waiting list. You may be interested to know that a number of health authorities have imposed similar resrictions. It was appreciated that such a development would cause some short term problems, particularly for those patients with high dependency problems; but its implementation is less damaging than removing equipment from existing patients.

The end result of the audit should mean:

(i) Continued provision of quality equipment to the majority of clients whom your organisation represents.

(ii) Introduction of effective treatment programmes to support those patients where a 'cure' is probable.

The final decisions on the scope of the service will be made by the health authority during late autumn, so that it is hoped that the use of a waiting list will be short term.

Julie Llewelyn, ASBAH specialist adviser (medical/continence) writes about some common continence problems

THE continence campaign, which was initiated in the April/May *Link*, is gathering momentum. What was unexpected, are the number of associated problems that are also coming to light.

One couple, whose eight-year-old daughter has spina bifida, are distressed and concerned that their consultant is promoting surgery as the only answer to her continence management. They feel that undue pressure is being put on them to follow his advice and not wait until their child is old enough to make decisions herself.

After speaking to the mother in great detail, it became clear that bowel management had never been tried. Nobody had every suggested that she could 'learn' to control and empty her bowels and so avoid soiling. Only more invasive options, including surgery, had been offered as a means of management.

A young man, who contacted us regarding his supply of continence pads, highlighted another problem. Although physically very able and attending college, he had always needed enemas to initiate a bowel action. When he was younger, his mother had administered this and then put a pad on for him to soil into. He had never changed this routine and had never been encouraged to sit on the toilet. Soiling into a pad was the norm for him and it has taken a great deal of encouragement to break this routine.

This illustrates the need to review an individual's bowel management regularly.

ASBAH Christmas cards – order forms available from Elissa Lowder on 01733-555988

Fighting on all fronts

Below is a suggested letter to your NHS Trust, if you are dissatisfied with the continence service or supplies received. Please feel free to change or add to the letter, to reflect your individual circumstances.

Your address

Date

Addressee

Dear [Manager or Director of NHS Trust]

My son/daughter .... [name] *aged* .... *years has spina bifida* [and hydrocephalus] *and as a result has problems of urinary* [and bowel] *incontinence. At the moment the supplies of [*...*] which are needed are not available/totally inadequate. In consequence his/her health is significantly threatened. It is well known that children with these problems need good care if they are not to develop infections and other complications.*

These supplies are an essential part of his/her health care and I am requesting that they be provided through the health service. I have been told by my [Community Nurse/Health Visitor/Continence Adviser etc] *that your Trust's policy prevents* [child's name] *being supplied as necessary. I believe this is contrary to national policy, and that of the District Health Authority, towards people with severe disabilities whose health care needs should be met.*

I would request you to give consideration to this, and I look forward to your reply. I would also like to receive information about your formal complaints procedure.

Yours sincerely

Barbie's friend Becky is now available

TOYS R Us has contacted us to say that Becky – Barbie doll's wheelchair user friend – will be available in all of its 60 stores nationwide from October/November.

The store phoned *Link* when it heard that we had published a story in the August/September issue, saying that although Becky was available in the United States, there were no plans to sell the doll in the UK.

This is good news for all Barbie doll fans who would like to add Becky, who has a fashionable and realistic wheelchair and bendable elbows and knees, to their collection.

Basic bowel management

By Julie Llewelyn
ASBAH specialist adviser (medical/continence)

REGULAR emptying of the bowels should be started at the usual age of 2-3 years to prevent constipation, making stools easier to pass and to reduce soiling and 'accidents'.

This is achieved by sitting on the toilet for periods of 10-15 minutes. The position on the toilet is important. Feet should be flat on the floor or a stool and the body should be well supported so that it is comfortable and safe.

Young children should never balance precariously on an adult toilet. It does not help them to empty the bowels and may make them frightened of using the toilet because they think they may disappear 'down the hole'. The use of a child's seat will overcome this.

Adequate fluid intake of approximately 6-8 cups a day and a high fibre diet should be encouraged and parents should be aware of foods which induce a bowel movement and give those when necessary.

Medication, suppositories and enemas may also be necessary when trying to establish a regular toiletting pattern.

Bowel management for people with spina bifida is never easy and requires patience and perseverance, often taking months to achieve the ideal situation.

Sometimes more complex management may be necessary when all else fails.

Adventure

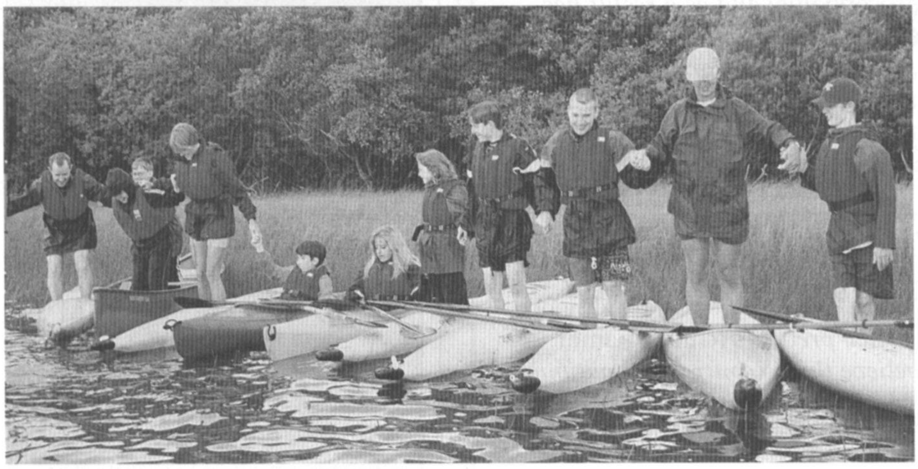
James Marshall, aged 14 from Chester, who has spina bifida, was among those who bravely chose to abseil down a railway viaduct

GREATER confidence and self-awareness were gained through physical activity and by talking to others when 11 youngsters joined an ASBAH Adventure Weekend, supported by the BBC Children In Need Appeal.

This second ASBAH Adventure Weekend was held at Low Mill Centre, Asrigg, in the heart of the Yorkshire Dales.

Low Mill Centre offers wheelchair accessible accommodation with several specially designed toilets and showers.

All the children and staff slept in bunk beds with the boys sharing one dormitory and the girls two to a room.

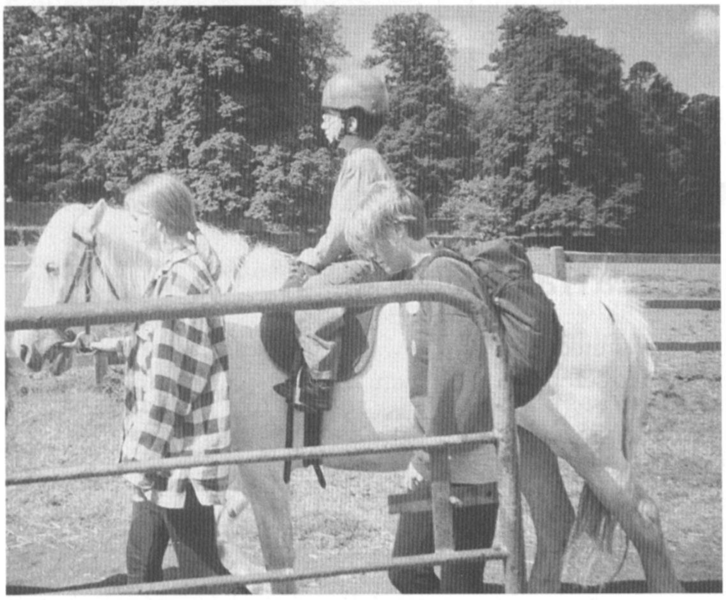


It proved quite a balancing act getting into a canoe and holding hands with the next person

Each child was allocated a 'key-worker' who met them on arrival and showed them their room while families were given a welcome drink as many had travelled long distances to give their son or daughter this opportunity.

The evening meal, once parents had been encouraged to leave, gave everyone a chance to make acquaintances – a prelude to the evening programme which included games to get to know everyone. An exercise in trust had one of a pair blindfolded and being led or directed around the grounds. The problem of not knowing left from right caused great hilarity.

Table tennis and a pool table proved popular occ[illegible]pations later in the evening before quietening down prior to going to bed.



Doug Oliver, aged 11, from Merseyside, goes pony trekking

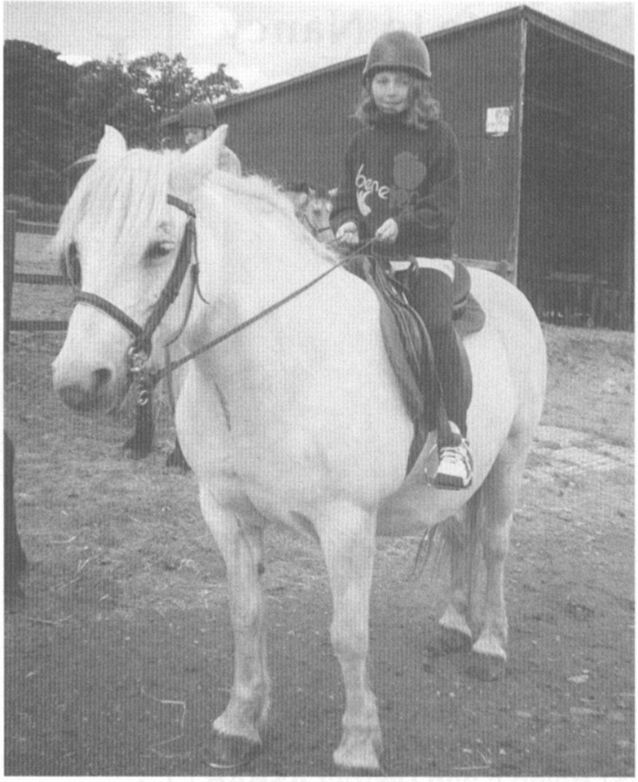
Georgie Donaldson, aged 14, from Lincolnshire, who has hydrocephalus, takes aim during the archery session

Weekend!

ELEVEN young people, aged 11-16 with spina bifida and/or hydrocephalus, joined a weekend of adventure – trying out a range activities like abseiling, archery, canoeing and pony trekking.

Not only were the activities exciting to try, but the opportunity to spend a weekend away from home and parents, and the chance to meet and talk to other youngsters and ASBAH staff, helped build the young people's confidence and self-awareness.

Here we tell the story of the Adventure Weekend in words and pictures.



Kirsty Goodier, aged 12, from Preston, who has spina bifida and hydrocephalus, makes friends with her mount for the pony trekking

The next day we were greeted by grey skies and rain, but, undaunted, the party split into three groups for archery, abseiling or water sports. All activities gave the participants the chance to explore new experiences or sharpen previously acquired skills.

Getting soaked was part of the fun and fortunately all had changes of clothes; the drying room at the centre was invaluable.

After hot showers, a change of clothes and lunch it was off again for archery, rafting or a walk of discovery around the village. A barbecue, modified due to the rain, and an evening of games and socialising rounded off the day.

Sunday morning was bright and sunny, proving a perfect morning for abseiling and pony trekking. Abseiling off a viaduct was a first for everyone, challenging nerves and ensuring a rush of adrenalin.

Water sports and abseiling were held only a few minutes from the centre, but a journey in a minibus through wonderful countryside, noting the locations used for *All Creatures Great and Small* as well as more historical features, ensured no one was bored on the way to the pony trekking.

The horses were very gentle and one young man who had been very apprehensive enjoyed the experience – so much so that he had a second ride.

After lunch there was the usual exchanging of addresses and telephone numbers, tracking down items of clothing and buying souvenirs from the tuck shop before being collected by parents.

All the youngsters gained in confidence and self awareness. Most of them are in mainstream schools and have little chance to discuss issues relating to their disability with others in similar situations. The time spent talking to each other and to staff was as valuable as the more physical activities.

We are most grateful to the BBC Children In Need Appeal for giving ASBAH the opportunity to run such a worthwhile event.

Greg Brassett, aged 15, from near Wisbech, Cambridgeshire, who has hydrocephalus, enjoys life afloat

Tribute to Nancy Maddocks

by John Glover
Chairman
St Helen's and District ASBAH

NANCY Maddocks, who was secretary of the St Helens & District ASBAH from its formation in 1971 for 25 years until she retired in 1996, passed away in September.

Nancy became involved through her husband Norman, who was a teacher at the local special school, and she was elected secretary at our inaugural meeting. Despite her own health problems and the loss of her husband, she carried on as secretary and threw herself into work – not only for the association but for a number of other bodies which concerned disabled people, and spina bifida in particular.

Her efforts were rewarded some years ago with a local Citizen of the Year award and in December 1995 she won the Whitbread Volunteer Youth Worker of the Year for the North West Region – reported in the Dec '95/Jan '96 issue of *Link*.

The St Helen's Association and its members owe a great deal to Nancy and I am convinced that without her it would not have thrived as it has. Even after retiring from the secretary's job, she wanted to be kept in touch with what was going on and she will be sadly missed by us all.

Living with spina

SPINA BIFIDA affects about one in every 1,000 children born in the United States, and a similar proportion in the UK. In *Living with Spina Bifida: A guide for families and professionals*, Dr Adrian Sandler presents a wealth of useful information on the medical, developmental and psychological aspects of the disability. The man's obviously a great listener, reports TONY BRITTON, in his review of this useful new book.

THERE are some small, often angry voices which are woven into the text as the doctor who wrote *Living with Spina Bifida* takes us through life's early stages.

Worried, confused, yet insistent that they need to be heard and to have their questions answered, the voices of the parents keep nudging the reader with their concerns, and provide a focus for much that is written in this 262-page book.

They are also included because the author, Dr Adrian Sandler, knows that parents are the best experts in the raising of their own children and have a fund of intimate expertise which the medical profession is daft to ignore. Parents who have been through the mill are pretty good, too, at advising others just starting out.

"My wife and I just got tired of feeling like we had to face all these problems alone. That's when we decided to join a parents group at the day care center. We met other parents who were also struggling, and we were amazed to find out that we could offer them help and advice. Suddenly, it dawned on us that we weren't doing so badly and that we were getting back in control of our lives."

"Having a child with spina bifida doesn't make your marriage fall apart. But not dealing with your feelings sure can. I was angry, confused, and becoming more and more distant. My wife had all the responsibility with Justin and the other kids. "I felt disconnected from the family and spent more and more time at work. Finally, we reached breaking point, and she spelled it out for me: either I got involved and started to share in family life, or I got out!"

It is this caring, sharing approach with parents, with many more examples, which characterises *Living with Spina Bifida*, published this September by the University of North Carolina Press in hardcover ($45) and paperback ($19.95) editions and available in Britain. Check sterling prices with your bookseller.

Adrian Sandler, who is medical director of the Olson Huff Center for Child Development at the Thoms Rehabilitation Hospital in Asheville, North Carolina, also has an innovative approach to his text.

There is an excellent glossary of terms right at the beginning of the book, not stuck at the back, almost as an after-thought. Most chapters end with extracts from letters by parents and, frequently, Sandler signals a wish to have a fireside chat, "parent to parent", by highlighting text with a thick, vertical red line in the margin.

Now and again, he gets heavily medical and polysyllabic. He then excuses himself to the lay reader by using a thick, vertical black line. Because he has gone "doctor to doctor", the reader is invited either to skip this section or read it, according to taste.

At the heart of the book, however,

bifida

Adrian Sandler, MD (right) with two-year-old Kevin Roberts and his mother Jennifer Rice. Sandler is the author of Living with Spina Bifida: A Guide for Families and Professionals. *University of North Carolina Press, September 1997. Photo: John Warner*

Sandler uses his medical perspective to take us on journeys through life – from conception, pregnancy and birth, through infancy and pre-school, into school and onto adolescence and transition to adulthood. He covers the key medical, daily living and emotional issues of each developmental stage, and there is something in the book to interest every professional and care worker involved.

Sandler supports the Spina Bifida Association of America and works at their summer camps as his rapport with parents of disabled children stems from plenty of contact with families outside the consulting room.

While there is guidance for parents through every stage, he keeps in touch with every important controversy – including the current debate about whether or not to select newborns for treatment if their outlook appears distinctly unpromising.

Sandler knows where he stands, and it is not 'playing God': "In my opinion, there are compelling arguments, both ethical and medical, against selection. First, the poor predictability of outcomes argues strongly against selective treatment. I have seen many babies with severe hydrocephalus in utero and at birth whose later development was similar to others with minimal or mild hydrocephalus.

"I have also seen a baby with multiple congenital abnormalities and severe scoliosis in addition to thoracic spina bifida, one of whom many of us might have considered for non-treatment; indeed, had his parents indicated a wish not to proceed with closure, we would almost certainly have discussed it with our ethics committee and gone along with the parents' wishes.

"In his case, his parents were adamant about doing all that could be done, and now, four years later, he is doing better than I or any of the health care team expected.

"Second, those of us who staff clinics for children with spina bifida know of children who were selected for non-treatment, who were supposed to die, but who survived in spite of all odds. It is likely that the quality of life for such unexpected survivors is poorer that it would otherwise have been had they been offered full treatment as newborns".

Sandler also sets the magnitude of incidence of spina bifida and hydrocephalus on an altogether different plane from the 1,000 known pregnancies which are affected every year in the UK with fewer than 100 babies being born alive (with proportionally similar figures in the United States).

In an introduction to spina bifida occulta, where the underlying defect is hidden beneath skin, he estimates that 3-5% of the population of the States has occulta but will not know so unless a diagnosis is made later in life, sometimes after worrying symptoms begin to show. Similar incidence figures are given for Britain.

There is a strong argument here for fortification of basic foodstuffs with folic acid to help prevent spina bifida, not just to boost folate levels in the blood of women who do not plan their pregnancies but also to reach those who do not even know they have spina bifida.

Do not be put off by the American bias of *Living with Spina Bifida*. There is lots of information which is not strictly relevant to Britain, but it is mostly at the back of the book. There is much more to be said in favour of having one of the few comprehensive, readable approaches to the subject to have appeared in years. In fact, for us, this is a publishing 'red letter'day.

***Link* brings you news of a clothing company that makes fashionable made-to-measure trouser**

Fashionable cl that fit!

A RANGE of bright and fashionable clothes is available this autumn, made to fit whether you use a wheelchair all of the time or whether you can walk short distances.

After three years of market research, the Wearable Clothing Company has brought out a new winter brochure of denims, flying jackets, fleece jacket and ski-suits – all in this year's colours – offered with an unbeatable made to measure service.

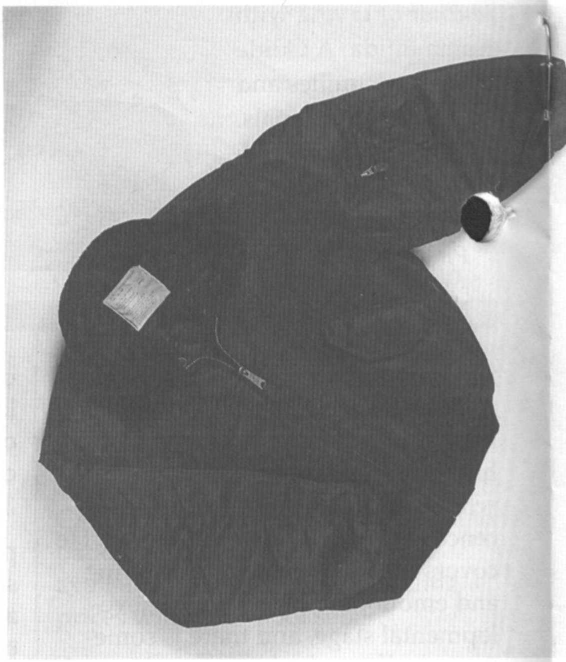
All the clothes are sold by mail order and stock garments carry a full money-back guarantee.

Wearable Clothing, run by Patricia Watson and a designer, has developed slowly in a largely unknown market, but both partners have a wealth of experience in the clothing trade.

Back in 1988, the pair established a waterproof clothing company for the emergency services, making coats and jackets for police forces and fire brigades throughout England.

Then a policeman told Patricia that his wife could not get a suitable jacket for her to wear in her wheelchair.

Patricia says: "This made me realise that no one in the UK was making clothes for wheelchair-users. The clothes in the shops are designed to be worn standing up, and they distort when the wearer sits down. Wheelchair-users need clothes which are *designed* for sitting down.



"The colours are in the latest combinations and the waterproofs are made from top quality breathable material, but the prices are not extortionate as the clothes are sold directly from the factory.

"We know that some wheelchair-users try to wear ski-suits to protect them from the cold, but they are very difficult to put on o
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Wearable is also se

Wearable's waterproofs look like the high fashion sports waterproofs everyone is wearing these days.

They come in three designs:

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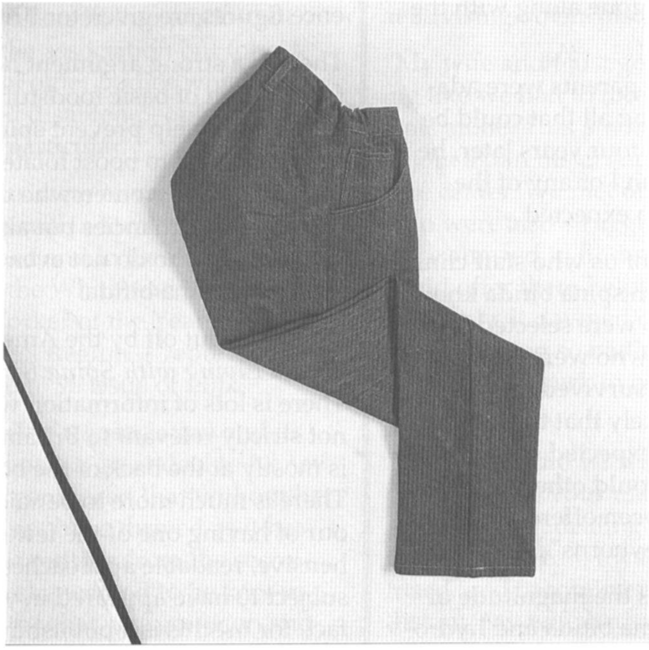
- **Standard coat**
be worn by any



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latest Polarfleece jackets. "We are keeping our jackets short so they are clear of the wheels, and our range includes fashionable flying jackets and warm down-filled jackets," says Patricia.

Well-known brands of t-shirts and sweatshirts such as Fruit of the Loom and Haines are also available.

There has been demand for party clothes, so with Christmas approaching Wearable is including a long velvet evening skirt and velvet trousers in this winter's colours for women customers.

Brochures from: The Wearable Clothing Company Ltd, Queenslie Business Centre, 19 Blairtummock Road, Glasgow G33 4AN. Tel: 0141-774 9000.

One satisfied customer ...

STUART Whittaker, who has spina bifida and hydrocephalus and uses a wheelchair throughout the day, was delighted with a pair of neatly fitting jeans made by Wearable, bought for around £40.

The denims are cut lower at the front and higher at the back, specially suited for a wheelchair-user, and are cut exactly to fit his leg measurements.

Zips have been added on the inside leg to make removal of his leg bag that much easier.

His mum, Evelyn, commented: "The jeans are a great fit and are very well made. They look very neat on him."

She added: "I filled out the measurement guide they sent with the brochure and then chatted on the phone to Patricia which is when we decided to put zips on the inside leg to help with Stuart's bag.

"The service and attention from Wearable has been great. They listen to what you've got to say."

The quality of the materials and workmanship is also highly praised by Mrs Whittaker.

"The quality of the manufacture is proved in the washing and we have to wash Stuart's denims quite a lot because his bag leaks occasionally. The denims have come up looking great," she said.

Stuart, aged 27, from Edinburgh, was so pleased with the denims that he has bought two pairs of winter trousers from Wearable and hopes to get a jacket later on.

Stuart is delighted with his denims

Bad news broken badly

PARENTS of children born with disabilities are often told about them in cruel and off-hand ways, says a new report by Scope.

One mother was informed that her daughter would be paralysed with the words: 'Who wants to be a Spice Girl anyway?'

Scope has called for improvements in the way professionals break the news that a child has, or is likely to have, a disability. It also wants closer liaison between hospital and community staff to help families once such a diagnosis has been made.

The charity launched the report – entitled *Right From the Start* – as part of a joint programme with 21 other professional and voluntary groups outlining steps to be followed.

The report stresses that doctors should give parents as much information as they have as soon as possible, as delay contributes to later distress and depression.

'By the way, did anybody tell you that your baby didn't live?'

By Gillian Smith from Leicester

Gillian with her sons Matthew (12), James (14), Edward (9), Tm (19) and Simon (21)

I was suspicious at 26 weeks that all was not well when I had simultaneous appointments with my GP and the hospital. My GP said the baby was head first and the hospital said it was breech, and turned the baby round. I was puzzled by this and read later that it was harmful to turn babies at such a late stage, so I went back to my GP who suggested I should be x-rayed.

I went back to the hospital at 40 weeks for the result and was told there was nothing wrong – just that a breech birth is more complicated and I would have to be induced. However, when there was nobody in the room, I read my notes which said 'single anencephalic foetus sitting in the breech position.' I had never heard of anencephaly before but presumed it concerned the head. I looked it up in a medical book later, and found that it was 'an abnormality incompatible with life'.

When I was admitted to hospital at 41 weeks, I asked a nurse what the problem was and she fobbed me off by saying: 'What do you know about babies?' in a tone of voice obviously meant to stop me asking questions. I was in labour for 32 hours, and although my husband was told of the problem, he was not to tell me, which he now regrets not doing.

After giving birth, the baby was whisked away and I never saw her. I was completely alone in the delivery room, when a nurse came in and stood at the doorway and said: 'Are you OK in there? By the way, did anybody tell you that your baby didn't live?'

I was absolutely devastated and horrified at the way in which I was told. In a complete state of shock, we agreed to the hospital burying our daughter, not realising that we would never be allowed to know where she was. The hospital wouldn't tell us and I just could not understand why we were not allowed to know. I even contacted the undertakers to see if they would tell me but they just said that, because the baby had never breathed, it was not a person – so forget about her.

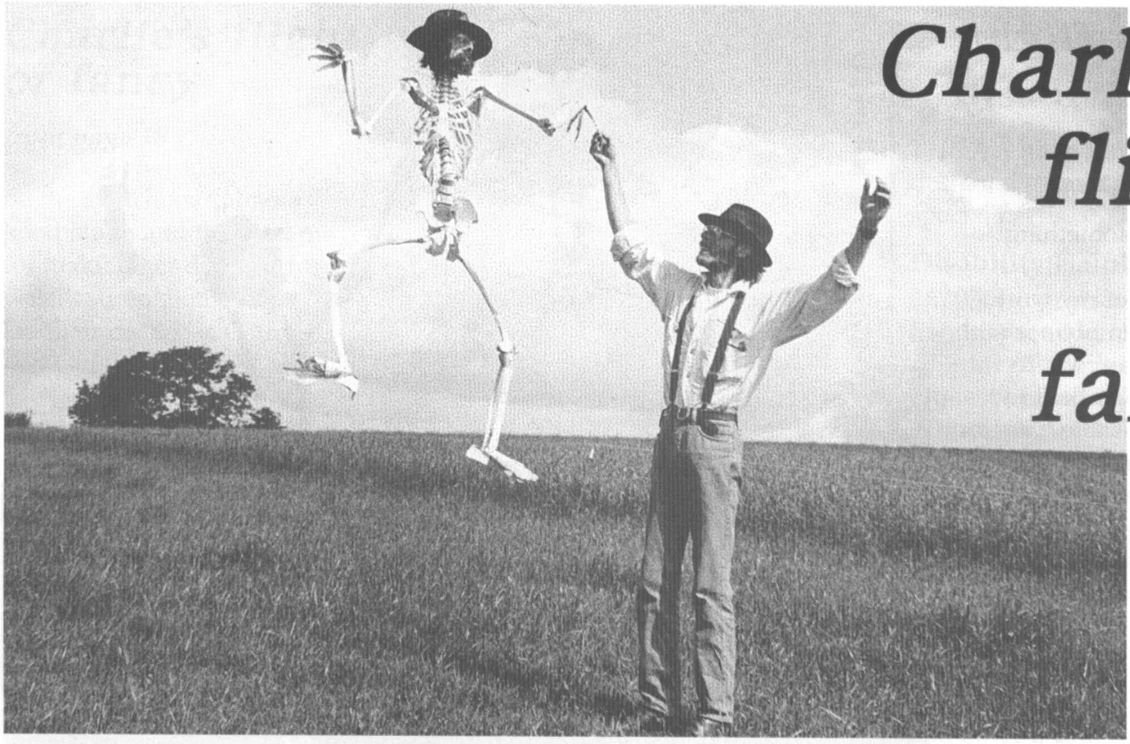
Eventually, after 13 and a half years, as a result of Esther Rantzen's programme *The Lost Babies*, we managed to trace her and now know exactly where she is buried. Once I knew where she was, I felt so much better. It made all the difference.

After losing my daughter in 1975, I was never offered folic acid for my subsequent pregnancies, despite being told that I would have to be especially monitored as there was now a 1 in 10 chance of it happening again. When I asked to take folic acid, I was told not to take any supplements for the first 12 weeks.

In 1969, my husband had worked in a pharmacy in Frome, Somerset, and he says that folic acid was very widely prescribed in that area for pregnant women. He says they stored drums of folic acid and were always giving it out to patients, but in the early '70s the Department of Health stopped doctors prescribing it.

My husband is a firm believer in the value of folic acid and encouraged me to take it for my subsequent pregnancies and we now have five healthy boys. I did not, however, take it for the first pregnancy.

Apart from pregnant women not being given the right advice, I would hope that they are now handled better when something goes wrong than I was in 1975.



Charlie's flight of fancy

Peter Kiddle and 'Charlie' dance for a photo shoot for an arts project in which disability is the main theme.

By Peter Kiddle

SOME 10 or 11 years ago in the mail at Christmas time came a catalogue – I think it was from the Natural History Museum, but can't be sure. Flicking through it I saw an offer of a life-size, cardboard, model human skeleton and had a brilliant idea for the finale of an open air show I was writing .... out of his coffin would come this bunch of balloons and off into the ether would fly the spirit of the villain of the piece.

The kit came just before Christmas, sheet after sheet of heavy card, each and every bone carefully named, to be pressed out and folded, and bone after bone to be pinned or clipped to its neighbours. Pages of instructions and a great box of paper-clips and an occupation for evening after evening over Christmas and the New Year.

Finally 'he' was finished, full-size and, with a few bits of elastic and a modified coat hanger, fairly animated.

As soon as the job was done and I stepped back from it, I decided it represented far too much love and labour to be flown away on a bunch of helium balloons and the show would have to have another concluding image.

So for year after year 'Charlie', as he became known, hung in the corner of my workshop, eerily looking down on the to-ings and fro-ings of other projects and shows, the skeleton out of the closet, waiting for his time to strut or dance.

Then, a few months ago, I decided I had a part for him.

Out of the blue came a phone call from a colleague in America. Karen has worked as the designer on shows over here and in the States with me for a long time, though there has been a break in the last few years. But last Christmas was the first in 20 years that she hadn't sent a card.

Her news was sad – a heavy box; slipped discs; and now, metal rods in her lumbar spine; callipers and a stick; 'partial disability'; terrible hassles with her employers. All in a year.

I was shattered, muttering sympathies as she slowly unfolded the story. I was baffled as to why she'd rung now, wondering where the story was going.

All the time I was wondering if I'd ever told her about my spina bifida, or if she was another friend I had performed to, masqueraded for. If she knew, I wondered, was it for consolation, sympathy, fellow feeling or advice that she'd phoned me now?

I was totally unprepared when she took breath and said: *'Well, Peter, the reason I'm phoning is to see if you'd collaborate on a project with me, which – just for now, maybe – I'm calling in-slash-valid ... Write it down ... get it?'*

In/Valid. Got it!

And she was off! For another half an hour of totally infectious ideas for a gallery show, drawings, paintings, photographs, sculptures and live performance by the pair of us, over here and over there ...

I'd forgotten – almost – what her enthusiasm is like! When she's fired, she's nearly overwhelming ... But not quite; not yet – and maybe not this time, I was thinking. When she wound down – as I remembered from before – it was:*'What do you think then? Do you need to think it over?'*

And this time I most certainly did

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Charlie's flight of fancy

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need time, I said. She was asking me to do something autobiographical, I said; something none of my work before – and certainly not with her – had come anywhere near... I was being asked to 'out' myself as disabled, as invalid even, when *I* didn't need a stick, didn't need callipers and, furthermore, as far as I was concerned, was still giving a passable performance as able and valid!

Yes, I *did* need time to think about it!

And did I have some thinking to do during the week before she rang back! A long week indeed of thinking, sometimes in the workshop, in old Charlie's company, the skeleton in my closet.

Within a week I agreed to give it a go, and told Karen of my idea of how Charlie would fit into it, and that I thought I'd start with him. I'd make him a mask, my 'life mask', give him one of my hats – yes! one of my blue fedoras! – and fly him, maybe on a kite, maybe on balloons and dance with him, Charlie on nylon threads and elastic, and have Gill and Cathy photograph us. Keep the balloons out of view and have us both on a hilltop and do a sequence of still photographs.

That, and several other ideas that had occurred to me, I offered to Karen, and we agreed to start work as soon as we could, and exchange ideas and images throughout the summer, for each other's comment and criticism, to see if we could do such a project together.

I made Charlie his face and beard, gave him an old pair of my spectacles and made him a good, strong tissue paper replica of a blue fedora. I got two five-foot diameter balloons and enough helium to inflate them fully, got the farmer's permission to take him into a field down the road from here, and waited.

Peter Kiddle and Charlie continue rehearsing their dance sequence, waiting for the professional photographer to arrive.

Well, the morning of Sunday 6 July was the first still, sunny morning we'd had here for a month. I got Gill – who works with me as a photographer – and Cathy ready for the trial run, warning them that I wasn't sure two balloons would give Charlie the lift he needed ...

But I needn't have worried. Just a little more gas and he flew! Cathy and I each took some snap shots and then I reeled him back to earth. I sat down for a cigarette, while Cathy went back home to look for some string for a final adjustment and we waited for Gill, the real photographer, to arrive.

I heard a car coming up the lane, looked to see Gill passing, looked up the lane towards our cottage where Cathy was going, and there, out of the corner of my eye, saw Charlie going too! The nylon line had snapped and off he was going, up, up and away. I screamed: *'Oh, no!'* and grabbed the camera, shooting off the rest of the film as fast as I could. Gill's daughter had seen him and Gill pulled to a halt, jumped out and watched Charlie flying away. Yards further up the lane Cathy had heard my shout, had turned and stood watching him too.

Up, up and off he went! He stayed long enough for a few snap shots, as you'll see, but obviously wasn't prepared to hang around for a proper photo-call.

I don't know what you'll make of it, especially if you're a little superstitious! Something that was not meant to be? An apt fate for an old friend, kept earth-bound for far too long?

Anyway, I phoned the police, in case there was any news of him coming down further west, around Plymouth or in Cornwall. The girl

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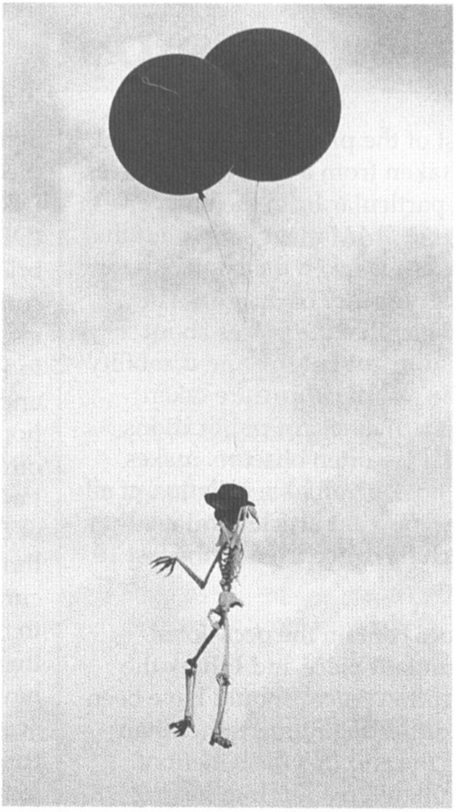
Charlie's flight of fancy

from page 18

on the switchboard had a good laugh and thanked me for making her day. And I wasn't sure whether to laugh or cry when Cathy and Gill finally joined me back in the field.

And I'm still not sure what to do, what it means, if it means anything at all! And, as I write, I'm just glad that the few photographs we managed to take *did* come out!



Charlie makes his escape – flying away on a pair of helium balloons!

Developing and printing by Gill Goddard

More on the In/Valid arts project

Peter Kiddle's contribution to **In/Valid** will take a number of forms. He wants to use a series of photographs and text to present: (1) the cause of, (2) his disguise of, and (3) confrontation with his physical disability. The first could involve the presentation and modification of x-rays. The second could revolve around his disguising through activities such as stilt-dancing. The third was to include a dance sequence with an airborne Charlie in a life-mask and costume.

Karen Watts and Peter are going to create parallel and complementary work on separate autobiographical bases, and a collaborative performance-dialogue – live or video-recorded. Karen will arrange a tour for the exhibition/performance in the United States, while Peter does the same in the British Isles. Their ambition is to invite contributions from other disabled artists and open the performance aspect of the project as a forum for others. Three dates – in October, December and January 1998 – have been arranged so far on the West Coast of America, in which the photos of Charlie will be featured. Peter will be going to the US in March when he plans to take other contributions to the exhibition with him.

If you would like to contribute to In/Valid, or have funding ideas, contact Peter Kiddle, Boreston Foot, Halwell, Totnes, Devon TQ9 7LD. Tel: 01548-821381.

AA services to disabled drivers

THE AA has a number of services designed to help members with special needs.

Disability Helpline (0800-262050) – provides members with free information on mobility related issues, including touring, route requests, facilities at motorway service areas, wheelchair maintenance, mobile phones and driving schools.

Disabled Travellers' Guide – contains practical information to help disabled people plan their travelling. It includes sections on: vehicles; driving in the UK; getting around London; travelling abroad; and other useful publications and organisations.The guide is available free to AA members. Non-members can purchase the book for £4.99 from AA shops.

Orange Badge Holders – discounted AA membership is available to Orange Badge holders:

Option 100 (Roadside service) £35.00 (save £5.00).

Option 200 (Roadside and Relay service) £64.00 (save £9.00).

Option 300 (Roadside, Relay and Home Start) £85.00 (save £15.00).

Membership database – Members may alert the AA to the fact that they have special needs. This information is held confidentially and used only when the member asks for assistance, so that the help provided is appropriate to the individual's particular circumstances.

Text Telephones – The AA's free national breakdown number is equipped to receive and return calls from deaf, hard-of-hearing and speech impaired members who have a text telephone.

For more details on any of these services, contact the AA, Norfolk House, Priestley Road, Basingstoke, Hampshire RG24 9NY. Tel: 01256-20123.

Darke culture by Paul Darke

FRAMED: Interrogating Disability in the Media, edited by Ann Pointon and published by the British Film Institute, was launched in June at the Museum of the Moving Image on the South Bank in London.

As a contributor to the book, I was invited along to mingle with the high and mighty of the British Film Institute and even a few members of the new Labour Government (as it was then).

The minister for film, Tom Clark – the ex-opposition spokesman on disability – was very impressed by the book and praised it highly as a major step forward in the fight against many an insidiously ignorant representation of disabled people (he couldn't have been after my vote, having only just been elected). I agreed with him, and not only because my name continuously pops up in the book!

Framed is split into five sections: *Cinema Portrayal; Television – Fact and Fiction; Opening Doors –Performance, Production and Training; Culture and Identity* and *Product and Control.* Each section is grand in scope and scale, and in the number and variety of pieces included.

Most of the pieces are not original but taken from a variety of sources – in particular from the now defunct *DAM* magazine – but that does not weaken the book either in its significance or insight. The very fact that the pieces about disability art culture and disability in the rest of culture are taken from a diversity of publications, which are often obscure, makes this book a valuable collation of all the significant articles and analysis which have occurred in the last 10 years.

It does contain the occasional redundant piece and I think the definition pieces should have been put at the beginning rather than near the end (for the benefit of uninitiated reader) but, having said that, it is a book to dip into with joy and relish.

Significantly, there is not a single piece specifically dealing with the Disability Programmes Unit (DPU), though it is given a very brief mention by its own staff, who contribute to the book on various issues – which is hopefully an indication of its imminent demise and/or self awareness (one can but hope!). Rather amusingly, this omission led to the DPU's leader, Ian Macrae, disseminating letters of disgust to the high and mighty, though, as many of the DPU's current and ex-members have said to me: 'they should think themselves lucky, it could only have been bad'. Taking that into account, I recommend that you all rush out and buy this book immediately for it is the best and most comprehensive collection of its kind currently available.

Win a signed copy of *Framed!*

YOU could win a copy of *Framed*, signed by Paul Darke, by answering correctly these three questions:

1. Who won an Oscar for playing the cerebral palsied Christy Brown in *My Left Foot*?
2. Who won an Oscar for playing a man with autism in *Rain Man?*
3. Who won an Oscar for playing the man with a learning difficulty *Forrest Gump?*

Send your answers on a postcard, with your name and address, to: ***Link, ASBAH, 42 Park Road, Peterborough PE1 2UQ**, by* ***8 December.***

The first selected entry with all three questions answered correctly will win a signed copy of *Framed.*

Making a case at the SEN Tribunal

ABOUT 1,600 parents lodged appeals to the Special Educational Needs Tribunal during its third year. The number is set to rise as parents become more knowledgeable about their rights to challenge decisions affecting their children's education.

In response to this, the Advisory Centre for Education (ACE) has developed an important new manual aimed at equipping parents – and those that advise them – with the legal know-how to make their own case.

Tribunal Toolkit – the first practical book aimed at parents presenting their own case at Tribunal – should give parents the confidence to put the best possible case for their child.

Welcoming the book, Trevor Aldridge QC, President of the Tribunal, said: "It helps the Tribunal to make the right decision in what are often difficult disputes if both parents and education authorities arrive well prepared and give all the information which is likely to be relevant."

Tribunal Toolkit: going to the SEN Tribunal. ISBN: 1 870672 50 X. Price: £12.50, plus p&p, from: ***ACE, 1b Aberdeen Studios, 22 Highbury Grove, London N5 2DQ. Fax: 0171-354 9069.***

Three generations with a disability

A personal view by Anthea E Hewitt
Secretary of Derbyshire ASBAH

Anthea's father

DERBY EVENING TELEGRAPH

Anthea

Andrew

ONE of the biggest problems I had as a young child was going to the toilet. This was, my parents said, due to constipation and I was given homemade suppositories, which were made by my mother from a jar of Vaseline.

I dreaded these things being inserted and, in any case, they did not work and usually came straight out again. I came to realise much later in life that I had no power in my bowel to hold or push.

Another remedy that was tried in conjunction with suppositories was green vegetables. I was made to eat sprouts more or less daily, which I hated and still do today. In those days, if food was not eaten at one meal, it was served up again at the next, after all, I was told: "there is a war on."

I used to sit on the loo for what seemed like hours and struggled to do what was expected of me. Nobody in my family had ever heard of spina bifida and I was labelled 'difficult.'

My feet were another big problem. They were short and broad, with high insteps, high arches, hammer toes, thick ankles and, therefore, no shapely heels. This meant that fitting and buying shoes was extremely difficult.

During PE in the gym, there were things I could not do like vaulting the horse and balancing on the beam. My teacher told me: 'You are just not trying.'

I won't bore you with all the little things which I lived with, not realising that I was any different to anyone else, but, as I was to find out much later in life, they were in fact symptoms which would develop into something more serious.

When I became a little older, the so-called constipation was dealt with by the doctor with constant visits for pills, rather than the dreaded homemade suppositories.

Although I had all these things to cope with, I lived a pretty normal life. I married at 24 and had my first child three years later.

The pregnancy did not run quite as it should. At three months I started haemorrhaging and was advised by the doctor to stay in bed. I was given two injections to clot the blood during the weeks in bed and, at just over five months, was allowed to get up and resume a normal life again.

I remember thinking at seven months that the baby did not kick very much, if at all, but there was a movement of sorts which I suspect was shoulders or arms, but not legs.

Again, all those years ago, there were not the tests which expectant mums get today, just a trumpet thing placed on the stomach so that the doctor or midwife could check the baby's heartbeat.

I was admitted to the hospital two weeks after the due date and given an enema, which, as you can imagine, kept pouring out.

I was then induced and my son was born 36 hours later with spina bifida and hydrocephalus. He also had a hole in the heart which, fortunately, sealed itself during the next 12 months.

My husband and I had never heard of spina bifida and were stunned by what we were told our new little baby would have to go through in his life.

continued on page 22

Anthea and Andrew in 1997

Three Generations with a Disability

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Andrew gliding off Sutton Bank, near Thirsk, Yorkshire, in 1987

Andrew had many operations like the closing of the spinal lesion, the insertion of a shunt and a great many straightening and corrective operations to both legs. Andrew used callipers and a rollater to get around, and needed lifting and carrying quite a lot during the early years.

At this time the "spinal spasms", from which I suffered, and which had previously been only very occasional and were usually connected in some way with the time of the month, became stronger and more frequent. When I discussed this with my doctor, he suggested that the spasms were possibly due to all the lifting I had to do.

Due to his incontinence, Andrew had to wear nappies until he was 10, which was embarrassing and unsociable for him. At the age of 10, he managed to get some control over his bowels and it was suggested that he try a special appliance to help with the urinary problem.

When I saw the appliance, I remember thinking that it was awful, but had to hide my feelings, so that Andrew would not be put off trying it. There is absolutely no comparison with the systems provided today. Anyway, we persevered and, of course, it was far better than having to wear nappies and was the forerunner of what he now uses.

It was also when Andrew was 10 that I discovered that I too have a form of spina bifida, known as spina bifida occulta. I was told that this was not unusual as a great number of the population have defective spines and, therefore, I had no need to worry.

When Andrew left school and went to the National Star College, he stopped using crutches and started using a wheelchair. Yet, despite no longer having the doctor's excuse that lifting my son was the cause of my back pain, I still had the problem.

Before I go on with my story, I want to tell you more about Andrew. He is now 30 years old and has been a stores co-ordinator for 10 years, working with computers. Fortunately, he passed his driving test when he was 18 and this enabled him to drive to work in his hand-controlled car. He is a bit of a dare devil and will have a go at anything, given the chance. He has been gliding, parascending, in a power boat, in a racing car and even off-road racing. These have generally been holiday pursuits.

Three years ago, I spoke to Mary White, the then ASBAH continence adviser, about my increasingly difficult bowel and bladder, and the continual problem of spinal spasms and back pain. Mrs White suggested that I see a specialist and undergo urodynamics. This I did, and was told that I did not, in fact, have spina bifida occulta, but a condition called sacral agenesis, which involves congenital loss of vertebral tissue at the base of the spine.

After a further year, my bowels

continued on page 23

Andrew off-road driving near Windermere in the Lake District in 1995

Three Generations with a Disability

from page 22

seized up completely and this also made passing water very difficult. There were various methods suggested to try and help with this, including the cardio med system, pills and even regular rectal syringing. They helped but, at my next visit to the specialist, arrangements were made for me to have an MRI scan. The scan showed that I had a tethered spinal cord. I was referred to a neurosurgeon to see what the next step should be.

The suggested surgery was a little daunting to say the least, and to help me make up my mind to go ahead with it, I went to the specialist unit for paediatric neurosurgery at the University Hospital in Nottingham to obtain a second opinion. This was particularly useful because I had had these conditions, albeit less seriously, since childhood. I realise I was fortunate to get this opinion, and it has been suggested to me that anyone with similar conditions to mine should, if possible, see someone with paediatric experience.

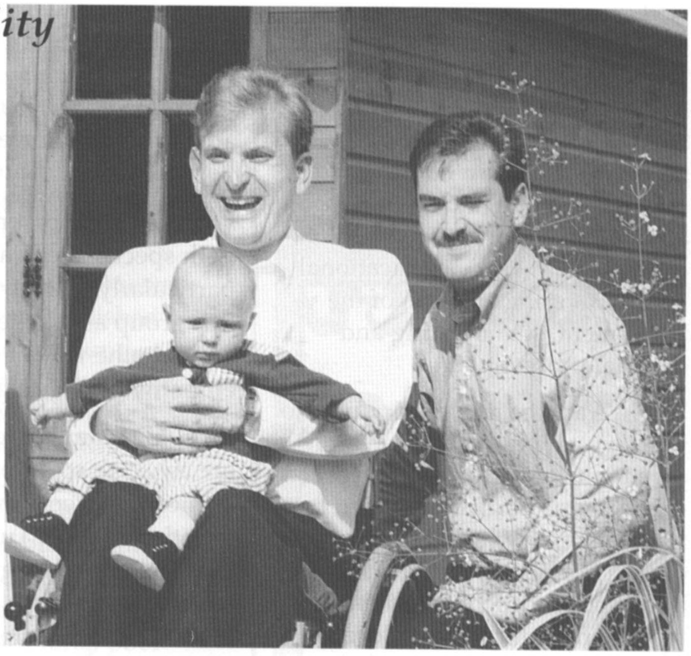
Anyway, it was decided that there was a slight risk with this surgery but, if I did not have it, I would probably need a wheelchair within the next few years. So, the benefits outweighed the risk and I accepted the recommendation and arranged to go ahead and have the operation.

Last November, the operation was carried out and about five months afterwards I began to make great progress.

I still take pills for my bowels but I only have to use the syringe occasionally and not every two or three days. My bladder is improving and, although I have a little twinge in my back from time to time, these are nothing like they were in the past.

My father was born with a club foot which was removed in his early teens and which meant he had to have an artificial limb. Despite the artifical limb, he raced on motorcycles, scrambled and also became an amateur rally driver. I think that is why Andrew is a bit of a dare devil where cars and speed are concerned. My father was a very clever man and became a qualified ophthalmic optician, but unfortunately died when I was 17 years old, after suffering from a brain tumour for two years.

Andrew and his brother Richard at Richard's son Jacob's christening party in August 1997

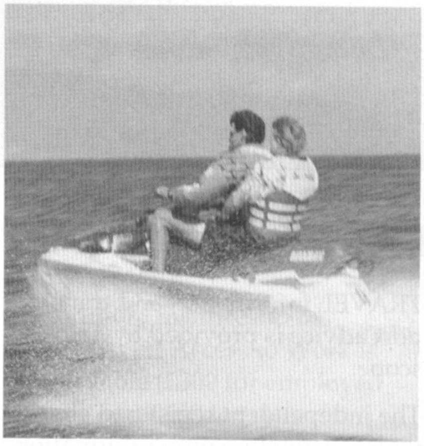


I am now 57 years old and am the mother of two sons, Andrew and Richard.

Richard is 28 years old and is a very healthy young man and, as far as I know, is free of any problems as far as disability is concerned. Richard and his wife, Sarah, went for genetic counselling but were told that there is no test which can prove that he cannot be the father of a child with spina bifida/hydrocephalus.

When Richard and Sarah started talking about wanting a family, I advised my daughter-in-law to make sure she took folic acid before getting pregnant and for 12 weeks into the pregnancy, because of our family history. She did this for both her pregnancies and I am pleased to say that she gave birth to a healthy little girl, who is now two years old, and she has recently given birth to an equally healthy baby boy.

In writing this article I wanted to emphasise the importance of taking folic acid, particularly if you have a family history of neural tube defects, like spina bifida. Secondly, I hope this article helps others who are having the sort of problems I had. Lastly, I wanted to thank Mrs White for her advice and for her suggestion that I see Mr Thomas in Sheffield. My thanks to Mr Thomas for his care and the tests which led to my referral to a neurosurgeon and, finally, to the Queen's Medical Centre for the operation that is making my life so much better.



Andrew jet skiing while on holiday with his mum in Tenerife in 1997

Advice line volunteers needed

IPSEA – Independent Panel for Special Education Advice – is a volunteer-based, national charity which gives free, independent advice and support to parents of children with special educational needs, covering all areas of the assessment, statementing and tribunal process.

IPSEA's advice line project aims to improve access to its services for all parents of children with special needs, but is particularly keen to target parents who may lack the confidence, ability or access to information which would enable them to fight for their children's rights. As a consequence, their children may receive less help than they are entitled to.

Central to the project is the expansion of IPSEA's telephone advice line which gives first step advice relating to the assessment and statementing process.

IPSEA is currently looking to recruit people to join its team of advice line volunteers.

Many of its existing advice line volunteers are parents of children with special needs and IPSEA is particularly keen to recruit from this group as it believes they bring much in the way of experience and empathy to advice giving.

Working from home, volunteers are asked to cover one three-hour session per week, for a three month period, ie Tuesday morning. They are then given the option of up to six months off the advice line. All relevant training, support and expenses are provided by IPSEA.

If you are interested in finding out more about becoming an advice line volunteer, contact: Christine Richardson, 4 Ancient House Mews, Woodbridge, Suffolk IP12 4DU. Tel/fax: 01394-380518.

Look what you're missing!

DO you receive *Lift*, ASBAH's free quarterly magazine for people aged 15+ with spina bifida and/or hydrocephalus?

If you don't, you have already missed thought-provoking features on **independent living** (Spring '97) and **relationships** (Summer '97), told in the words of ASBAH young people.

In the Autumn issue we will be interviewing people about their experiences of looking for and keeping a job.

You can always send a stamped addressed envelope and ask our Information Department for photocopies of any articles from back issues that interest you.

But don't miss out in future, get on the mailing list for Lift straightaway by sending your name, age and address to: Tony Britton, ASBAH, 42 Park Road, Peterborough PE1 2UQ.

Transport helpline

TRAVEL information and transport advice is provided by Tripscope.

The independent registered charity has a helpline with information for people who have difficulty getting out and about, plus a newsletter with news of accessible transport and places to visit.

Tripscope's lo-call helpline number is 0345-58 56 41 (with minicom), or write to: Tripscope, The Courtyard, Evelyn Road, London W4 5JL.

DLA review

FROM July onwards more than half a million Disability Living Allowance (DLA) claimants will receive notification of a visit or a questionnaire to complete.

This is a comprehensive review of more than half a million DLA recipients:

- 250,000 people receiving **both** the highest rate ***mobility component*** and the highest rate ***care component*** will be interviewed by a visiting officer to complete a questionnaire designed to establish continuing entitlement to DLA.
- 269,000 people receiving **both** the higher rate ***mobility component*** and the middle rate ***care component*** will be sent the questionnaire to complete.

Claimants who have had contact with the DLA unit regarding initial or fresh claims or reviews or renewals will not be contacted.

This will not involve people in receipt of Attendance Allowance or those in receipt of just one DLA component or anyone on the lower rates.

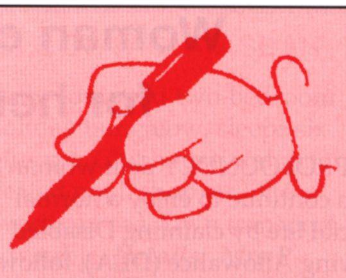
The Royal Association for Disability and Rehabilitation (RADAR) told us that claimants will be able to arrange for someone to be with them at the visit and that it should be arranged at a time convenient to the claimant.

Send a teddy

EVERYONE loves a teddy bear, but one national charity knows exactly what a friend a teddy can be.

On request, Good Bears of the World (UK) Trust sends teddy bears free of charge to sick, injured or disturbed children, the lonely, elderly or infirm.

For more details contact: Good Bears of the World (UK) Trust, 256 St Margaret's Road, Twickenham, Middlesex TW1 1PR.



Dave's diary

AFTER ditching our luggage at the hotel we set off to explore Paris. We bought postcards and found somewhere to write them. We sat writing and drank delicious French beer outside a typical Paris café. Ordering beer is something I've learned from experience. My school French lessons seemed obsessed with pencils, rulers and windows. I sometimes imagine droves of pupils landing on the continent, asking to measure people's windows!

The beer was followed up with two celebratory dinners (one each for Mum's and my birthdays) and a breakfast where the French for 'and another ...' was so frequently uttered the waitress wore a track to our table. The dinners were similarly great but not without incident.

That first evening I ate kebabs. I enjoyed them but got into a tug-of-war with one stick. An amoeba could have worked out what was going to happen! I yanked the kebab and chucked the lot down my new white shirt! This display was topped by my two brothers, who settled a minor argument by running up and down the street showering each other with banana cream crepes (pancakes to thee and me). And so to bed.

One of my crepe-covered brothers was dismayed to find we were sharing a room. There is a malicious story going round that I snore like a drunken hippo. This is wholly untrue. I merely breath deeply at night. I lay awake late that night for fear of the corrective nasal therapy known as 'pillow over the head'.

Next day, we packed our bags, ate the monster breakfast and set off round Paris. I'd packed my usual 10-ton overnight bag (though I still forgot to bring a toothbrush, razor, etc) and now wasn't looking forward to carrying it. Fortunately, my long-suffering brothers kindly relieved me of that burden. I also borrowed some money, as I'd been clever enough to lose my wallet before the holiday and cancelled my cards before it was returned to me. Despite their kindness, it still irked me greatly that I was physically, linguistically, and now financially, dependent on my family. It also meant I was unable to stand my share of the bill for Mum's 'do' later on.

We went to a very smart restaurant (all mirrors and polished wood) and were surrounded by starched waiters. They unbent at the end of the meal to sing *Happy Birthday* in French to Mum, who was taken by surprise and promptly burst into tears! The food was (again) delicious but I think I had the best starter. The others chose fish and all came down with chronic food poisoning, poor devils. Just goes to show you shouldn't eat food that stares back at you!

We returned to the train station. Service was sadly lacking going home. We got stuck in a sweat-box waiting room and the staff there (unlike their counterparts at Waterloo and on the train) seemed to be conspiring to be as unhelpful as possible. We were soon tired, irritable and hot. I buckled when faced with an escalator (I hate them) and wanted to use the stairs. We tried to communicate this need to the (English speaking) French guard who didn't understand and brusquely asked us: 'What is it you want?' Well, at that particular moment I wanted to bounce him off the electrified rail! Eventually, we got downstairs, away from the staff and boiling hot waiting room, and boarded the train homeward.

David Fulford-Brown

New help for employers

DISABLED people and their employers will benefit from changes to Access to Work , announced by the Employment and Equal Opportunities Minister, Alan Howarth.

Access to Work last year helped 10,000 people and has an annual budget of £19 million. The scheme helps disabled people find and keep work through contributions of up to 80% of the cost of the additional help needed to do a job.

However, there were instances when the rules worked against the people the programme was designed to help.

Mr Howarth said: "Disability organisations had found that when they specifically wanted to employ a disabled person, someone with practical experience of the needs of their clients, Access to Work was restricted. The Employment Service will no longer refuse help simply because an employer requires a disabled person to do the job."

In addition, the thresholds below which Access to Work is not payable (£300 for employed people and £100 for self-employed people) will only apply in the first year.

Woman can claim DLA for her social life

A PROFOUNDLY deaf woman can continue to enjoy a normal social life by claiming Disabled Living Allowance (DLA), following a House of Lords judgment in her favour.

Ms Halliday had been claiming the middle rate of DLA care component on the grounds that her use of an interpreter for social purposes represented 'reasonably required attention throughout the day in connection with bodily functions.'

The Secretary of State appealed against Ms Halliday's award, asserting that social activities were merely desirable and not reasonably required.

Lord Slyn, in the leading judgement, rejected the contention of the Secretary of State. Lord Slyn said: "The test, in my view, is whether the attention is reasonably required to enable the severely disabled person as far as reasonably possible to live a normal life. He is not to be confined to doing only the things which totally deaf (or blind) people can do and provided with only such attention as keeps him alive in such a community."

How much attention is reasonably required and how frequently it is required would have to be worked out by the adjudication officer in each case. What is reasonable will depend on the age, sex, interests of the claimant and other circumstances.

The DSS Policy Unit has indicated that nearly 3,000 disabled people have been awarded DLA and AA as a result of the original decision on Fairey / Halliday. Had the decision not gone in Ms Halliday's favour then many of these could have lost up to £33.10 per week in benefit + the passported benefits which rely upon DLA or AA.

Campaign group Disability Alliance says the implications of the Fairey / Halliday case will not necessarily only effect those with sensory impairments. Hearing is only one of the bodily functions. Others include walking, sitting, sleeping, getting in or out of bed, undressing, eliminating waste products; all of which a person who is not suffering from any disability does for her / himself.

Anyone who thinks the Fairey / Halliday result may affect them should seek further advice from a local advice agency.

Emergency service for electric users

A NEW emergency breakdown service for users of electric wheelchairs and electric pavement vehicles is available from the AA.

The 'get you home' service is available in most of England, and some parts of Scotland and Wales. The AA uses a network of local suppliers with appropriate vehicles, equipment and training.

This means electric wheelchair users no longer have to rely on passers-by or their own initiative when their vehicle breaks down.

Mobility Assistance membership costs £40 to new members, and AA personal roadside members pay £30 in addition to their subscription. Members with electric wheelchairs and electric pavement vehicles, who are registered with the AA's Invalid Carriage scheme, can use the improved service immediately at no extra cost.

For further information call free on 0800-477499.

DATES FOR YOUR DIARY

Monday 10 November

South Thames ASBAH 'At Home Day', 10am-3pm, United Reformed Church, 20 Widmore Road, Bromley. Speakers: Leonie Holgate on Behaviour Problems and Hydrocephalus; Caroline Berkley, ASBAH specialist adviser (medical / continence), on Treatment of Pressure Sores; and Peter Walker ASBAH specialist adviser (education). Members and families free. Professionals £10 including lunch. *Full programme and booking forms from: Margaret Holmes tel: 0181-290 1330.*

Monday 10 November

ASBAH support group, Disability Resource Centre, Poynters Road, Dunstable, 1-3pm. *Valerie Bottoms, tel: 01582-605749* Also meet on Monday 8 December.

Tuesday 18 November

Disability Alliance training course, Benefits and Residential Care, 356 Holloway Road, London N7 6PA. *Vincent Luttman, tel: 0171-247 8776.*

25 November

Disability Alliance training course, Care in the Community, 356 Holloway Road, London N7 6PA. *Vincent Luttman, tel: 0171-247 8776.*

Tuesday 25 November

Disability Equality Training Course, introductory course led by Barbara Lisicki, Greater London Association of Disabled People, 9.30am-5pm, at 336 Brixton Road, London SW9 7AA. *Brenda Ellis, tel: 0171 346 5805.*

Tuesday 25 November

Exhibition of Pressure Relief and Postural Support Cushions, the Disabilities Living Centre, Lenton Business Centre, Lenton Boulevard, Nottingham NG7 2BY. One day only. 10am-3pm. All welcome, free parking, level access. *Tel: 0115-9420391.*

HOLIDAY ACCOMMODATION

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

SELSEY, WEST SUSSEX (SASBAH)

Fully equipped, purpose-designed for wheelchair access mobile home. Sleeps six, ramp and large veranda, payphone, colour TV, midi stereo etc. Clubhouse entertainment, heated swimming pool, free site bus service. Nature reserves and places of interest nearby. ***Details from Mrs B Nunn, tel: 01903-763473.***

WEYMOUTH BAY

Fully-equipped, wheelchair accessible caravan – sleeps five; on Haven Holiday Park, full use of all facilities – heated indoor & outdoor pools, bars, children's club & full entertainment programme. Three miles from Weymouth. ***Details from: Margaret Humphreys, tel: 01494-714270 (Bucks & E Berks ASBAH).***

mar y sol

MAR Y SOL – Tenerife

Wheelchair accessible apartments. Heated pool with hoist. Restaurant, poolside bar. Equipment hire. Sunshine guaranteed all year round. Ring today for cheapest prices. ***Sue Abbott, tel: 01753-685718. 123 Coppermill Road, Wraysbury, Staines, Middx TW19 5NX.***

ALGARVE – Portugal

Wheelchair friendly luxury villas with swimming pools or small friendly hotels with adapted rooms. ***Sue Abbott, 123 Coppermill Road, Wraysbury, Staines, Middx TW19 5NX. Tel: 01753-685718.***

ISLE OF WIGHT ASBAH

Fully equipped two-bedroom holiday bungalow, sleeps six plus cot. Clubhouse, indoor heated pool, shop etc. Site overlooks sea. Own transport advisable. ***Details: Mrs P Burden, 36 Sherbourne Avenue, Binstead, Ryde, IOW, PO33 3PX. Tel: 01983-564604.***

FRANCE – Ile d'Oleron, near La Rochelle

Mobile home for wheelchair users. Fully adapted (shower etc), sleeps six, near beach, disabled owner. ***Brochure from: M Mardle, Fricourt, Filey Road, Old Heath Road, Southminster, Essex CM0 7BS. Tel. 01621-785899.***

FOR SALE

Invacare Scooter £1,000. Mr Bert, 2 Marsh Lane, 81 Marsh Road, Leagrave, Luton LU3 2RN, tel: 01582-502688.

Rifton hand-driven tricycle, suitable for child with limited or no use of legs. Adjustable, to suit child up to 48" height. Absolutely immaculate condition. £150. Phone: 01273-492935.

LINK Rates

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Small adverts for the next issue of *LINK* (December) should be submitted by Monday, 3 November. Please send them to the Editor.

Display Rates on application, from the Publicity Manager.

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