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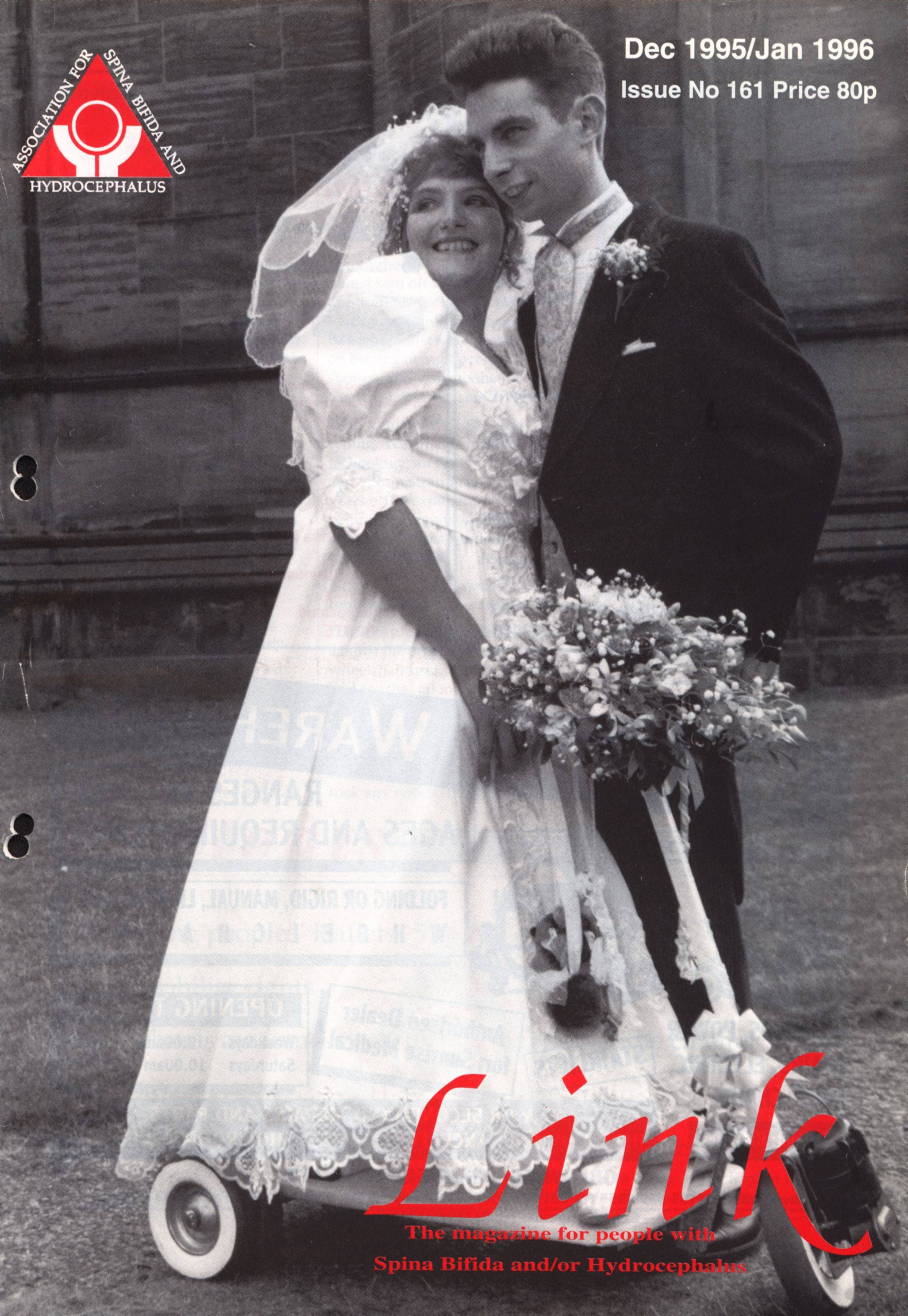

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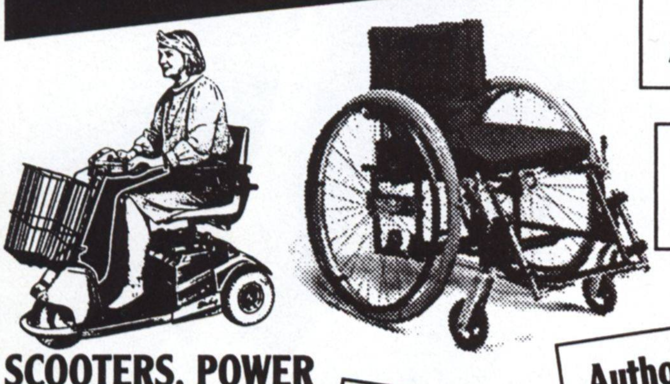

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Walk down the aisle made Kirsten's day

A LIFELONG dream came true when Kirsten Smith walked down the aisle on her wedding day.

"I sort of glided down the aisle. I can't remember actually walking because the day passed in a kind of a haze. Afterwards, my legs were killing me," said 21-year-old Kirsten – who married Mark Battle at Oulton Church, Leeds, in August (*pictured right*).

Kirsten, who has spina bifida, stepped out of her wheelchair for her big day. Nothing was going to hold her back.

"I had been absolutely determined to be like any other bride. And, with this in mind, I went looking for a physiotherapist who would help me. When I found one, the first thing I asked was 'Do you want a challenge?' She did me proud," said the new Mrs Battle.

Sheer determination has carried Kirsten through ever since she moved south to Burnham, near Slough, 20 months ago to be with Mark, who works as a warehouse man near Heathrow Airport.

She went job hunting in a big way.

"I was determined to pull my weight, and not become dependent on Mark for income," said Kirsten.

"From the April after I came down here, I sent off at least 2,000 applications for jobs. Looking for work turned into a 24 hours in the day job. I must have spent £1,000 on buying newspapers and stamps, and visits to the Job Centre. It cost me a small fortune."

With a clutch of GCSEs, RSA typing, a certificate in computer technology, an NVQ in business and administration and over two years office experience in Leeds behind her, you would have imagined bosses would be crying out for her skills.

Not so. Most employers failed to reply and rejection was the norm.

"Basically, people discriminated against me because I'm a wheelchair user. One firm even told me that taking me on would destroy the image and credibility of the company.

"I had to wait until my story was told in the local paper before firms took any notice. Then I had a queue of people wanting to talk to me. There were eight job offers very quickly."

Kirsten eventually accepted a full-time job with a translation company as an audio-typist, working at home. She feels that someone 'down south' is at last valuing her skills.

She has got at least one other marvellous thing to look forward to in the near future. Mark and Kirsten expect to make their family complete with a baby. "I'm definitely pregnant and the baby is due at the beginning of June," said Kirsten in October. "It's all turning out rather well!"

Contents

ASBAH is a registered charity

***Cover:** After walking down the aisle to marry Mark, Kirsten Battle posed for pictures on a special scooter. Full story this page.*

ASBAH ● STAFF MOVES

● SUFFOLK lost Barbara Dawes as its part-time fieldworker but a replacement has been appointed.

Barbara has moved to a job with the North Essex Health Promotion team. After five years with ASBAH, she said: "I'll miss the contact with the clients and families, and all my colleagues. I've learnt a lot with the team at ASBAH and this will stand me in good stead for my future work."

Eastern Region co-ordinator, Mary Malcolm, said: "Barbara has been a great asset to the Eastern Region team in our first year. She will be sadly missed."

Val Meyer Hall , who has an 18-year-old adopted daughter with hydrocephalus, is the new Suffolk fieldworker. Val plans to combine her ASBAH role with an existing job as part-time co-ordinator of the Stowmarket Opportunity Group – a support group for families with children with disabilities.

● A NEW full-time secretary for Northern Region and START has been appointed to replace Jackie Dennison.

Anna Haigh comes to ASBAH from a job at the Leeds/Bradford International Airport. She said: "I am looking forward to doing something worthwhile and a job which is more people-orientated."

Anna lives in Otley, West Yorkshire. She enjoys cycling, swimming and reading.

● KAREN Sharma, part-time education adviser in Northern Ireland for two and a half years, leaves in December.

The departure is reluctant but necessary as her husband's job demands a move to Germany. Karen said: "I will be very sad to be going. I've gained such a lot."

With a background in special needs in mainstream schools, as education adviser Karen has spent a great deal of time helping parents with special educational assessments and statements.

She has also been involved with helping clients transfer between schools – a critical time for many ASBAH service users.

School visits have been another important part of her work; meeting and talking with teachers about the needs of particular children and hopefully raising awareness of the disability generally.

Karen said: "The work has brought me into contact with the child as a whole. I have found the family contact very rewarding. It's been great working as part of a team too and the Northern Ireland staff have been super to work with.

"It's a lovely job and very exciting because you're always learning something new."

One of the most important aspects of the work, she says, is the fostering of good home-school links. "One of the highlights has been when you know you've made a difference, even with one child, for example, in cases where the parents have not been happy with a school placement and you have helped them find another."

A replacement for Karen will be found as soon as possible.

● FOLLOWING continence adviser Mary White's decision to go from full to part-time, money has been released for a new part-time post.

Interviews for a new half-time medical disabled living adviser (DLA) took place in November.

The new post-holder will be based at national centre in Peterborough and will be qualified to answer inquiries on a range of medical issues relating to spina bifida and hydrocephalus.

Withdrawn services prompt court action

GLOUCESTERSHIRE County Council's refusal to restore services to more than a thousand of its home care service users has prompted a judicial review.

The Royal Association for Disability and Rehabilitation (RADAR) received permission to bring the review by a High Court judge.

Previously, the High Court ruled that, because it had not individually reassessed service users, Gloucestershire had unlawfully withdrawn home care services provided under Section 2 of the Chronically Sick & Disabled Persons Act 1970. Following this judgment, the council had been expected to restore the withdrawn services and then carry out reassessments before deciding whether they were still needed. Instead, the council wrote to all 1,240 service users saying they would have to ask for a reassessment before services would be restored.

Unless Gloucestershire agreed to restore these essential services, RADAR pledged to apply to the Court for the case to be put in the 'fast-track' so that the hearing could take place before Christmas.

ASBAH leaflets to guide young people through life

A SERIES of free leaflets providing information and signposts for young people as they travel through adolescence is being published by ASBAH.

They will all feature a brand-new cartoon character drawn by David Swift, which will develop a personality as more and more of the leaflets are published.

The leaflets give tips about a wide range of issues of interest to teenagers, and tell them where they can get more information and advice.

The first three in the series of nine leaflets are expected to be delivered by the printer any day now. They are called:

1. **This Is Your Life: ten tips for a healthier happier you**
2. **Keep It Clean: top tips for looking good**
3. **Continence and You.**

The **Keep It Clean** leaflet will contain a check-list which can be stuck on the bedroom or bathroom mirror to help improve the daily personal care routine.

Three more leaflets are in the pipeline and should be ready to send out in February or March. Provisionally, they are titled:

4. **Let's Talk About Sex**
5. **More Talk About Sex**
6. **Friendship Matters.**

The cartoon character we shall be introducing in a new series of leaflets being prepared by ASBAH for young people with spina bifida and hydrocephalus.

Another three subjects – all of crucial importance to young people – will be selected for turning into leaflets later on next year.

"All the leaflets will be written in an easy-to-read style and in each leaflet we shall recap on all the points raised in the form of a short checklist," said ASBAH information officer Gill Winfield.

"Cartoonist David Swift provides a cartoon character who should make each leaflet instantly recognisable," added Gill.

Services committee chairman Austin Crowther commented: "It will be good to see ASBAH leading the way in giving out this sort of information. I have been wanting us to produce leaflets like these for years."

● ***To receive copies of the leaflets as they become available, send your name, address and age to: Gill Winfield, Information Officer, ASBAH House, 42 Park Road, Peterborough, PE1 2UQ.***

Officers & Staff

ASBAH report on the findings of a recent profile of local associations

Your vital statistics revealed

By Gill Winfield
Information Officer

HOW many members do local associations have? Are there more with spina bifida or with hydrocephalus? What are their ages? These are some of the questions we set out to answer earlier this year in a survey of local association membership.

Twenty-somethings in the lead

Membership of the 27 associations which took part in the survey totalled 2,500 individuals with one or both of the disabilities. By far the largest group overall was that of the 20-30-year-olds with both spina bifida and hydrocephalus. This was also the largest grouping in any individual association.

For members with spina bifida alone, the majority were again in the 20-30-years age group. Possibly many of these members will be those who have 'grown up' with the support of their local group and maintained contact with them.

The "golden oldies"

We only asked for membership numbers for people up to 50 years of age but we underestimated the staying power of the older generation. Quite a few associations had to add their own category for their members over 50 (though we don't know who holds the record for the oldest member).

The young set

A rather different picture emerged of members with hydrocephalus alone. Here, the greatest number were children, in the 0-9 age range. Perhaps this is an indication of the increasing number of premature babies who are surviving but have hydrocephalus as a result of prematurity.

Local association membership of those with hydrocephalus alone varied dramatically with some associations having no members with just hydrocephalus, while others had almost as many in this group as they did with both disabilities.

The big and the small

There was tremendous variation in the size of local associations. The largest had more than 1,100 members while the smallest reported to us had just six. Half a dozen had numbers in the hundreds but the majority had between 10 and 80 members. Even some of these reported that they were not all active or 'paid up' members but those who were on the group's mailing list.

Obviously, some groups are more active than others with greater member involvement and more funds and activities available to their members. But even the smallest groups can be a vital contact point for families or individuals when they are first diagnosed as having a baby with either spina bifida or hydrocephalus; or when an adult acquires hydrocephalus; or has spina bifida occulta which is causing problems.

All local associations now have a pack of up-to-date information provided by national ASBAH which they can use to answer enquiries. The Information Department is always happy to help with any queries from local groups and if we don't know the answer, we may 'know a man who does!'

● ***All 69 local associations in England and Wales (affiliated and non-affiliated) were contacted and asked for anonymous details of their membership. The response rate was almost 40%, with 27 completed questionnaires being returned.***

Disability Discrimination Bill becomes law

THE DISABILITY Discrimination Bill, which had been criticised by disability groups for not going far enough, has finally became law.

Various amendments made in the House of Lords were debated in the House of Commons on 31 October, with Labour MPs claiming the Government had made U-turns on several issues.

The main changes pushed through were the inclusion of people infected with HIV and those with a history of disability.

Other amendments passed included:

- The duty of an employer to make reasonable adjustments, where any physical feature of premises causes substantial disadvantage to a disabled person compared to those who are not disabled.
- The meaning of discrimination when comparing whether an employer's treatment of an individual is less favourable.

Points raised here included the scrapping of the 3% quota applicable to the number of disabled people employed by local authorities; the introduction of a national helpline giving advice to people on their rights as defined in the Bill and the question of equal pension and insurance rights.

- The exclusion of small businesses (employing less than 20 people) from making provisions for disabled people under the legislation.
- Protecting the rights of disabled people doing contract work.
- A clause to provide the Secretary of State with the power to impose provisions in taxis for wheelchair access.
- Schools declaring arrangements for the admission of disabled pupils in their annual report.
- A new clause on access arrangements in leased premises.

However, Clause 12, which would have toughened up discrimination in relation to the supply of goods, facilities and services, was narrowly defeated.

Supporting this amendment, Labour's disability frontbencher Tom Clarke said: "The Lords amendment is yet another challenge to the inadequate scope and coverage of the Bill. Ministers were forced to concede that the Bill should protect those with a history of disability and those likely to be disabled in future, and they suffered defeat in the Lords because of their refusal to extend protection to those with an ill-founded reputation for disability.

"The effect of the Lords amendment is to outlaw discrimination against those wrongly perceived by providers of goods and services to be disabled."

However, Alistair Burt, Minister for Social Security and Disabled People, said extending the definition in this way would lead to confusion and be unworkable.

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, 123 East Barnet Road, New Barnet, Herts EN4 8RF. Tel: (0181) 449 0475. Regional Co-ordinator: Gina Broughton, BA (Hons).

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, Five Oaks, Ben Rhydding Drive, Ilkley, W Yorks LS29 8BD. Tel (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

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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.*

Chains of support

THREE UK mayors are raising money during their mayoral year for projects associated with spina bifida and hydrocephalus.

■ The Lord Mayor of Belfast, Councillor Eric Smyth, is hoping to raise £50,000 for several projects related to spina bifida and hydrocephalus in an appeal, launched in September.

The Lord Mayor has an adopted four-year-old son, Matthew, with spina bifida and hydrocephalus who inspired his choice of good causes.

The aim is to purchase lightweight wheelchairs and replacement urodynamics equipment at the Royal Belfast Hospital for Sick Children. An additional aim is to increase public awareness about the disabilities and how the risk of spina bifida can be reduced.

Several fund-raising events have been planned including a charity ball, country and western and gospel concerts, parachute jumps, quiz nights and sponsored walks. So far, £8,000 has been raised and the appeal will continue until June 1996.

Cllr Smyth said: "In Ireland, the incidence of spina bifida is four times greater than the world average.

"The appeal target of £50,000 is surely an ambitious one, but I have no doubt that, with the traditional generosity of the people of Belfast, it can be realised."

Lord Mayor of Belfast, Cllr Eric Smyth, with son Matthew and Gene Fitzpatrick, of PHAB

Mayor and Mayoress of Milton Keynes, Councillor Bruce Hardwick, and his wife Helena

■ The Mayor and Mayoress of Milton Keynes, Councillor Bruce and Helena Hardwick, have so far raised around £2,500 for ASBAH, with more money flowing in all the time from various events.

Their grandson, Luke Hardwick, who is aged 16 and lives in Darlington, has spina bifida.

Cllr Hardwick said: "I chose ASBAH as my charity for the year because of the excellent work it does for both the people who have these conditions and the families.

"The support needed by the disabled person's family is often under-estimated and ASBAH does give excellent help to the families."

In September, Luke, a wheelchair-user, represented a County Durham school in the BT Kielder Challenge in Northumberland by tackling a variety of outdoor challenges at the Calvert Trust Centre.

Sue Davies, ASBAH fieldworker for Herts and Beds, said: "The Mayor of Milton Keynes is very supportive of any project relating to disability. To promote the ASBAH appeal, he has produced an excellent leaflet which illustrates our work and his own personal experience of disability through his grandson and the problems those like him have to face."

■ The Lord Mayor of York, Cllr John Boardman, and his wife Ann have chosen North Yorkshire ASBAH as one of their charities.

The couple have an 18-month-old nephew, Jamie Darvill, who has spina bifida. Jamie lives in Salford.

Cllr Boardman said: "NYASBAH deserves support because of the practical and moral support, and the advice it gives to families. The difference that help has made to Jamie and his family is immeasurable."

continued at foot of page 9

Lord Mayor of York, Councillor John Boardman, and his 18-month-old nephew, Jamie Darvill

Schools fail to recognise a good opportunity – even when it's free!

MANY schools have missed out on a chance to offer disability awareness training to pupils and staff – because they have stuck a highly-accaimed video on the shelf instead of using it.

REPORT BY LIZ CAWTHORNE

Earlier this year, 27,000 copies of the video *Nobody's Perfect* were sent free of charge to every school in the country in a unique operation to salvage something of value from the closure of the Understanding Disability Educational Trust (UDET) after the trust had run out of money. The rescue operation had the blessing of the Charity Commission.

But inquiries by *Link* – sparked by *Your Voice in ASBAH* member Carole Armour – have revealed that the UDET video and special supporting notes for teachers are being wasted in many areas.

The video uses simple story lines to get pupils and staff to accept children with special needs in their midst. The aim is to achieve greater understanding of their need for full participation in school life so that mainstream schools do more than pay lip-service to integration. RADAR, which now stocks the video, is trying to revive interest in it.

Two issues ago, *Link* reported that the UDET video had been sent to every school. But Carole Armour, who lives in Leicester, said she simply did not believe it.

"I have been into schools in Leicestershire and they haven't got these training materials. I've also got a friend who is a teacher in Essex, and she hasn't seen them either," she said.

Since then, a straw poll carried out by half-a-dozen ASBAH field-workers and disabled living advisers showed that they too had seen no evidence that the UDET video was being used in schools in their areas. Spot checks were made at schools in South London, Greater Manchester and North Staffs.

Martin Sissons, education officer with RADAR, which has now taken over the distribution of video; said the lesson to be learned was that teachers did not appreciate even high quality teaching aids unless they paid for them.

"Because these materials were distributed by UDET out of the blue, schools didn't recognise what they were," said Mr Sissons.

"In a small survey I carried out, only 10% of schools recognised them. UDET's sole aim was to distribute these videos to 27,000 schools and we have since found that teachers need to be made aware of the materials before receiving them.

"Reviews, like the one in *Link*, work far better than sending things out on spec. We are now selling the packs to cover our costs and, once schools have paid for them, they are more likely to use them."

Leonie Holgate, our specialist hydrocephalus adviser who welcomed the UDET training materials in *Link* two issues ago, commented: "The good thing about the pack is that it can be incorporated into the National Curriculum. I know of several schools using it and I am still publicising it."

Leonie added: "The Government wants all children to be integrated into mainstream schools and for this to be successful the very first step must be to use these materials, as well as improving access.

"Both staff and children need disability awareness training so they are ready to accept children with special needs. At the moment these children are isolated, not integrated."

■ ***The UDET pack – video and teacher support notes – is now priced £9.00 and available from The Education Officer, RADAR, 12 City Forum, 250 City Road, London, EC1V 8AF.***

So far so good for one scheme

A PIONEERING scheme to raise awareness of disability in schools has been set up in Leicestershire.

Four men and women, who are members of Leicestershire ASBAH, have offered to go into schools and discuss disability with pupils.

They show the UDET video, *Nobody's Perfect*, and base their

continued on page 10

Chains of support, from page 8

Other fund-raising activities in York include:

- An Assize of Ale – or glorified pub crawl through York – raising £1,500.
- Open days at the Mansion House with visitors taking coffee.
- Shows of the civic silverware with an hour-long talk and request for donations.

Future events planned include a Lord Mayor's charity ball, a visit from the BBC radio soap *The Archers* and a number of street/store collections at Christmas.

The other cause supported by the Lord Mayor of York this year is the children's leukaemia unit at St James's Hospital, Leeds.

House appeal launched by Treloar School

A £2.6 MILLION appeal for a new home for severely disabled children has been launched by the Lord Mayor Treloar School in Hampshire.

Supported by the Prince of Wales, the appeal aims to raise the money for a purpose-built house for the younger boarders, who are aged between seven to 12. Some of these will have spina bifida and hydrocephalus.

At present, these children are accommodated on two floors in an Elizabethan building. This building was acquired by the Trust in the 1950s, but it is no longer suitable for their needs.

Ten years ago only 20% of the children attending the school were in wheelchairs. Today, the figure is closer to 80% and the building cannot be adapted to meet the demands posed by the increasing severity of their disabilities.

Designed by architects Macallan Penfold, the house will provide plenty of light and space for its young residents, with 48 bedrooms accessible on a single floor.

The extra space provided by the house will also enable the school to lower the age of admission for day pupils from seven to five.

The New House Appeal was launched in October at the Merchant Taylors' Hall in the City of London.

The trustees aim to raise sufficient funds for the new house to be ready by September 1996, and £600,000 has already been raised.

Donations should be sent to: Treloar Trust, New House Appeal, Upper Froyle, Alton, Hampshire, GU34 4JX.

So far so good for Leicestershire project, from page 9

talks on their own personal experience of disability. Any expenses that are not met by the schools are paid for by ASBAH.

Carole Armour, a member of both our *Your Voice in ASBAH* user-group forum and Leicestershire ASBAH, said: "We think disability awareness training in schools is very important. We describe what it's like to be in a wheelchair and why we may need help doing certain everyday things.

"To give a very simple example, I explain that I can't change a light bulb and have to ask someone to do it for me because I'm a wheelchair user. We also explain why we find public transport difficult and that we have to use ramps rather than steps.

"It's all very basic knowledge but, because most of the youngsters haven't experienced disability, they aren't aware of it."

Carole usually lets one or more of the pupils try out her wheelchair and they are amazed at how much strength is needed to handle it.

The schools project started just over a year ago after Gary Farnsworth proposed the idea in the local association newsletter. Three more people showed an interest and, after a slight delay due to a changeover in fieldworker cover, letters were sent out to 12 secondary schools north of Leicester. In addition, Gary contacted four schools in his home town of Market Harborough.

From these initial letters, seven responded positively by requesting a visit.

So far, Gary has visited one school and he has been booked to conduct a staggering 13 sessions over 10 days in another.

Another group member, David Dixon, has six sessions booked in February and March. As *Link* went to press, he was expecting a booking from another school in November. David's able-bodied wife, Lucie, is also a member of the project.

Carole and Lucie have visited two secondary schools so far and hope that repeat visits follow.

"The four of us plan to meet soon to see how we're doing and possibly contact more schools," said Carole.

"We're going to play things by ear as we don't want to get swamped with requests for visits. There is only a limited number of us and we don't want to over-stretch ourselves."

The response from all schools visited so far has been very positive.

"Perhaps this is a project that could be easily adopted by other local associations," added Carole.

Europe holiday guide

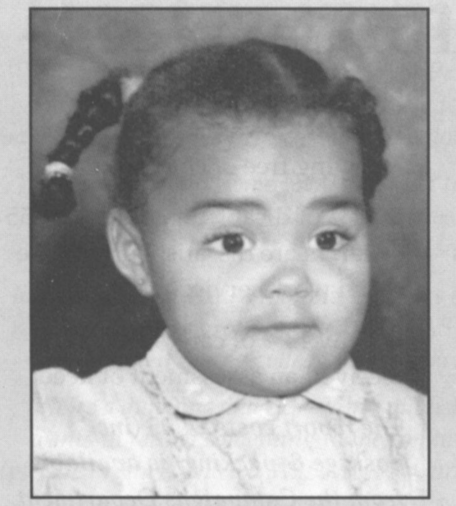
HOLIDAY and travel information on 32 European countries – from Israel to Iceland – is contained in a new book for people with disabilities.

There are details on national sources of information, accessible transport, specialist services and tour operators who can cater for visitors with disabilities.

Accommodation includes hotels, self-catering cottages, youth hostels and holiday centres.

The guide also gives general advice for disabled people planning an overseas trip and further sources of information.

***European Holidays & Travel 1996: A Guide for Disabled People* is available, price £5, from: The Royal Association for Disability and Rehabilitation (RADAR), 12 City Forum, 250 City Road, London, EC1V 8AF.**


Poppy: born with no problems

Fighting for the rights of your unborn child

Carol Anderson is concerned that mums-to-be are being pressed by maternity staff into making decisions to terminate pregnancies based on scans which may not be 100% accurate. LIZ CAWTHORNE tells her story.

A MOTHER gave birth to a perfectly normal baby after defying advice from doctors who predicted the child would be severely disabled with hydrocephalus.

Now she is warning other mums-to-be to think carefully about hospital advice based on scans which may not be 100% accurate.

Carol Anderson, aged 29, says she will never get over the trauma she went through during the pregnancy after being told that, at 17 weeks, Poppy – her second child – had much more fluid in her head than was normal.

She was put under tremendous pressure to terminate by a hospital in Bristol who told her that Poppy had a 25% chance of survival and, if she survived, was likely to be severely disabled.

"They insisted I should have a termination as they said it was the normal course of action if such abnormalities are found at an early stage," Carol said.

"I refused as I am totally against termination but they still insisted. My argument is that, if everyone in this situation terminated, how do medical staff know if the outcome is as they predict?"

Carol, who was brought up a Catholic, continued with the pregnancy but was obviously full of fear for the future. She had to give up her job as a shop assistant and believes the stress she was under triggered a premature birth at 34 and a half weeks.

"Those weeks of waiting were sheer hell. I couldn't bring myself to tell anyone about what I was going through because many of my friends were pregnant at the same time.

"I think the way I was treated by the hospital was disgusting. Nobody wanted to give me any support when it was realised that I would not terminate.

"The 17 and and a half weeks' wait from the scan until my daughter's birth were very traumatic and stressful, and it is so still."

Less than two hours after the birth, following a detailed examination by a paediatrician, Carol learned that Poppy was, in fact, perfect.

Carol said: "At first, I didn't even ask if she was disabled, I was just pleased she was alive.

"But no one has ever explained to me why the scan had shown enlarged ventricles – I was just regarded as very lucky that Poppy was normal. I'd like to know why the diagnosis was made, why all the fluid they noticed in the brain disappeared and why it was there in the first place?"

During the first few months of her life, regular checks were made on the size of Poppy's head.

Carol said: "Her head is the smallest part of her as she has grown into a very tall and stocky two-year-old."

Carol attempted to take legal action over the advice and behaviour she received at the hospital, but this was later dropped because the hospital said the advice had been given in good faith.

Determined not to be intimidated by the health care system, Carol and her husband Tony decided to have a third child 17 months later.

This time around, although Carol had scans, she attended a different hospital in Bristol for her ante-natal care.

Carol said: "I had scans for my third child because I didn't want anything to beat me, and was curious to see if they would again

more on page 12

ASBAH in Radio 4 appeal

TV PRESENTER Jill Dando will present a BBC Radio 4 appeal on behalf of ASBAH on Sunday 7th January next year in *The Week's Good Cause* slot.

Appeal to women in London

ANGELA Smith is the new women's officer for *Women in Residential Care* – a project run by the Greater London Association of Disabled People (GLAD).

The project, funded by the Joseph Rowntree Foundation for 18 months, aims to:

- ■ Empower disabled women living in residential care to come together to discuss issues which concern them.
- ■ Offer social contact, training and peer support.
- ■ Enable women to make contact with the disability movement and independent living schemes.
- ■ Produce a leaflet on guidelines for women in residential care.

Angela would like to hear from any disabled woman living in residential care who would like to participate in the project.

For details contact: Angela Smith, Women's Officer, GLAD, 336 Brixton Road, London, SW9 7AA. Tel: 0171-274 0107 (voice/minicom).

How to run a charity shop

A NEW guide showing how to maximise opportunities and profits while managing charity shops has been published.

The Charity Shops Handbook by Hilary Blume covers: premises and stock; pricing goods; recruiting and managing volunteer helpers; designing shop layout and display; preventing shoplifting; understanding the legal and financial requirements; and safety regulations.

Priced at £10.95 (inc p&p), it can be obtained from the Charities Advisory Trust, Radius Works, Back Lane, London NW3 1HL, tel: 0171-794 9835.

Fighting for services

DISABLED people and their carers have spoken out in a new report about how care in the community has become a system within which they have to fight for services, support, adaptations and equipment.

More than 1,500 disabled people and 1,300 carers were surveyed for *Disabled in Britain: Counting on Community Care*, published by Scope, which shows that under the relatively new care system:

- ● 18% of disabled people have had to start paying for a service which they were formerly receiving free of charge.
- ● 31% of disabled people and 355 of carers are dissatisfied with the social work service.
- ● Only 13% of carers have received an assessment of need.

The report costs £4.95 (inc postage & packing) is available from the Campaigns Department, Scope, 12 Park Crescent, London W1N 4EQ, tel: 0171-636 5020.

Note for 'L' drivers

LEARNER drivers with disabilities in Northern Ireland will not, unfortunately, benefit from the cash help available for lessons, says Margaret Young, ASBAH's Northern Ireland co-ordinator.

The Motability scholarships mentioned in the autumn issue of *LIFT* are only applicable to BSM schools and there are none of these in Northern Ireland.

However, those living in the Grimsby and Cleethorpes areas can use a fully adapted automated car when learning to drive at BSM Grimsby.

The driving school offers special rates for courses and a Banstead-trained instructor who can visit potential students in their own homes to talk through what's involved. ***Contact: BSM Grimsby, 7 Bethlehem Street, Grimsby, DN31 1JN, tel: 01472-340981.***

Information award

NOMINATIONS are invited for the first *Getting the Message Across Awards* for outstanding achievement in providing information to disabled people.

The awards are organised by the National Information Forum and organisations or individuals can be nominated. Closing date for nominations: 15 January 1996. ***For a nomination form, contact: Ann Darnbrough on 0171-582 7603.***

Fighting for the rights of your unborn child, from page 11

show enlarged ventricles.

"I learned that Poppy's scans had been passed on to the second hospital and a doctor there told me he would have given the same advice to terminate."

After a relatively trouble-free pregnancy with Dominic, Carol wants other mums-to-be to think carefully before following hospital advice to terminate.

She said: "There is always a chance that they might have a beautiful baby like mine, so they should weigh up the evidence given by hospitals carefully. I am so glad, and thank God, that they did not get through to me.

"Poppy is now a very intelligent child but at the moment I don't want to let her out of my sight – I am still scared of losing her and get paranoid over colds and germs."

Poetry in motion

FROM verse to our purse... a Peterborough-based publishing group asked its poets to waive copyright payments so that the firm could make a donation to charity.

The result – a handsome £900 donation to ASBAH, which was presented to ASBAH executive director Andrew Russell (second from right).

Ian Walton and Paul Wootton, directors of Peterborough's Forward Press group, turned up at ASBAH House with two of their young colleagues to make the presentation.

"We're a dynamic and expanding publishing house which wants to return something to the community," said Paul (pictured right), who left ASBAH last Christmas after three years as our business liaison manager.

Motability cuts prices of its lease cars

MOTABILITY has cut advance payments on its lease cars – in some cases to zero – making it easier for disabled people to get around.

Motability has also introduced a new form of contract hire finance on smaller cars, called the "constant lease."

On the constant lease, the amount paid by the hirer remains the same over the three-year lease period instead of going up in line with inflationary increases in the higher rate mobility component of Disability Living Allowance (DLA). Customers will benefit by having any allowance increase paid directly to them by the DSS.

Motability says the savings have been achieved by negotiating with the car manufacturers to reduce prices, combined with a new and competitive insurance contract with Royal Insurance. With 240,000 cars and a 17% growth rate in vehicles over the last few years, the charity has the largest fleet in Europe.

A Motability spokesman said: "Advanced payments have been cut on many models and the constant lease available on smaller models means that, for the first time, customers will be able to run a car and put money in their pocket."

Several cars have a rental below the £32.65 a week DLA higher rate mobility component.

Small cars requiring no advance payment and whose lease costs in October were less than DLA included: Renault Clio, Peugeot 106, Vauxhall Corsa Merit, Rover 111, Nissan Micra, VW Polo and Ford Fiesta Azura 1.1 CFI.

Examples of big cuts in down-payments on larger cars are the Ford Fiesta Azura 1.1 CFI five-door £50 (down from £300), Ford Escort Encore 1.4 EFI five-door £275 (down from £550), Rover 114 SLI automatic £300 (down from £600), Vauxhall Astra Merit three-door automatic £1,000 (from £1,237).

Disabled people on the Motability scheme don't have to drive themselves. They can be driven by a carer or member of the family.

The Motability Charitable Fund gives grants for advance payments and vehicle adaptions where scheme applicants need additional help to acquire a vehicle which suits their particular disability. The Government-funded Mobility Equipment Fund, administered by Motability, provides grants for people with more severe disabilities who may need to drive from their wheelchair.

Anyone who receives the higher rate mobility component of DLA for three years can apply for a Motability vehicle and most applications are successful.

More people claim DWA

THE NUMBER of people claiming Disability Working Allowance (DWA) went up by 483 from April 1994 to January 1995, according to the latest Government figures.

There were 5,685 DWA recipients in April 1995, compared with 5,202 in January 1995 and 4,040 in April 1994.

The average weekly payment of DWA in April 1995 was £45.51, compared to £44.86 in January 1995 and £41.87 in April 1994.

The average weekly earnings of recipients are just over £80, compared to just over £76 in April 1994.

Just over 64% of recipients qualified for DWA because they were receiving Disability Living Allowance.

Just under 38% had children, a slight rise since April 1994.

WHAT MAKES THESE ORDINARY PEOPLE REA

TO BECOME adventurers, people with disabilities first need to become "devout realists" about who they are and what they can do.

Taking a hard look at yourself may be difficult to cope with, but once you have peeled off any illusions you can go forward and find your own true level.

Your first taste of adventure may not be much in the eyes of others, but it is important to set yourself achievable goals which you can build on.

John Hawkridge *(pictured right in the Himalayas)* has cerebral palsy and uses sticks. He believes his adventuring spirit was first sparked by fishing. This developed into walking and rock climbing.

To date he has completed many long-distance walks in Britain and the Himalayas and has travelled to 40 countries.

At 47 , he is a governor of Outward Bound and vice-president of Phab Northern Ireland.

Take each adventure o
time, says disabled mo

"If everybody achieved their full potential, it would be a wonderful world," he said. "Adventure has been the greatest thing in my life but it comes in different forms – it could be sheltering from the rain as a child, going on a boat trip or climbing Everest.

"You have to serve an apprenticeship and do things in stages – like climbing the rungs of a ladder.

"If you reach rung two and someone offers to take you to rung five then they've stolen the two intervening rungs from you.

"Adventure is a progressive thing and disabled people are the same as able-bodied people – they have as much right to be lazy as anyone else.

Disability, he said, only became evident in the presence of other people wh
not have the same disability and it
should not be regarded as a reason
to try new things.

"To take things to the enth degree,
you've as much right to risk your l
anybody else."

The important thing is to allow pe
to choose for themselves and for t
enjoy it.

"I'm damn certain I don't want
someone else to make decisions for
I find water the greatest adventure
because there are only a few secon
between life and death. We all hav
right to do these things but there a
lot of people trying to make decisi
for us."

"Everything I have done has been

To the top of the world's sixth highes

IF AT FIRST you don't succeed ... there's always something else to try instead. This was the advice given by Norman Croucher, now a veteran mountaineer, who lost both legs when he was 19 in a railway accident.

"There has always been a progression in what I've done. And I have never done anything without lots of preparation."

At 19, he had already had a taste of rock climbing and hill walking and was determined to continue – despite having no legs. But he received no encouragement from anyone during convalescence.

He forced himself back into the outdoor activities he loved. For years, he satisfied his craving by exploring lower English peaks before tackling a 3,000 ft peak in Wales.

He was then keen to have a stab at the Alps, loftier peaks still, but before trying these he realised that "toughening up" the stumps of his legs was required. To do this, he decided to trek across the length of the British mainland – from John O'Groats to Land's End.

He suffered greatly in the first few weeks of the walk. After that his stumps gradually withstood the gruelling distance and, at the end of three months, he was ready for an even bigger challenge.

"The Alps kept me going for some years but then I wanted to go for some of the bigger ranges. So I started climbing in Peru," he told the seminar.

According to Norman, there are two advantages of having artificial lower limbs. The first is that your feet cannot get frost-bitten; the second is that, although he tends to be the slowest walker of the party near the base of the mountain, his performance gets much better above 20,000 feet.

In the end, a broken artificial limb prevented him reaching the summit of his first-choice mountain on this particular trip. But he was very pleased with what he chose to do instead.

"I couldn't keep up so I looked around for an alternative peak and found a smaller one of 16,000 feet. I set off on my own, with someone below keeping an eye on me with a telescope. Much of the time I was crawling, so I padded my knees. It took three days to reach the base of the snow field."

The last stretch was particularly treacherous. Norman had to wriggle round and over a terrain riddled with 300 foot ice peaks.

"I did climb the other, higher mountain later but, honestly, I didn't fin

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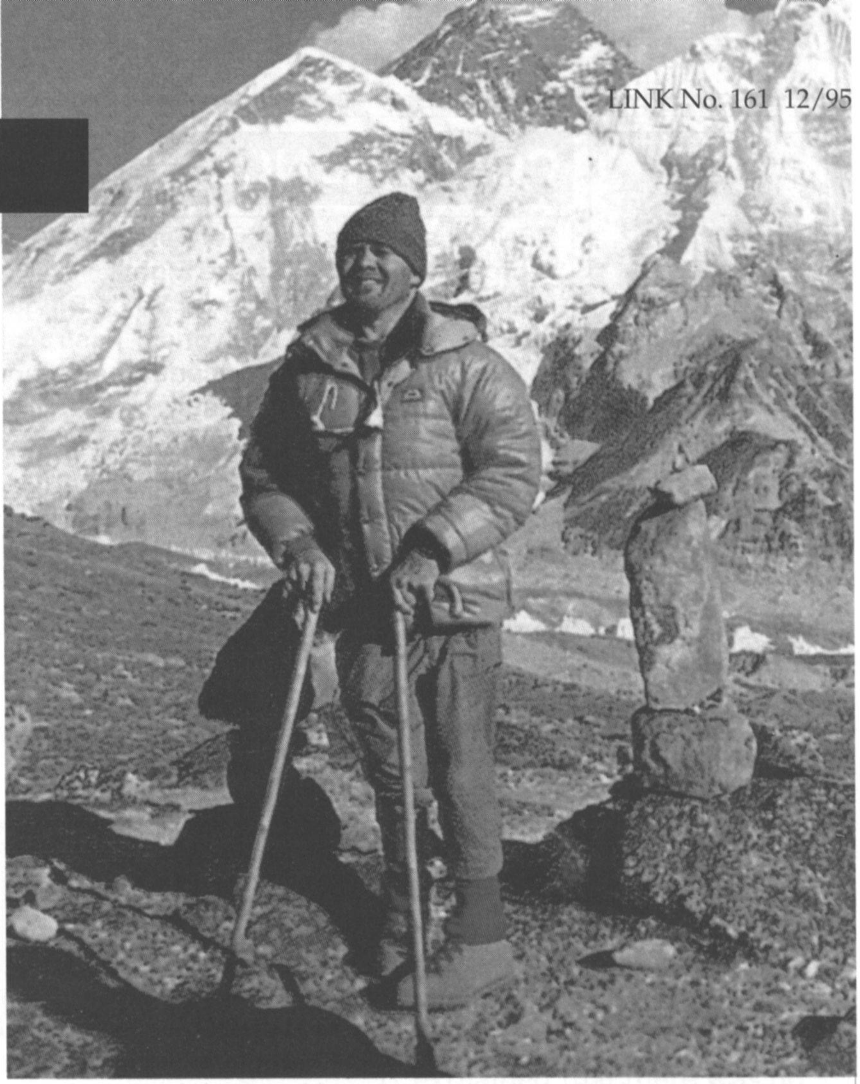
personally motivated. I look at the great climbers and I know I will never achieve what they have done – they are probably at rung 15 – but they have inspired me to get to rung five.

"I've either gone on my own or in a two-man team, with the other member not knowing a lot about mountains. I've kept things to a minimum with a maximum of personal input so I'm in control."

John has climbed the highest mountains in the British Isles and, in 1988, helped make the BBC 1 TV documentary *Everest – The Hard Way*. He has published two biographies, *Sticks and Stones* in 1987 and *Uphill All The Way* in 1991. The photo on the right is taken from the cover of his second book. He was unable to walk for two years after surgery in 1959.



st peak

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"The ambition to climb
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"RISK in all departments of our lives is essential – otherwise life is boring. I could have stayed at home today and watched the match but I didn't."

This message, from mountaineer Doug Scott, was the underlying theme of a seminar aiming to give people with disabilities the impetus to see an original idea for adventure through to completion.

The Disabled Explorer seminar, organised by The Expedition Advisory Centre and MacIntyre Adventure, was held at The Royal Geographical Society in London.

As well as people giving accounts of their expedition experiences, either as individuals or as group members, there were exhibitions from organisations running outdoor adventures for disabled people.

Expeditions highlighted ranged from a cross country trek across Iceland by motorised trike by quadriplegic explorer and photographer, John Birdsall, to the worldwide underwater exploits of leading marine scientist and wheelchair-user Nic Flemming.

Walking, camping, mountaineering, rock climbing, caving, scuba diving, sailing, canoeing, surfing, snorkelling, swimming and white water rafting were some of the activities discussed. *Link* only has the space for two gripping yarns from explorers with disabilities and, overleaf, some medical advice for those planning to join their ranks.

"Just because someone's in a wheelchair doesn't mean they can't feel the wind in their hair, the rain on their face, touch snow or feel the loneliness of being on a peak," said Steve Bull, lecturer in physical education , who led the Integrated Norway Expedition '94.

p and meets some extraordinary adventurers

CONFERENCE REPORT

SENIOR services manager Teresa Cole represented ASBAH at the Eighth International Conference on Spina Bifida and Hydrocephalus, in Sydney, Australia. In this report, Teresa concentrates on one of the conference highlights.

THE LIVES of healthy children and adults do not have more value than those of people with disabilities.

And although it may be an honorable aim for able-bodied people to bring the likelihood of congenital disabilities to almost zero, medical research cannot get rid of disability which already exists.

This was the thrust of a speech by Stefan Krusche, a 28-year-old German with spina bifida – a presentation considered by many as the hit of the conference.

He said: "I personally don't look on it as a high aim to produce only strong human beings – resistant against illness – who can work longer and more efficiently in industry.

"But, unfortunately, the genetic technological aims which are planned in Europe and other industrial areas are not far from this direction.

"For me, it should be a much more recognised aim to change positively the life conditions in the world so that not only the strong ones in the sense of Darwin can manage their lives, but also the weak ones."

Nevertheless, he saw prevention of disability as important. "It is important that pregnant women receive early reliable information about the conditions of their unborn children, specially if there are risk factors for a disability in the family."

But he doubted whether human genetic counselling was really fair. "If there are probabilities that a disabled baby could be born, it is not sufficient to tell only the possible form of disability.

"I think it could be helpful to bring the pregnant woman in contact with parents of handicapped children, if she is ready for that.

"A more informed decision for or against abortion can perhaps be taken if the pregnant woman has an opportunity to see what life with a handicapped child is really like."

Adventure spirit, from centre pages – a medical view

WHAT are the special medical issues which need to be borne in mind when integrating people with disabilities on an expedition?

Richard Miles, consultant paediatrician at Hinchingbrooke and Addenbrookes Hospitals in Cambridgeshire, has a special interest in neurological disabilities including hydrocephalus, and has accompanied expeditions to the Alps, Kilimanjaro and Pokalde.

For climbing expeditions, special considerations may be needed for people with learning difficulties, epilepsy and hydrocephalus.

Some of the possible problems, such as infection, altitude, temperature and accidents, are common to both able-bodied and disabled expedition members.

Many infections can be immunised against and, to help prevent malaria, those with learning difficulties can be reminded to take tablets each day.

Gastro-enteritis can be a big problem in foreign places and is more difficult for those with continence problems, hygiene problems and those needing to take special care with their fluid balance.

Exposure to the elements – altitude, heat and cold – may be less easy to diagnose and evacuation more difficult than for able-bodied people.

Dr Miles said: "It is important for expedition leaders to know in advance how they are going to recognise that a team member has moderate mountain sickness. You get less mountain sickness if you go up slowly and have rest days."

People with learning difficulties are perhaps more likely to have accidents on expeditions due to lack of concentration but again advance planning will help prevent problems of evacuation.

Specific medical issues to be considered in the expedition planning stages include:

- Epilepsy – get the medication right.
- Cerebral palsy
- Neuromuscular diseases
- Severe learning difficulties
- Visual and hearing implications
- Hydrocephalus
- Heart disease
- Lung disease
- Bowel diseases
- Diabetes.

Dr Miles said: "I knew a woman aged 55 who climbed to 19,000 feet and who had had severe learning difficulties and epilepsy all her life. The day after the climb she had uncontrolled fitting and had to be evacuated 5,000 feet. But she had no regrets about having the experience. We shouldn't wrap people with epilepsy in cotton wool."

Finally, Dr Miles gave the following checklist of medical questions to be asked when organising an expedition:

- How many people?
- For how long?
- Where?
- Types of disability?
- Specific drugs required?
- Export licence needed? (For some drugs).

Hydrocephalus Network
News

ASSOCIATION FOR SPINA BIFIDA AND HYDROCEPHALUS

CHRISTMAS 1995

ASBAH, 42 Park Road, Peterborough PE1 2UQ
Tel: 01733 555988 Fax: 01733 555985
Reg Charity Number 249338
Network Co-ordinator: Rosemary Batchelor

● ***Dr Bayston's series of three 'back to basics' articles for HN News has been put together as a special report and is available from: Rosemary Batchelor, Disabled Living Advisers Co-ordinator, ASBAH House, 42 Park Road, Peterborough, PE1 2UQ. Please enclose an A4 sized envelope and a 29p stamp.***

The treatment of hydrocephalus

By Dr Roger Bayston
MMedSci MRCPath
ASBAH's Honorary Consultant in Hydrocephalus

IN THE first article of this series I explained that hydrocephalus, irrespective of its cause, was due to accumulation of cerebrospinal fluid (CSF) within the ventricles of the brain, resulting in raised pressure inside the head. In principle the solution is simple, that is to insert a tube into the swollen ventricles and drain off the excess fluid, thereby returning the pressure inside the head to normal again. Historically, many attempts to do this have been recorded but the results were usually disappointing, due to rejection of the tubing by the body's defences, to infection, or to blockage of the tubing. However, this began to change in the 1950's.

Charles 'Casey' Holter, the son of an American engineer, was found to have hydrocephalus. The surgeon explained that there was no satisfactory treatment. John Holter, the child's father, questioned the surgeon and gained an idea of the sort of treatment required, if only it existed. He experimented at home and soon developed such a device, made from silicone rubber which had

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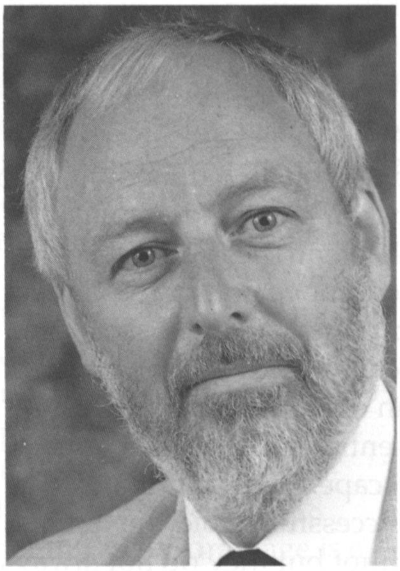
Emergency advice

AT ONE of our recent consultation meetings with local associations, and following a discussion about ASBAH's Hydrocephalus Alert Card, members drew our attention to a problem about ambulance procedure when there is a crisis over a shunt malfunctioning.

Ambulance crews have been insisting that, unless they have been called out by a doctor who has instructed them otherwise, they must go to the nearest casualty department rather than a neurology unit, even when told of the urgency of specialist treatment for possible shunt infections or blockage.

It would seem worthwhile for members to ask their GPs to agree to an arrangement whereby the **GP calls the ambulance**. He or she could then authorise referral to an appropriate hospital, where the proper tests and treatment can be started without delay.



Dr Roger Bayston

Treatment of hydrocephalus, from page i

never been implanted into people before. The surgeon decided to try this, with great success. The Holter valve soon became the treatment of choice for hydrocephalus, and it also revolutionised the treatment of spina bifida, removing the principal cause of death and encouraging orthopaedic and urological surgeons to develop procedures to improve mobility and continence. Other similar devices were developed soon afterwards, all made from the same material and having similar valve mechanisms.

In the 1960's investigations were proceeding into how CSF was produced, and drugs were tried experimentally to reduce the rate of CSF production. Some of these showed initially promising results, but they had unpleasant side effects and their use was abandoned. However, new investigations are now being undertaken on drugs which might reduce CSF production in the hope of avoiding a shunt, but even if this approach is successful it could be many years before it is used.

A relatively new approach, based on an old method, is to pass a tube (endoscope) into the ventricles and to use this to remove part of the CSF-producing mechanism (choroid plexus), or to make an opening in the wall of the ventricle to allow CSF to escape. Such techniques, if successful, avoid the use of a shunt but they do not always work, and some patients will have a type of hydrocephalus for which the treatment is not suitable.

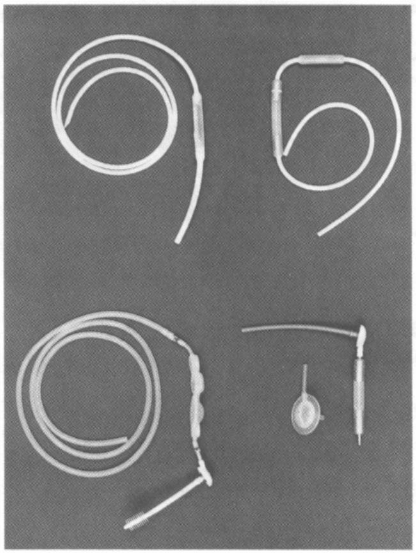


Figure 1: *Different types of shunt in use. Due to revisions of part of the shunt, sometimes in several different hospitals, parts of different shunt systems can be found in the same patient. Included here are the Hakim, Denver, Holter, Accuflow and Multipurpose shunts, and Rickham reservoirs.*

Today there are numerous types of shunt (***Figure 1***) but while they all look different they work in a very similar way. None can be said to be significantly better or worse than another, and the shunt is usually chosen by the surgeon on the grounds of experience, cost and personal preference.

Originally shunts were inserted so that a tube drained CSF from the ventricles in the brain, through the valve and through another tube into a vein in the neck and then into the heart (ventriculo-atrial or VA shunt, ***Figure 2a***). While these are still used, most nowadays drain the CSF into the abdomen (ventriculo-peritoneal or VP shunt, ***Figure 2b***) and the bottom tube can be felt over the ribs.

Despite all these developments, shunting can have complications. These can be divided into under-drainage, over-drainage and infection. Under-drainage, in which the fluid is not removed quickly enough and the symptoms of hydrocephalus return, is one of the commonest problems. It is usually due to blockage of the upper or lower tubes of the shunt tissue, though it can be due to the shunt breaking or its parts becoming disconnected from each other. It is rarely due to the valve itself, which usually continues to function in the same way for years. Pressure may sometimes build up rapidly, resulting in loss of consciousness, and treatment is required as an emergency. However, in most cases the onset is more gradual, and can follow a minor illness such as a cold. Headaches

continued on page iii

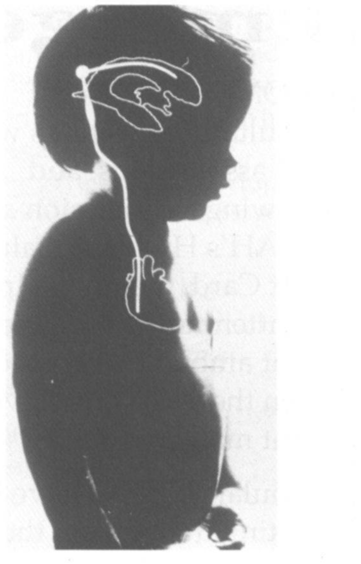


Figure 2a: *Route of a ventriculo-atrial (VA) shunt, from the ventricles in the brain to the atrium in the heart.*

Treatment of hydrocephalus, from page ii

increase in frequency and severity, often worse on waking in the morning. Vomiting and dizziness also occur, and sometimes other symptoms which vary from patient to patient. In these cases the parents or carers will be able to recognise the symptoms from previous episodes. Specialist hospital staff are now fully aware of the various presentations of 'blocked shunt' but non-specialists and family doctors may not be.

Shunt blockage can also have much more subtle consequences and the headaches may be infrequent, the main problem being behavioural deterioration. In older children this might take the form of increased irritability, 'laziness', poor or disruptive school performance or even more antisocial activity. This may be very difficult to distinguish from the usual teenage angst but, if there is any reason to suspect that the deterioration in behaviour is not 'normal', assessment must be carried out by an experienced educational psychologist with a knowledge of hydrocephalus. The basis for the effects of high CSF pressure have been explained in the previous article. If the shunt is to blame, a dramatic improvement can result from appropriate treatment, though this form of shunt problem is particularly difficult to diagnose. It may be necessary to monitor CSF pressure, often over 24 hours. This can be done using a pressure monitor in the scalp connected to a recorder. In this way pressure can be recorded during sleep and changes in posture. Scans to show the size of the ventricles are particularly useful if they can be compared to previous scans, though in someone with clear symptoms of either high or low CSF pressure they may also serve to support the diagnosis.

In the case of over-drainage, the shunt allows CSF to drain from the ventricles more quickly than it is produced. If this happens suddenly, usually soon after the shunt is inserted, then the ventricles in the brain collapse, tearing delicate blood vessels on the outside of the brain and causing a haemorrhage ('subdural haematoma'). This can be trivial or it can cause symptoms similar to those of a stroke. The blood may have to be removed, and in some cases if this is not done it may be a cause of epilepsy later. If the over-drainage is more gradual, the ventricles collapse gradually to become slit-like ('slit ventricles'). This often interferes with shunt function causing the opposite problem, high CSF pressure, to reappear, but unfortunately the slit ventricles do not always increase in size again, producing the situation where there is very high CSF pressure with headache, vomiting etc but very small ventricles on scan.

The symptoms of over-drainage can be very similar to those of under-drainage though there are important differences. Headaches, dizziness and fainting occur and are often worse **after** getting up from lying down, whereas the headaches caused by high CSF pressure are often worse on waking, **before** rising in the morning. However the best way to diagnose the problem, having recognised that one exists, is to measure the CSF pressure over 24 hours.

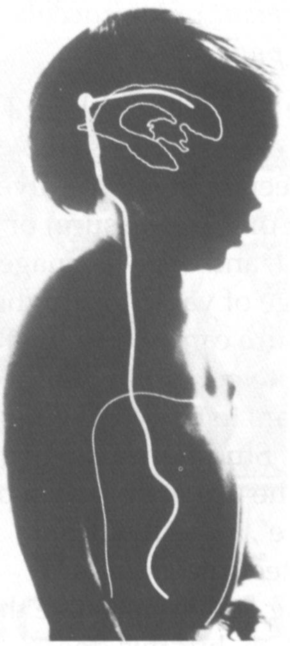


Figure 2b: *Route of a ventriculo-peritoneal (VP) shunt, from the ventricles in the brain to the peritoneal cavity in the abdomen.*

Under-drainage can be caused by blockage of the shunt tubing either at the top end, by tissue plugging the entry holes or by the position of the tube changing; or at the bottom end, by tissue in the abdomen sealing off the drainage tube. In VA shunts blockage can occur at the bottom end as the child grows, and a revision operation is sometimes necessary to lengthen the shunt at the age of 12-18 months. Over-drainage is a

continued on page iv

Treatment of hydrocephalus, from page iii

more difficult problem. There is no clear relationship between the type of valve (high or low pressure) or the brand, and over-drainage. A change of valve to a higher pressure cannot be relied upon to cure it, though it appears to do so in some cases. Studies have shown that the use of an 'antisyphon device', a small button inserted into the shunt tubing, will often solve the problem, but this does not always work. Some shunts have these built-in, but neurosurgical opinion varies as to whether they should be used. To change a valve pressure it is necessary to remove the valve and insert another. A relatively new shunt, the 'programmable' or adjustable shunt, is intended to allow adjustment of the working pressure of the valve without operation. The valve contains magnets which allow the setting to be changed by laying a second magnetic device on the scalp. This is undoubtedly useful where the need for a valve of a different pressure arises, but the adjustable valve is no less prone to over-drainage than any other and it cannot be used to treat this condition.

It has long been believed that a raised protein level in the CSF will block the shunt, and in babies with hydrocephalus shunting has been delayed until the protein level has fallen. Recent research has shown that a raised CSF protein level has no ill-effect on shunt function, nor does it increase the risk of infection, and there is now no reason to delay unless blood is also present.

The third complication of CSF shunting is infection. This is almost always due to bacteria from the skin getting into the CSF or shunt at operation, and is remarkably difficult to prevent. Antibiotics have not been shown to be of benefit for this purpose, and other measures often have only a temporary effect, though obviously the care and expertise of the surgical team is one of the most important factors in reducing the rate of infection to a minimum. However, even in the best of hands, infection still occurs. One of our recent developments has been a process which makes shunts resistant to bacterial infection, and we hope that the current clinical trials will show that it is capable of reducing shunt infection by more than 80%.

In VP shunts infection will usually show itself within a few weeks or months of operation as a shunt blockage, though there may also be occasional fever and abdominal pain. Redness and swelling may be seen over the lower shunt tubing. It is important to distinguish between blockage of the VP shunt due to infection and that from other causes as the treatment is different. In VA shunts blockage due to infection is rare, and many months or years can go by before the infection becomes apparent. During this time there will be tiredness, irritability, poor appetite, various aches and pains, skin rashes and other signs but all of these can be due to common disorders. A blood test will usually reveal anaemia and this is an important though, on its own, not a specific indication of infection. Blood cultures and even CSF cultures can be negative. Later, blood may appear in the urine due to secondary kidney damage.

While shunt infections can sometimes be very easy to diagnose, they are often difficult and any delay increases the chance of further damage. Special blood tests have been developed which promise to allow a reliable diagnosis to be made early, but these are not in current use due to lack of funding.

VA and VP shunt infections are both treated in the same way. Until recently, this involved operations, long periods in hospital and disappointing relapses before a new 'clean' shunt could eventually be inserted. We have recently developed a new approach which shortens the time taken to treat most shunt infections to 7-10 days, with a very low relapse rate, and this is gradually being adopted by others. Unfortunately the infected shunt still has to be removed, though in future it may be possible to treat these infections successfully without taking out the shunt, and research into this aspect is continuing.

Though complications of shunting remain an important problem in the treatment of hydrocephalus, I hope I have managed to explain some of their mysteries, and to show that solutions are being found.

Veteran wins award

By John Glover

NANCY Maddocks, who has spent a third of her life as secretary of St Helen's & District ASBAH, has won an award for her voluntary work – just months before she plans to retire.

Nancy (*pictured*) is the North West Regional winner in the Older Volunteer Youth Worker category of the Whitbread Volunteer Action Awards.

Nancy's late husband, Norman, was deputy head teacher at the local special school for physically handicapped children. He was invited to attend the inaugural meeting of St Helen's ASBAH on 3 February 1971 and Nancy, a State Registered Nurse, went along with him.

She agreed to become secretary of the newly formed association – a job she has devoted much of her time to over the 25 years.

This role led to her involvement with a number of other local bodies connected with the NHS, local government and other voluntary organisations on behalf of those with spina bifida and also other, mostly physical, disabilities.

I nominated Nancy for the award because I felt that her considerable efforts under two treasurers and several chairmen were largely responsible for the continuing strength of the association.

The work she does represents some two to three days per week of full-time work and her dining room usually looks more like an office!

During this time, she has also coped with the loss of her husband Norman in 1980, the same year that she was diagnosed with cancer of the larynx, her recovery during a long spell of treatment, and the tragic loss of a much-loved grandson in a road accident.

Nancy had intended to retire from her "part-time voluntary" job at the association's AGM in May but was persuaded to carry on until its 25th anniversary in February.

LOCAL ROUND-UP

Please send your news items to: Liz Cawthorne, Link Editor, ASBAH House, 42 Park Road, Peterborough, PE1 2UQ

By the time you read this, Nancy will have travelled to London where she will be entertained to dinner at the West End's Tara Hotel.

This was to be followed next day by a visit to the Whitbread head office for lunch in the presence of Princess Michael of Kent for the award presentation. At the same time, the winner of the Whitbread Volunteer of the Year – selected from the regional finalists present – was announced.

Congratulations Nancy and we wish you the best of fortunes.

John Glover is chairman of St Helens & District ASBAH.

Love is in the air!

ROMANCE is in the air at South Thames ASBAH with three weddings in two months.

Active committee members and wheelchair basketball players, Chris Brazil, aged 36, and Nicola Cardy, 24, who both have spina bifida and hydrocephalus, tied the knot at the end of August.

Wedding bells chimed at around the same time for South Thames chairman, Charles Harper, who also has spina bifida and hydrocephalus. Charles, aged 43, met his future wife Karen after moving house to St Mary's Bay, Romney Marsh, Kent.

Yet another committee member, and community worker, Gillian Trew, married Rev Stephen Taylor, minister of the United Reformed Church in Bromley where South Thames holds its meetings.

South Thames ASBAH secretary, Margaret Holmes, said: "Romance must be in the air at South Thames ASBAH! It's unusual to have three weddings so close to each other. We wish all three couples every happiness."

LOCAL ROUND-UP

SASBAH staff changes

A NEW education adviser has been appointed at Sussex ASBAH.

Jeanette Robertson, a teacher for many years with considerable expertise in the field of special educational needs, replaces Mary Rudling.

Another staff member, Polly Turner, training officer for 5 Grand Avenue housing project since it opened nearly 10 years ago, left SASBAH in November. Polly will be missed by all who knew her.

Derbyshire ASBAH secretary Anthea Hewitt (left), and chairman, Joyce Sellors give out folic acid leaflets on their stand in Boots

Folic acid awareness

DURING Spina Bifida Week '95, Derbyshire ASBAH set up a stand at Boots The Chemist in Derby to talk about and give out leaflets on folic acid.

By talking to women in the store, some interesting information was gathered. Women who were already pregnant tended to know 'everything' about folic acid. Those mums with children over three or four had heard about it but their knowledge was vague. And those with children aged five plus had no knowledge at all of folic acid.

This led the local association to believe that doctors are certainly advising patients who are already pregnant and in future, hopefully, before they get pregnant.

Anthea Hewitt, secretary of Derbyshire ASBAH, said: "I would therefore like to see posters on folic acid during the Government's soon-to-be-launched campaign. These posters could be displayed in all surgeries which patients can read whilst waiting to see the doctor as they now do with the posters on subjects like cancer and the 'no smoking' campaign.

"I would also like the subject to be fully discussed in schools during Personal and Social Education Classes (PSE) so that the mums and dads of the future are well informed."

Go-ahead youngsters learn to drive

By Sue Davies
Herts & Beds fieldworker

FOUR younger members of Bedford & District ASBAH were funded to go on a four-day driving course at Banstead Mobility Centre in Surrey.

Accommodation was provided on site in the 'Rainbow Centre' – a seven-bedroom wheelchair-accessible bungalow.

All those taking part had previously attended Banstead for a driving assessment. Now was the chance for some intensive practice and to increase confidence in the otherwise often protracted process of learning to drive.

Over the four days, each participant received 12 hours of driving lessons and four hours of road safety and knowledge of the highway code.

The evenings were filled up too with different activities each night, including a trip into London/ Victoria on the train to see a show.

Maureen and Ron Simmonds (chairperson and treasurer) clinched the success of the week by extensive forward-planning. They ensured smooth access in/out of train stations, on/off trains, in/out of restaurants, in/out of theatre/ cinema, etc – all the important details that, had they been left to chance, would have very quickly undermined these young people's positive and focused energies on the theme of the week – to get them on the road, confident, mobile and independent.

Those taking part were: Stella Alabi (18), Sharon Owens (18), Colin Brookbanks (18) and Michelle Bailey (18).

Maureen and Ron Simmonds write: 'Thanks to Sue for all her hard work and support during the course. It was a great team effort! Thanks to Colin, Sharon, Michelle and Stella for good company and lots of laughs! I think of all the things we have been involved with during the last 12 years with ASBAH, this will certainly be one of the most memorable.'

Darke at the cinema *by Paul Darke*

WHERE would someone start if one wanted to get involved in making a film?

There are the obvious places – art schools, film school, even a university or college. You may be able to make a film with friends at the local adult education centre.

Above all, you must have an idea, along with a desire that is unrivalled, and a rhinoceros hind in order to take all the rejections.

As we can see from the majority of dross that hits our television and cinema screens, talent seems to have little bearing on the situation.

Alternatively, one could apply to the Arts Council of England for funding under the Disability Arts Video Project. This project has been specially set up to promote film and video making amongst people in the disabled community. It isn't for professionals specifically, it is to promote new film makers and new films.

The idea is what is important, though it has to be about the disabled experience and done artistically and with great originality.

There are two types of bursaries available – a research and development award, and a full award. The R&D award is of a maximum of £2,000 and is designed to enable a film/video maker to develop their idea and investigate more thoroughly the requirements needed to make the project become a reality. The full award is from between £10,000 and £15,000 and the entire budget must not exceed that amount even if you have funding from elsewhere also.

The video/film itself must be no longer than 20 minutes in length. The closing date for the R&D bursary applications is May 1996, and the closing date for the full award is in July 1996.

You can get an application form from your regional arts board, or you can contact ***Will Bell*** at the ***Arts Council of England headquarters at 14 Great Peter Street, London, SW1P 3NQ, or telephone him on 0171-973 6455, quoting Disability Arts Video Project.*** Look out for the scheme's advertisements in the disability press.

As a member of the selection panel, I wish to impress upon people that the scheme is designed to create and encourage new film-makers who have a desire to produce a work of originality and perception.

All the help that can be given will be, and your regional arts board film officer should be your first port of call.

Don't be put off by jargon and seemingly insurmountable problems. The scheme has been set up to enable you to make the film that could change a world. But a cautionary note: many people apply and limited resources dictate that only a few succeed. It could be your turn!

I went to Germany in December to be a judge in a festival of short films about and by disabled people called 'The Way We Live.' Hopefully I'll see one of your films in it next year. In my next column or two I'll tell you all about it.

Planning ahead for the future care of someone with special needs

Paul Muldoon of Peterborough solicitors Bryan Barnes & Co suggests you take particular care when drawing up your Will.

OFTEN we are asked the question how to provide for beneficiaries with learning disabilities or with some condition which may restrict their capability to live independently.

In circumstances such as this what we must never do is to leave our assets to other members of the family in the hope that they will provide for the family member with special needs.

The first objection to this course is that they have no legal responsibility to provide for that family member. Furthermore, there is the possibility of the family member receiving the funds dying or divorcing or becoming bankrupt during the lifetime of the family member with special needs.

There could in any of these circumstances be alienation of funds from the one who needs them most.

Also, if the person with special needs is, for example, housed by a local authority and no provision is made for that person under the Will of, for example, a parent, the local authority could seek to apply to the Courts for provision for the person in their care under the Inheritance (Provision for Family and Dependents) Act 1975.

So how do we proceed? What we should not do is to leave any assets direct to the person with learning disabilities or other special needs because this could affect entitlement to state benefits, local authority top-up, etc.

There are various types of trust which can be used to provide for the family member with special needs but obviously the type of trust will depend upon that individual's circumstances and requirements. The way forward therefore must always be to seek professional advice from a specialist in this field. This is a minefield so we must not leave anything to chance!

Lifting tips for carers to avoid back trouble

Link reader offer

A WELL regarded manual, which helps train nurses to lift and move patients without risking their backs, is being offered to *Link* readers at a special discount price.

Producers of the guide, the National Back Pain Association (NBPA), says there is no reason why the manual should not be available to help families of people needing similar care at home.

The NBPA says that home carers usually receive little or nothing in terms of formal training in correct handling practices, and are at even greater risk of back strains and injuries than nurses.

A NBPA spokeswoman said: "We hear from a great many people who injure their backs as a result of caring for someone at home."

The guide has 120 pages of good illustrations and clear text – written by the professional education committee of the NBPA and the Royal College of Nursing – showing lifting and handling techniques with high dependency patients in a variety of settings.

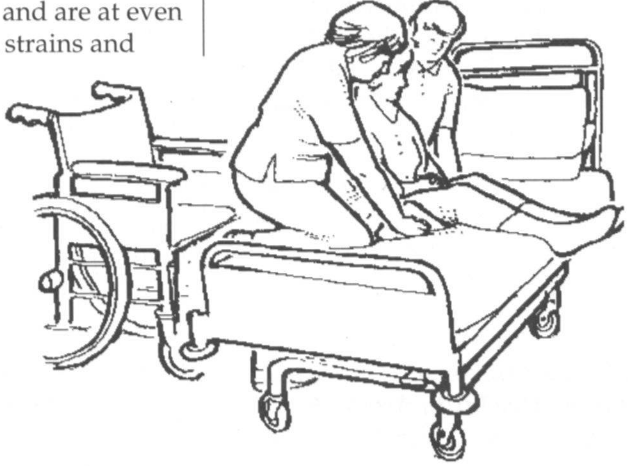
Most of the references assume the 'patient' is able to provide a minimum of co-operation, and the main emphasis is on avoiding back injury, while providing good quality care.

The NBPA works for people with back problems. It funds medical research; supports a network of self-help branches around the country; operates a helpline for sufferers and their families, and produces literature to help people avoid back injury.

The charity also has a free helpline for those currently suffering from back problems on 0181-977 5474.

If you would like a copy of *The Guide to the Handling of Patients* – at a special price of £13 per copy – write to: *The National Back Pain Association, 16 Elmtree Road, Teddington, Middlesex, TW11 8ST.*

To claim the discounted price, you should quote with your order *SB/LINK – 1.*



Using a through-arm hold and handling sling to transfer a patient who cannot stand, into a wheelchair.

Illustration courtesy of the National Back Pain Association

Girls and boys go out to play

PLAY TIME for children with disabilities is the subject of two new booklets.

- *An Equal Opportunity to Play* is designed to help play providers address issues of equality for children with disabilities and special needs. Areas covered include management, networks, recruitment, training, access, publicity, activities, resources/equipment, communications and facilitating integration.
- *Checklist for Accessible Play* has been updated and aims to help play providers make their play environment accessible to all children.

The booklets cost £3.50 each (including p&p) and have been produced by HAPA, a charity working to develop better play opportunities for children with disabilities and special needs.

Both booklets are available from: HAPA Ltd, Fulham Palace, Bishop's Avenue, London, SW6 6EA. Tel: 0171-731 1435 (voice/ Minicom).

Winning access to the countryside

REGIONAL winners of the 1995 BT Countryside for All Awards have been selected for their innovation and high standards of provision and consultation in opening up the countryside for disabled people. They are:

- London – Woodlands Craft Centre, Sutton.
- Southern Home Counties – Seven Sisters Country Park, East Sussex.
- South West – 'Wheelchair Walks in Devon,' Obelisk Publications.
- Midlands – Coombe Abbey Country Park, Coventry.
- Northern Home Counties – Newsletter by Eastern Region, Countryside Commission.
- North East – Bolton Abbey Estate, Yorkshire.
- North West – Grizedale Forest Park, Cumbria.
- Scotland – Lochore Meadows Country Park, Fife.
- Wales – Countryside Garden at Maelor Hospital, Wrexham.
- Northern Ireland – Countryside Garden at Belfast Royal Hospital.

The LINK diary

This and That!

WEDDINGS and babies are in the air. You've only got to flip through recent issues of *Link* to realise that these happy events have become a central activity in many of our families.

Thanks to the insistent prompting earlier this year of Mukti Jain Campion, editor of specialist magazine *Disability, Pregnancy and Parenting International, Link* this year finally caught up with the fact that most mothers with disabilities have special needs which need careful thought and planning if difficulties are to be avoided.

Kirsten Battle, our bride pictured on the cover with husband Mark, has been doing just that as she prepares for the arrival of her first child next June.

Well ahead, Kirsten is buying a pram and a cot which both need special adjustments so that she can use them both from the comfort of her wheelchair. And she promises to provide 'road test' reports on the models she is buying when she has put them through their paces.

The handle on the pram is being lowered and extended to fit on her wheelchair so Kirsten – with hands still free – can push her baby safely. And, instead of having drop sides, the cot will have a gate built into the side so mum will find it easier to put baby to bed.

"I'm told that these are fairly standard modifications nowadays for mums with spina bifida. You just let the specialist companies know who you are and they are offered," said Kirsten. "Like any mum, of course, I want the best for my baby and, of course, I'll let you know how we get on!"

AS PRETTY as a picture and, after being featured in our latest round of leaflets and posters, perhaps we should tell readers a little bit more about her!

The young lady is Victoria Mason (above right), who also graced two front covers this year – those of ASBAH'S Annual Report and Review *and the last issue of* Link.

Victoria, aged five and a half, lives with her family in Swineshead, near Boston, Lincolnshire, where she has joined her older sister and brother, Kimberley and Simon, at the local primary school.

"The school is very wheelchair-accessible and she is doing very well. What really worries me now is what happens when she has to move to the next school," said her mother Valerie.

No warning came of Victoria's spina bifida before she was born. After a scan, a perfectly-formed baby had been expected.

"We were in shock but we took it a day at a time. That was all we could do. We didn't know anything about spina bifida at all," said Valerie.

"What was worse was that all the professionals we spoke to were so negative. They made the future with Victoria sound so bleak. We weren't given anything to look forward to until Mary Castle, ASBAH's area fieldworker, turned up with a photo album full of lovely children in wheelchairs."

The family saw quite a lot of Mary Castle for the first three years. Lately they have been supported by people like education adviser Peter Walker on Victoria's statement.

"The ASBAH photographer took the pictures of Victoria on the first day of the school summer holidays. They were lovely – a real boost to her confidence".

STUDENTS on a BSc psychology course at Thames Valley University have been putting my Information Department colleagues Gill and Margaret through the hoop this term, with a flood of requests for information about spina bifida and hydrocephalus.

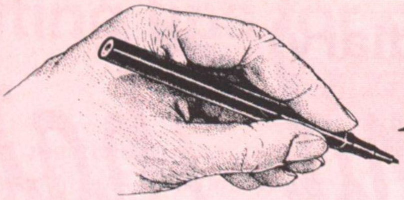
"We had 40 separate letters and phone calls for material to help with coursework. When we told one of the students that we were receiving a lot of inquiries, she said there were 200 students on the course. They each had to look at spina bifida and hydrocephalus from a different viewpoint – as professionals, patients, parents or other carers," said Margaret Black.

In an attempt to stem the flow while they sorted out some sensible information-sharing, Gill Winfield phoned the course tutor three times but did not manage to get through. So she decided to appeal directly to the students' better natures, asking them in a standard letter to share the information sent out with each other.

"When one of the students got through to me and I was told there were 200 on the same course, I thought 'Oh my God!'" said Gill.

"One or two are still getting through the switchboard when it's not clear where they're from. Just today, one said she had been trying to speak to a paediatrician. Surprisingly, no paediatrician had wanted to speak to her!"

TB



Letters

We invite letters for publication. Send them please to: *Editor, ASBAH, 42 Park Road, Peterborough PE1 2UQ.* The Editor reserves the right to edit letters for publication, so keep them as short as possible.

I AM researching and compiling a book about the experience of motherhood. I would like to hear from anyone who feels moved to poetry or prose, longer accounts or just anecdotes about their personal experiences.

I am interested in feelings and comments on the following topics: pregnancy, childbirth, motherhood, joy, frustration, post-natal depression, infertility, miscarriage, stillbirth, having a child with special needs, working mothers, and feelings about our own mothers.

It is my aim to create a book which reflects the most heart-felt experiences of real women, not just those of experts. It is also my intention to donate a percentage of any royalties I might gain on publication to mother and baby-related charities.

I would be very grateful for any help you could give in this matter.

Mrs Deborah Hayward MA
BA (Hons) PGCE
4 St Albans Downs
Nonnington, Dover
Kent CT15 4HN

TWO YEARS ago, I had a subarachnoid haemorrhage complicated, classically, by hydroceph-alus. Brilliant though they all were with my acute problem at Frenchay Hospital, they could offer very little support afterwards but they did suggest ASBAH as a contact. Thank God they did. Through ASBAH I met Shirley Hinde, the fieldworker for Somerset, and over the past 18 months she has been my help and support. My rock.

Shirley's kindness, generosity and knowledge have helped me get through trying times. If I've needed information, she's been there. If I've needed someone to talk to, she's been there. Maybe we expect too much from the medical profession (actually, I don't think we do). All I know is that without Shirley I would have felt bereft, isolated and forgotten.

She has been a friend as well as an expert to turn to. Due to my somewhat vague state these days, I'm dreadful at getting round to answering letters, answering messages on the answerphone. I must come across as quite ungrateful. I'm not; I'm just very exhausted and confused a lot of the time. And Shirley seems to understand, so I don't have to add guilt to my problems!

Shirley has been fantastic. So I thought I'd let you know what a wonderful job she's doing and say thank you for ASBAH, and thank you for Shirley.

Jane Franklin
Ashbrittle, Somerset

DATES FOR YOUR DIARY

January 1966

ASBAH Northern Regional Day, Get Moving, looking at mobility issues for 13 - 16 year olds, and their parents. *Joan or Rose, ASBAH (Northern Region), Five Oaks, Ben Rhydding Drive, Ilkley, W Yorks LS29 8BD, tel: 01943-609468.*

Monday, 15 January

One-day training course: The New Law: The Disability Discrimination Act 1995. Sandwell Education Development Centre, West Midlands. Cost: voluntary organisations £30. ***Details: Robert Mottram, Disability West Midlands, Moseley Hall Hospital, Alcester Road, Moseley, Birmingham, B13 8JL.***

March

START understanding behaviour course, three-day midweek course to help families where a child with spina bifida and/or hydrocephalus is displaying behavioural problems. Venue to be arranged. *Joan or Rose, ASBAH (North), Five Oaks, Ben Rhydding Drive, Ilkley, West Yorks, tel: 01943-609468.*

Saturday, 2 March

ASBAH Council meeting, Peterborough.

21- 23 May

Midlands Naidex, National Exhibition Centre, Birmingham.

24- 26 May

Scottish Mobility Roadshow, The Royal Highland Centre, Ingliston, Edinburgh, 10am-5pm daily. *Free entry. Leaflet from Disability Scotland, tel: 0131-229 8632.*

31 May - 1 June

Northern Ireland Mobility Roadshow, King's Hall, Belfast. *Disability Action, tel: 01232-491011.*

Saturday 22 June

Grand reunion for ex-pupils of Exhall Grange School in Coventry. *Details: David Moss 01476-70373; Chris Wood 0181-372 6256 or Linda Chaplin (née Jones) 01449-722685.*

30 August - 1 September

Northern Mobility Roadshow, *Leaflet from Sheffield City Trust (Eve Croft), tel: 0114-243 5355.*

ASBAH PUBLICATIONS

The Learner Driver with Spina Bifida and Hydrocephalus – Notes for Driving Instructors by Barbara Simms BSc, MSc and Warren Nichols DipDI, DTpADI. 28-page booklet, revised May 1995. Price: £1.75.

This booklet provides basic information for driving instructors and others concerned with offering advice on driving to those with spina bifida and hydrocephalus.

To place your order or inquire about this booklet, please contact: Information Department, ASBAH, 42 Park Road, Peterborough, PE1 2UQ. Tel: 01733-555988. Fax: 01733-555985.

A NEW full-colour poster, publicising national ASBAH and what we do, is available by contacting ***Gill Winfield, Information Department (see above for details).***

HOLIDAY ACCOMMODATION

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

mar y sol

Mar Y Sol – Tenerife
Wheelchair accessible apartments. Heated pool with hoist. Restaurant, poolside bar. Equipment hire. Ring today for cheapest summer and winter prices.

Algarve – Portugal
Wheelchair-friendly luxury villas with swimming pools or friendly hotels with adapted rooms.

Sue Abbott, 123 Coppermill Road, Wraysbury, Staines, Middx TW19 5NX. Tel: 01753-685718.

STAFFFORDSHIRE, ALTON

Wheelchair-accessible holiday accommodation in country cottage, B-B or H-B. *Details: Jean Ditchfield, tel: 01538-702189.*

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).

SOLVING mobility problems wherever you live and whatever your journey is the aim of Tripscope. It can help with planning and organising journeys.

All you have to do is make one telephone call in office hours. Inquiries can also be made by letter or on tape.

Tripscope's information service is free to disabled and elderly people and those who care for them – but donations are always welcome.

London – for UK (except SW) and International – 0181-994 9294.

Bristol – for the South West and South Wales – 0117-941 4094.

MEMBERSHIP

INDIVIDUAL ASBAH membership – receive publications and voting rights at twice-yearly Council meetings. £17.50 a year (waived for those on benefit). ***Details: Company Secretary, ASBAH, 42 Park Road, Peterborough, PE1 2UQ.***

LINK Rates

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Cheques and postal orders should be made payable to 'ASBAH'.

Small adverts for the next issue of *LINK* (February) should be submitted by Thursday, 11 January. Please send them to the Editor.

Display Rates on application, from the Publicity Manager.

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