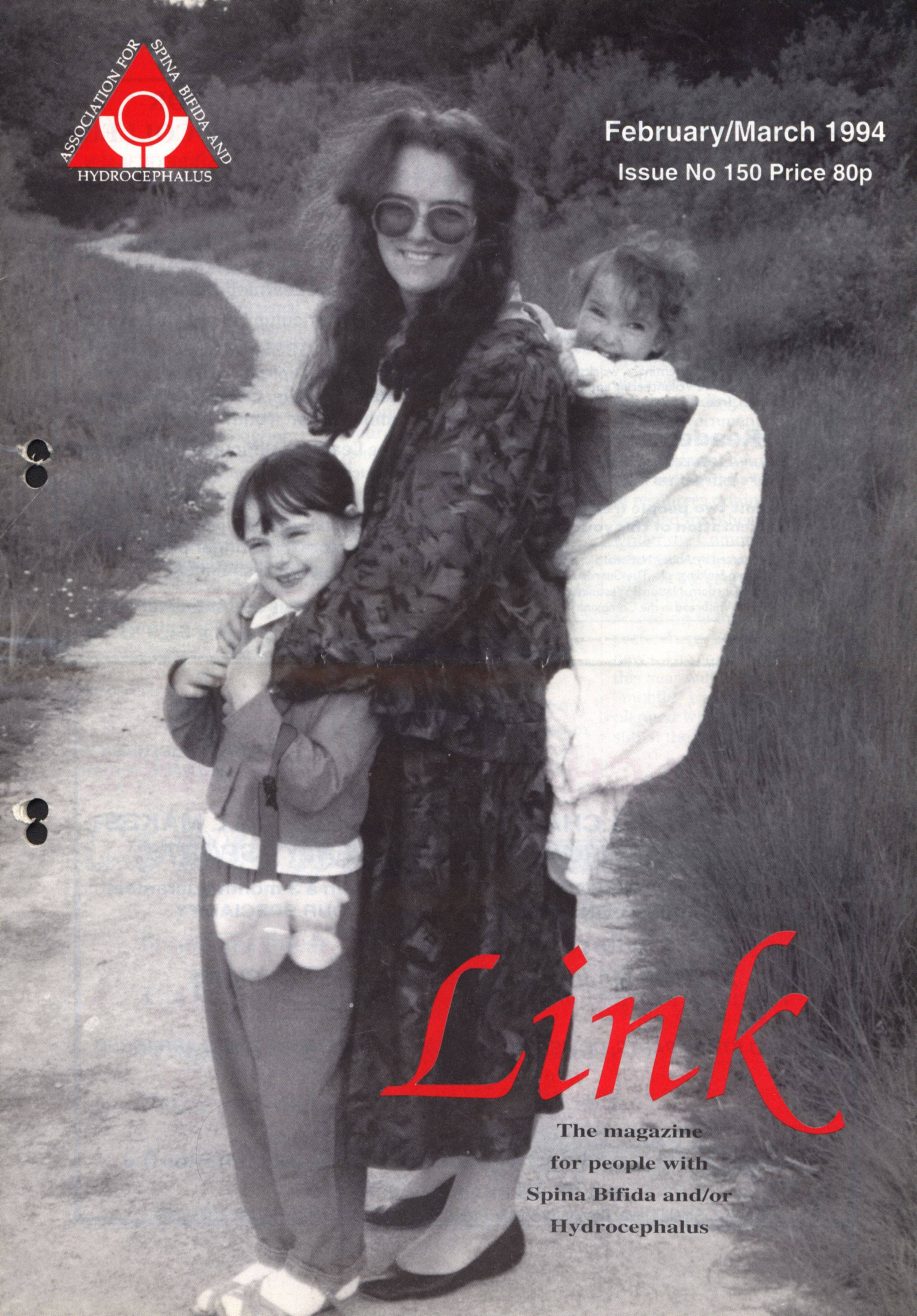

ASSOCIATION FOR SPINA BIFIDA AND HYDROCEPHALUS

February/March 1994
Issue No 150 Price 80p

Link

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for people with
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Comment

IF THIS issue of LINK reaches you slightly later than usual - and looks slightly thinner - I apologise. I know some editors like to give the impression they're superhuman, but this one isn't! I encountered a wandering virus and succumbed. I'm very grateful to my colleague Tony Britton for "plugging the gaps" at the last moment. A couple of features originally planned for this issue will appear in the next. So there is still time for readers to send in their personal holiday experiences: they would prove very helpful to other LINK subscribers.

A WORD about two of the features in *this* issue. We recently looked at the pain of bereaved parents when a child dies at, or soon after, birth. In the current edition of LINK we consider two different stories, both demanding tremendous emotional honesty and courage on the part of the parents concerned. In the one (pages 16 - 17) the heart-breaking decision was made to terminate the pregnancy when it was discovered via a pre-natal test that the baby had *severe* spina bifida. It was certainly not a decision lightly made. Please don't jump too hastily to harsh moral judgements; read their story first.

In Sophia's case (pages 10-11) her mother was encouraged to seek an improved quality of life for her through a plastic surgery technique. But not without an initial struggle with the medical hierarchy! Tissue expansion is now fairly routine and we'll have more information about what's involved in a future issue.

A HARD decision was also required when it came to the future of FIVE OAKS (pages 4 - 5). Its function is unrivalled in the country and the quality of its services unquestioned. But the funding demands of recent government changes have meant that ASBAH has had increasingly to subsidise local authorities - basically out of resources originally destined for other purposes. Under the Community Care scheme, funds are supposed to "follow the client", but that doesn't always happen according to the client's preferences. But it isn't all bad news. The courses planned this year will go ahead and a "mobile" training unit is planned with Joan Pheasant still at the helm.

Jeanette Dixon

Contents

ASBAH is a registered charity

Cover: Sophia, her mother and elder sister enjoy a day out , backpacking (see page 10)

August closing date for Five Oaks

Assessment service goes 'on the road'

FIVE OAKS - our 14-bed training, assessment and activity holidays centre at Ben Rhydding in West Yorkshire - is being forced to close.

The decision was announced with deep regret to staff and residents on 8 December. It was taken after months of waiting to see both if the economic climate would improve and whether referrals by social services departments would pick up in response to new brochures and marketing activity.

ASBAH has also looked into other ways of managing activities at Five Oaks to reduce costs and maintain the quality of service.

The centre will close by 6 August at the latest when a placement has been found for the last long-stay trainee. At present, there are five long-term trainees in residence.

In the meantime, a total of 23 staff will qualify for redundancy payments whenever they choose to leave.

Closure is being delayed both to safeguard training programmes and help staff find new jobs. Every resident is being helped on to the appropriate next stage of life.

Five Oaks staff published their programme of activity holidays for 1994 which will go ahead as planned. Details are published in the activity holidays section on pages 12 and 13 of this magazine, and will also appear in the next LIFT magazine. Copies of the full-colour programme can be obtained directly from Five Oaks, tel 0943-603013.

"The morale and commitment of staff here remains very high", said Five Oaks manager Joan Pheasant.

Despite the sad news, staff, residents and friends of Five Oaks enjoy their annual mince pies and sherry get-together just before Christmas. Photo: Telegraph & Argus, Bradford.

"And, while we've got the staff, we shall continue to run activities aimed at helping young people achieve their potential', she added. "As ever, the courses will be exciting to take part in and good value for money."

Executive director Andrew Russell commented: "The high quality of assessment and training at Five Oaks, its management and staff - many of whom have worked there for years - are not in question. The centre has done very good work over 17 years, giving greater independence to hundreds of people.

Mr Russell said that financial pressures on local authorities, following the introduction of the NHS and Community Care Act, had reduced the demand for Five Oaks' services.

"Since the responsibility for funding residential care and training was switched from central government to local social services departments, it has been clear that local authorities regard sending their clients 'out of county' as a rare luxury", he added.

"Even when local authorities have agreed to pay our fees, ASBAH has been meeting half the true cost from our general charitable income. A deeply worrying aspect of this is that high-quality assessment, such as is available at Five Oaks, could be priced out of the market."

Under the Community Care arrangements, the needs of people with disabilities must be assessed before social workers draw up their 'care packages'. Assessment is the key to the provision of both funds and future planning.

This year, ASBAH expects to subsidise the centre's work to the amount of £150,000.

Because detailed professional assessment is so important, ASBAH will launch a new initiative which will take the expertise built up at Five Oaks over the years 'on the road'.

A small Service Team for Assessment, Rehabilitation and Training (START) will be set up to promote this service nationally to social services and other authorities, with the aim of running assessment courses for clients around the country.

The START team will be located in due course with a new ASBAH Northern Region, both under the leadership of Joan Pheasant. Our aim is to set up both services in the next financial year.

The modern property 'Wharfedale', which stands in the grounds of Five Oaks, is owned by Sanctuary Housing. This is expected to continue to run in much the same way as at present, as it is home to the tenants living there.

Five Oaks and its grounds will be sold. The house was built in the 'thirties and bequeathed to ASBAH in the mid-'seventies.

Tony Britton

Karl Goddard, the Sheffield boy whose televised battle to walk in time for school touched the hearts of the nation.

THE wheelchair option was avoided when Karl Goddard's battle to walk in time to start school was featured in BBC TV's 'Children's Hospital' series just before Christmas. The agony in the faces of both Karl and his mother touched millions of viewers as school became the object of a gruelling obstacle course for four-year-old Karl, who has spina bifida.

One telling sequence: Karl, using his crutches to inch his way up the ramp as a schoolmate in a wheelchair cruised past at a rate of knots.

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Folic acid 'Watchdog'

ASBAH featured prominently in a BBC1 'Watchdog' programme on 24 January.

Veteran campaigner Anne Robinson presemted an itemabout folic acid - "the vitamin which no one knows about but which could prevent 2,000 babies a year being born disabled".

Putting ASBAH's case about the government's barely noticeable health education initiative was Rachel Stanworth, disabled living services manager. She asked, with an expressive shrug: "The government's campaign - where is it?".

They're on the move

RADAR's new address is 12 City Forum, 250 City Road, London EC1V 9AF, tel 071-250 3222. The Association for Continence Advice has moved to The Basement, 2 Doughty Street, London WC1N 2PH, tel 071-404 6821, fax 071-404 6876 (contact person, Dorita de Gerecz).

They walked up to the top of the tallest mountain in Africa - and came back with almost £18,000 for ASBAH.

Amanda Lowther (left) and her husband Hugh carried out a two-day snowy safari to the peak of Mount Kilimanjaro in Kenya as a sponsored climb, exclusively for us.

After their adventure, the Northamptonshire couple called in at our National Centre in Peterborough recently where they met staff - including Mrs Pat Waller (second left), the newly -appointed fieldworker their generosity helped to pay for.

Pat's work in Leicestershire and Northamptonshire was also made possible by a matching grant from the local Association.

"This was a wonderful effort, with an exciting result; Mr and Mrs Lowther were delighted to meet the new member of staff they helped put in place", said executive director Andrew Russell.

RADAR seeks views on tables in toilets

RADAR director Bert Massie wants to hear from readers who have views about the provision of changing tables in accessible toilets.

"We have had representations from people who would like to see tables installed as well as others who feel that this would not be a good idea. It is, as usual, one of those subjects where both sides of the argument have valid points to make", Mr Massie told *Link*..

He said provision of tables would make life easier and more hygienic for those whohave to change baby's nappy on the floor of the toilet - as well as alleviating posture problems for carers who may be elderly or disabled themselves.

On the other hand, able-bodied parents may also want to use the changing tables - leading to greater use of the toilet and more mess.

Equipment to keep the tables clean and free from infection would also need to be provided, and this would take up space.

"RADAR has previously had correspondence from disabled people who would like us to help in persuading providers of toilets to install these tables in accessible toilets", said Mr Massie.

"We have tended to pass these letters to local authorities asking them to assist; in some cases, we have been successful in helping to have these installed locally.

"However, there are some disabled people who have expressed the opinion that they would not like to see these tables installed. I feel that we should be looking at this subject fully with a view to formulating a uniform policy."

Letters to Bert Massie, RADAR, 12 City Forum, 250 City Road, London EC1V 9AF, tel 071-250 3222.

NATIONAL COUNCIL FOR VOLUNTARY ORGANISATIONS

SLAMS BUDGET DEAL

THE November Budget increased the tax burden on charities and voluntary organisations for the second time in a year. Measures still to filter through from last year's March budget, such as VAT on fuel and power and cuts in tax credits on dividends, will cost charities £100million a year, said the National Council for Voluntary Organisations (NCVO).

NCVO welcomed the £28 childcare allowance for families receiving Family Credit and the extra help provided through the Home Energy Efficiency Scheme. But reductions in benefits for long-term unemployed people and disabled people will increase hardship and place greater demands on voluntary organisations.

☛ **Childcare** - NCVO welcomed the new allowance as an incentive to single parents to seek work. But the payment would not cover the true costs of childcare and no additional payments are proposed for families with more than one child. Good quality, affordable childcare was in serious short supply, particularly in rural areas.

☛ **Incapacity Benefit** - The Chancellor announced a tightening up of entitlement to benefit through an Incapacity Benefit. This will replace Invalidity Benefit from 1 April this year - with an objective medical test, subject to tax, for new claimants.

More stringent rules will mean that disabled people eligible for support are likely to be completely excluded from access to activities such as volunteering. Those who become ineligible are likely to face greater pressure under the new Job Seekers Allowance.

☛ **Compensation for VAT on fuel and power** - Not applicable to disabled people, unless they are also pensioners. And then VAT at 8% will cost a single pensioner an extra 68 pence a week, with only 50 pence coming through in compensation. VAT at 17.5% will cost a single pensioner an extra £1.49 per week - they will get only £1 in compensation.

☛ **Access to work** - Announced prior to the Budget, the government intends to increase the costs to employers of employing disabled people. Employers will be discouraged from employing those disabled people who require additional support in the work place.

Coupled with more stringent rules for those in receipt of Incapacity Benefit, this will result in more disabled people being forced on to Income Support.

Help & Advice

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

London, Surrey, Kent, Sussex

123 East Barnet Road, New Barnet, Herts EN4 8RF. Tel: (081) 449 0475
Regional Co-ordinator: Gina Broughton.

Northern Ireland

73 New Row, Coleraine, Northern Ireland BT52 1EJ. Tel: (0265) 51522
Regional Co-ordinator: Meta Harvey.

Rest of England and Wales

National Centre, 42 Park Road, Peterborough PE1 2UQ. Tel: (0733) 555988

EVENTS

9 - 11 March

'Charityfair 94': Business Design Centre, Islington, London, 3rd trade and public fair for charities and the voluntary sector, organised by the Directory for Social Change. 9.30am-6pm, 9 March; 10am-6.30pm, 10 March; 10am-5pm, 11 March (see our free admission offer on page 2)

12 March

Essex Study Day: 'Continence Management in Spina Bifida and/or Hydrocephalus', Moulsham High School, Brian Close, Chelmsford. 10am-4pm. Organised by Essex ASBAH in conjunction with national ASBAH. ***Contact Barbara Dawes, 0245 287004.***

Saturday, 19 March

'The Cost of Incontinence': one-day multi-disciplinary conference organised by Derby and District ASBAH, Post Graduate Centre, City Hospital, Nottingham. 9am-4.30pm. Fee £15. ***Anthea Hewitt, 20 Burley Hill, Allestree, Derby DE22 2ET, tel 0332-841893.***

Saturday, 26 March

ASBAH Study Day 'Towards adulthood with spina bifida and/or hydrocephalus',

Harpenden Day Centre, Leyton Road, Harpenden, Herts, 10am-4.30pm. Fee: £5 per person at £10 per family/£15 for professionals.

26/27 March

Spina Bifida and Hydrocephalus residential weekend, organised by ASBAH South East Region, venue: Meldreth Manor School, Royston, Herts. ***For both events: Lynn Thomas, ASBAH House, 42 Park Road, Peterborough PE1 2UQ, tel 0733-555988. Closing date for applications: 1 March.***

Conference helps 'Your Voice' stay fresh, loud and lively

EIGHTEEN months after it was set up, our 'Your Voice in ASBAH' group is planning to hold a conference in Peterborough on Saturday 30 April to report back on progress and set the seal on future activity.

A major TV presenter, who occasionally fronts items on the BBC2 disability programme 'From the Edge', is being invited to brighten up proceedings.

YVIA chairman Jonathon Burke said: "Your Voice has covered a lot of ground so far - including getting representatives on ASBAH's top decision-making committees. But we need feedback both on where the group is going from here, and where members with disabilities are going as individuals.

"What do the members want from YVIA now? How can they contribute personally towards the sea-change in attitudes towards the involvement of young members with disabilities which has taken place within ASBAH these past few months? We want answers on 30 April."

Jonathon has written to every local Association, inviting them to nominate delegates to the conference (and pay for their travel), or make a contribution towards conference costs.

"Local Associations made YVIA work when they paid for their members to attend the inaugural meeting in May 1992. I hope they will be as generous again, so that the voice of young people with spina bifida and/or hydrocephalus can stay fresh and loud."

Hospital merger scheme fears - Midland ASBAH

PATIENTS needing vital corrective surgery for spinal deformity could lose out if West Midlands Regional Health Authority closes the Royal Orthopaedic Hospital, Birmingham.

Dozens of children and young adults with spina bifida from throughout the West Midlands depend on the Royal for treatment to severe spinal curvatures.

But - if the service moves to Birmingham's Selly Oak Hospital, as is planned in April - adults could lose their place in the queue for surgery.

Extra accident and emergency cases being put through Selly Oak could force many children with spina bifida to travel to orthopaedic hospitals miles away from home.

Eileen McCabe, chairman of Midland ASBAH, has already protested to Health Secretary Virginia Bottomley that children might find themselves being treated instead at Oswestry or in Oxford.

"Adults would be competing for beds and theatre time in a network of hospitals already stretched to capacity - the probable outcome being that they would not receive the necessary surgery and treatment they require", said Mrs McCabe.

Gillian's diet triumph

FOR MOST people, shedding nearly 14 stone is the equivalent of climbing Mount Everest - next to impossible.

But, to 25-year-old Gillian Machin, it was like scaling the highest peak with both feet tied together. She has spina bifida and cannot go anywhere without a wheelchair.

At the beginning of 1992 Gillian, who lives in Stockport, was a colossal 23 stones and was firmly rooted at base camp.

Her sister, Tracy, asked Gillian to be chief bridesmaid at her wedding and the thought terrified her.

Gillian *(pictured both before and after her diet)* took one look at a picture of herself and realised there was no way she could ever fit into a bridesmaid's dress sized between 18 and 26.

"I just wanted to look my best for her," said Gillian, who joined a Weight Watchers club and vowed to shed not just pounds but whole stones.

By September, she could now fit into her dress and now - amazingly - Gillian is positively waif-like, weighing in at just over nine stone.

ABOUT WEIGHT WATCHERS

Weight Watchers hold 3,400 meetings each week in the UK. Based on the principles that dieting should be safe, sensible and fun, their aim is to re-educate the way we think about food.

To find out where your nearest meeting is being held, contact Weight Watchers, tel 0628-777077.

Her life had been transformed from drab stay-at-home dreariness to hope and activity.

"I didn't do very much," she recalls. "I stopped driving around because I wasn't very comfortable in the car and there wasn't enough room for the steering wheel."

She even had to stop going to the cinema because the seats were not big enough.

Gillian suffered pressure sores all over her body because she was so big and heavy. It got to a stage where the doctors told her she had to lose weight.

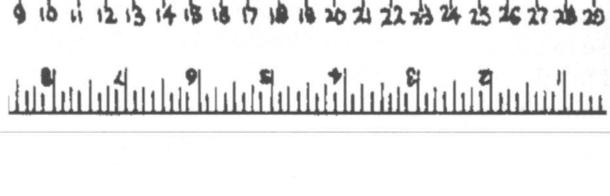
Now Gillian is young, free, single and eager to make up for lost time.

"People are more willing to help me now I have lost weight," observes Gillian.

"They seem to recognise me as a person - I know it sounds awful. Whereas people used to walk past, now they talk to me more," she said.

And she has a message for anybody attempting to lose weight against the odds: Keep going.

This article first appeared in Metro News, Manchester, on 8 October 1993.



A RIGHT TO LIFE

Photo: Aimee and Louise looking at their little sister, Sophia, for the first time.

WHEN Sophia was born on a damp autumnal day the doctor said to my husband: "Congratulations, you have another little girl."

An odd thing to say, perhaps, to parents of a newly born spina bifida baby, but years later we agree with him. He was the first and, for over a year, the only professional to be optimistic about our little one.

She was transferred within the hour to a London hospital. The consultant told my husband to "pray she dies quickly". We wondered, if this was the attitude of the medical professionals, what chance did she have? For five days I couldn't eat, sleep or stop crying, not because she was handicapped but because they'd taken her away. On the sixth day they brought her back.

She had a 70% open lesion, no cyst, no protection - just an open wound oozing cerebro-spinal fluid. We were told to have another baby as soon as possible. We asked for an appointment with a plastic surgeon and were refused. After two failed shunts prevented granulation of the wound (a scaring form of skin covering) it became more important to find a way of stopping the CSF leaking from the lesion. This was a constant threat to her life.

We asked the consultant what would happen if meningitis occurred. He replied that it was not their policy to treat spina bifida children of Sophia's severity. This was not good enough - our child deserved to be given the same chance as a normal child. Just because she wouldn't be able to walk didn't mean she should be left to die.

We rang our ASBAH fieldworker Shirley Moore, who completely understood everything we felt and told us to ask for second opinion. My GP referred us to a plastic surgeon. Our appointment was cancelled after our London consultant wrote to the plastic surgeon advising against closure as Sophia was paraplegic. We called Shirley again and she agreed to assist us in finding an optimistic neurologist. The team chosen were Dr Verity and Mr Holmes at Addenbrookes. Our GP referred us and as soon as we met Dr Verity we knew it was right for us. He told us that, if or when Sophia contracted meningitis we would choose the course to take, not him, and he agreed to take the case. That was in November '89.

The following month Sophia became ill. We went to our local hospital with our GPs letter and awaited confirmation that it was a shunt failure. It was, but the consultant wouldn't send us to Addenbrookes. He told us we had to go back to London. I refused; things became heated. He said we couldn't change consultants. We told him of our meeting with Dr Verity and our intention to transfer Sophia's case to him. More time was being lost by this useless conversation, so I told him that I would carry Sophia in my arms to Accident and Emergency at Addenbrookes if necessary, but she was *not* going back to London. He then agreed to the transfer. When your child is so ill you don't need negative attitudes, you need positive ones, and this is what we found at Addenbrookes.

Within 30 minutes of arriving a scan had been completed and immediate surgery scheduled. We stayed at the hospital with Sophia and the staff put our other two little girls in spare beds. Sophia came back from surgery about 1 am and we stayed with her.

The following day we had a visit from Mr Lambert. He explained that he was a plastic surgeon and that Dr Verity had asked him to

Hydrocephalus Network
News
ASBAH, ASBAH House, 42 Park Road, Peterborough PE1 2UQ.
Telephone: 0733 555988 ● Registered Charity Number 249338

ASSOCIATION FOR SPINA BIFIDA AND HYDROCEPHALUS

February '94

End of the ride after an oilwell gusher!

HE MAY have been saddle sore and weary - but Martin Walker finally rode into Lytham St Anne's, Lancashire, with a feeling of elation and almost £3,500 for ASBAH.

Offshore oil rig worker Martin Walker had cycled the 316 miles between Aberdeen and Lytham St Anne's, Lancashire, in just 24 hours to raise money to help raise money to develop the Hydrocephalus Network.

The ride took place after dozens of colleagues, friends and family had dug deep into their pockets to support the trip. Martin had a huge amount of support from his oilrig mates in the Ninian fields off the coast at Aberdeen.

Martin went the final few miles again last August - this time to cheers from girlfriend Cathy McKissick, who lives at Lytham, and a civic welcome from borough mayor, Councillor Jean Wilding.

"I had a great time, and was buoyed up by all the support I got from people on the rigs and back home in Lancashire", said former red beret Martin (40), who lives in Preston.

"Then to have congratulations from the mayor capped it all. She showed us round her town hall and let Cathy's son Thomas try on the mayoral robes. We ended up having tea in the mayor's parlour."

The money was passed on to Val Cushing, an area fieldworker with ASBAH. It will be spent on the Hydrocephalus Network - which keeps over a thousand people with the condition in touch with each other.

A FAMILY in Bristol have a baby daughter, born prematurely in April '93, and who has hydrocephalus alone. They would like contact with another local family, child similar age, also with hydrocephalus alone. Please contact Rosemary Batchelor, HN co-ordinator, tel 0733 555988 (Wednesdays or Thursdays).

LETTERS

Thanks, Jayne says Leonie

(Disabled Living Adviser, ASBAH)

Jayne thanks HN News readers for reading her letter *(HN News, Summer '93)*. I think she should be thanked for writing this very honest and revealing letter. Without a doubt Jayne has put into words what so many other young people must feel.

Young people should not be pressurised to achieve goals which are not of their choosing or design. The emphasis these days is so often upon young adults becoming 'independent' or living on their own before they wish for it or have the confidence to cope. It is essential that the young person's own wishes are carefully considered and sensitively dealt with. Perhaps the emphasis should rather be on the ability to make choices and of being listened to, as was stated in this letter. There is no stigma about living at home and it is quite wrong to hustle someone into independent living at the expense of their self-esteem and self-confidence. This is, in fact, courting disaster as many have learnt to their cost.

It is interesting that I have had some correspondence with a lady living in Sydney who had experienced very similar stresses to those Jayne mentioned both in school and later, resulting in depressive illness. People with isolated hydrocephalus are peculiarly vulnerable because their appearance and general performance do not always indicate the underlying difficulties and onlookers so easily make incorrect assumptions, eg. Jayne was accused of being lazy when she found a subject hard and asked for assistance. Even asking for assistance can be extraordinarily difficult for someone with hydrocephalus because it is not easy to explain the problem. Initiating the whole process is also near impossible for some. Then to be called lazy is the final straw.

Sadly, there are children and young people going through the system who are being misunderstood. The challenge is to increase the awareness of all those dealing with these young people . ASBAH both nationally and, very often through local Associations, is constantly involved with promoting these aims. Finding the right pace for taking the next step is crucial. The young person must be allowed to move forward when they are ready and no attempt made to accelerate the process unless it is done judicially and with ample support.

I do hope other young people will be inspired to write about their feelings, it does not all have to be climbing mountains and parachute jumping, as amazing and praise worthy as that may be. Letters such as Jayne's can provide such comfort to many who are achieving in a different way.

My own computer

My name is Angela I am 13 1/2 years old, I have had hydrocephalus since I was a baby.

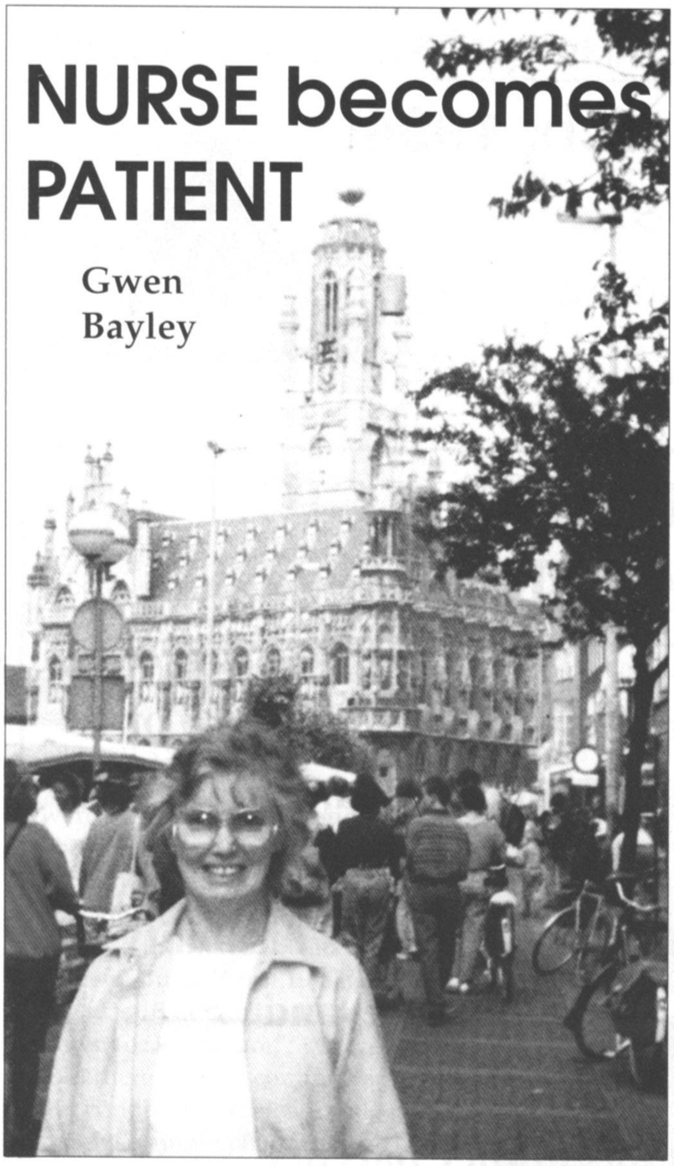
I attended Sandylands County Primary School, Morecambe and now attend Heysham High School. I am in Year 9 this term.

My hobbies are going to the Youth Club and swimming and using my computer which I received this year from BBC Children in Need. I would like to thank ASBAH for helping me get it.

Angela Dyson

NURSE becomes PATIENT

Gwen Bayley



Hi! My name is Gwen Bayley. I'm 55 and a State Enrolled Nurse. I reversed my role of patient/nurse ten years ago.

When I suffered a sub-arachnoid haemorrhage I woke up in the side ward of the 30-bedded ward I used to run at might. For a fleeting second I wondered if exhaustion had overtaken me and I had got into a bed! It was only when the medical staff assured me that I had been unconscious, having collapsed at home, that I realised what had, in fact, happened. A lumbar puncture was organised and confirmed their suspicions.

I was then transferred to Hull Infirmary where I underwent an operation to relieve the massive bleed I'd suffered. It was found I had an aneurysm that had burst (this is a blister on an artery that inflates and then leaks). The neurosurgeon said it was possibly due to the way I was born - a forceps delivery. My mother had related the trauma of my birth. After a prolonged labour, the 'miracle' (as it was thought of in those days) of the forceps was used to expedite the delivery. After 45 years, the guarantee had run out.

After ten days I returned home and attempted to resume life as a wife and mother. Things did not go easily; I was left with double vision and unsteady gait. But, with the aid of a walking stick, I could exercise the dog - a dachshund called Max. I was constantly in pain, there was no comfortable position to relieve my discomfort. Only regular pain relievers seemed to help.

A return to Hull Infirmary was organised for an exploratory procedure to assess the pressure on the brain of cerebro-spinal fluid. This revealed that I had hydrocephalus. Once again, surgery was the solution. I was to have a valve fitted to relieve the pressure - a 'miracle' procedure, relieving me of the pain. A further procedure corrected the double vision. So I began to learn to live again.

It was brilliant. I was able to see straight, I had no pain to complain of and a steady gait. I have learned to live with my shunt. I find I am easily fatigued - not necessarily through physical effort. Using my concentration can cause me to fall short of energy. Sleep is the only solution - not always convenient, but necessary! I try to leave myself plenty of time to rest during the day.

I'm employed at the moment as a Mobile Warden, attending sheltered accommodation and calling each resident to make sure they are well and have no problems. The work varies from dealing with personal problems to practical tasks. It could be a matter of deciding whether to call in a GP, fixing a towel rail or (as once) catching a mouse!

In 1989 my husband Bob suffered a minor stroke , from which he made a full recovery. But perhaps we have each gained a deeper understanding of people and their problems: things *don't* always run like clockwork. We lead a happy, relaxed life, Bob enjoying his game of golf when the weather permits. I hope this article gives some help or inspiration to you, the reader.

AMILY WEEKEND⊃FAMILY WEEKEND⊃FAMILY WEEKEND⊃FAMILY WEEKEN

25th - 27th March, 1994

Venue:

Meldreth Manor School,
Royston, Hertfordshire

ASBAH SOUTH EAST REGION FAMILY WEEKEND

A residential weekend for families with a child aged 5 or under with hydrocephalus and/or spina bifida, and their brothers and sisters.

- ☆ **A chance to learn more about your child's disability**
- ☆ **Facing the future - school and beyond**
- ☆ **Children's programme**
- ☆ **Time to relax and meet other parents**

Open to families living in London, Kent, Sussex and Surrey. Cost £10 per family

Meldreth Manor School is a purpose-built centre for children with disabilities, set in a beautiful rural landscape with an attached riding school.

All diets can be catered for
Local GP on call
The school has a strict no-smoking policy

ASBAH THANKS THE BBC CHILDREN IN NEED APPEAL FOR ITS SPONSORSHIP

CLOSING DATE FOR APPLICATIONS - 1st March
Details from Lynn Thomas, ASBAH House, 42 Park Road, Peterborough PE1 2UQ, tel 0733-555988

look at Sophia. He told us that although he couldn't close her back by known methods, he though he had an idea that might work. If tissue expanders (the type used for breast reconstruction) were implanted in her sides and inflated with saline solution, the skin should expand as per the "pregnancy principle" (his own words). Then when enough skin had grown he could effect a seal over the lesion. Great in theory, but would it work? Having nothing to lose, we agreed.

We would have to wait to start the procedure as the plastic surgery unit was closed for a while. In February 1990, we took Sophia to have the expanders fitted. That same day a colleague of Mr Lambert's said "It won't work, you know." *Very* encouraging. There were some problems along the way: Sophia rejected the expanders and had to have one changed. Then one ruptured through the skin and had to be resewn. But in April 1990,when she was 18 months old, she went down for a "closure". We were told there may be complications to her condition - her level of paralysis might change (it did) and she may become incontinent (she did). Such would be the price of life.

The operation was expected to take between four and six hours; it took just two. It was closed. A total success, a little tight but that should ease. Now to wait and see if it would hold. It did!

The following month, Sophia was given the go ahead to be handled. For the first time in my life I held my little girl as every mother can, cuddling , kissing and holding in a way that had been denied to us for so long. Touching and feeling parts of her that had never seen light, hidden always under large sterile dressings. For the first time her sisters saw her tummy and tickled it. Joy flowed through us all that day in a way and with a quality many people never experience. Sophia had received that which for so long had been denied her - the 'right to life'.

Within a very short time it became clear we hadn't been quick enough in our race for Sophia's back closure. She had developed TB meningitis, a rare and slow-developing disease. Once stabilised, using intensive therapy and stimulation, much of Sophia returned to normal but not all. This is why it is important to be quick in at least stabilising a child's back to prevent further disability.

Sophia today is a happy little girl; she has learnt to sit a little, to walk in a swivel walker and to chase her sisters in her electric chair. She goes mainly to Southview Special School and part-time to her sisters' school. She rides and swims and we go camping throughout the summers. She has been up mountains, down caves, through forests and rivers - even on cable cars.

To have a positive attitude towards treatment is essential. To have a positive attitude towards life is equally so.

Life for the family of a disabled child is a bit like that of a surfer who rides the waves, knowing he or she will fall off, but will get back on again, hoping to ride a little longer. The bad feelings don't last, the good feelings do - as memories.

Colleen Gardiner

Below: Sophia in her swivel chair, contemplating the flowers

Use it - while you've got it!

It's our last year at Five Oaks (see page 4), and we're determined to go out on a high note! We're busy right through to 6 August with activity holidays. Why not join us?

Outdoor and Recreational Pursuits Courses

16 - 23 July ● 23 - 30 July

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

Watersports you can try include sailing, canoeing, waterskiing, swimming and canal boating. For those of you who would like to take to the skies, how about having a go at the breathtaking sports of microlight flying or guiding.

If, on the other hand you prefer dry land, you could try abseiling down the Cow and Calf Rocks at Ilkley, caving, skiing, orienteering, racket/ball sports, ice-skating, fencing or archery.

You might also like to combine some of these activities with the gentler but fascinating pursuits of arts and crafts, photography or film-making.

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

Fishing Weekend

8 - 10 July

In the relaxing surroundings of Ilkley Lagoon, the Fishing Weekend will teach you all the skills of coarse fishing. Many large fish live in the lagoon and you will be able to pit your wits and skill against carp, tench, perch and chubb.

With luck you will make at least one big catch (tales about "the one that got away" are not allowed!), but dinner will be provided - even if you don't catch a bite!

Day Tripper Weeks

20 - 26 March ● 5 - 11 June

Day Tripper Week lets you choose from a wide range of trips out and activities, to give you a wonderful variety of days out.

Perhaps you would like a trip out to the coast, or a spot of bird and animal watching. Bump into your friends on the dodgems at Lightwater Valley Theme Park, learn to ski, or test your skill at tenpin bowling.

Enjoy a canal boat cruise, visit some of the historic towns of the Yorkshire Dales or have a flutter at the races. For your evening entertainment, perhaps you would enjoy a trip to the cinema or take part in an outing to the theatre.

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

Wildlife Week

18 - 25 June

If you enjoy watching wildlife programmes on TV, now is your chance to see some of Britain's beautiful animals and birds for yourself. During the week, we shall be on the wildlife trail among the Yorkshire Dales, Lake District and along the coast.

You will need patience to spot a herd of deer on a remote hillside, but it's worth it! With luck you might also see a golden eagle or other bird of prey soaring overhead or swooping down to catch its dinner!

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

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

Driving Course

24 - 30 April

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

You will have driving lessons twice a day. First of all, you will be taught off the road. This is so you can learn the basics safely away from other traffic.

You will be taught about how to judge space, good road positioning, decision-making and reaction times. These are all essential for safe driving. Our instructors will watch how well you do these tasks and give helpful advice on how to improve and develop your road skills.

When you are not driving, you will be given help and advice about the Highway Code, road safety, car maintenance, the cost of running a car and the legal aspects of driving.

Special advice for people with disabilities will also be given - including how to get the best driving tuition, suitable adaptations and car controls, getting a wheelchair in and out of your car safely, and Motability.

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

Fashion Course

26 June - 2 July

Our Fashion Course is run with the expert help of Fashion Services for People with Disabilities, and will cover all aspects of clothes design - from choosing the right material to finishing a stylish outfit.

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

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

Activity Holiday Weeks

Throughout the year

Why don't you get away from it all with a Five Oaks Activity Holiday Week? During the school holidays, we have an exciting variety of things for you to do.

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

We offer weeks for children and weeks for adults. There's something to suit everyone.

What an activity holiday costs at Five Oaks

Day Tripper Week (6 nights)	**£216.00**
Driving Course (6 nights)	**£295.00**
(plus cost of driving lessons)	**£135.00**
Fashion Course	**£216.00**
Fishing Weekend	**£72.00**
Activity Holiday / Respite Care (per week)	**£379.75**
Outdoor and Recreational Pursuits Course (7 nights)	
16 to 23 July	**£290.00**
23 to 30 July	**£379.75**
Wildlife Week	**£252.00**

At-a-glance guide to what's happening

March

20 - 26: Day Tripper Week

26 - 2 April: Activity Holiday Week

April

2 - 9: Activity Holiday Week ● 24 - 30: Driving Course

May

28 - 4 June: Activity Holiday Week

June

5 - 11: Day Tripper Week ● 18 - 25: Wildlife Week

26 - 2 July: Fashion Course

July

8 - 10: Fishing Weekend

16 - 23: Outdoor and Recreational Pursuits

23 - 30: Outdoor and Recreational Pursuits

August

30 July - 6: Activity Holiday Week

How to book your holiday at Five Oaks

Bookings can be made at any time as Five Oaks will be open right through to 6 August. Provisional bookings can be made over the phone but, please note, that we can only confirm your place when we have received your completed application form.

For further information, all inquiries and bookings, please contact:

Sarah Peet
Five Oaks Centre
Ben Rhydding Drive
Ilkley
West Yorkshire LS29 8BD
Tel 0943-603013 / 0943-609468 / 0943-602743

ASBAH's EDUCATIONAL POLICY

"Whatever the origin, nature and seriousness of their handicaps and disabilities, disabled people have the same fundamental rights as their fellow citizens of the same age, which implies first and foremost the right to a decent life as normal and full as possible."

(UN Declaration of the Rights of Disabled People 1975).

ASBAH supports this declaration and believes that all children and adults are of equal value and have the right to have all their human needs met. One of these is the right to education.

EDUCATIONAL AIMS

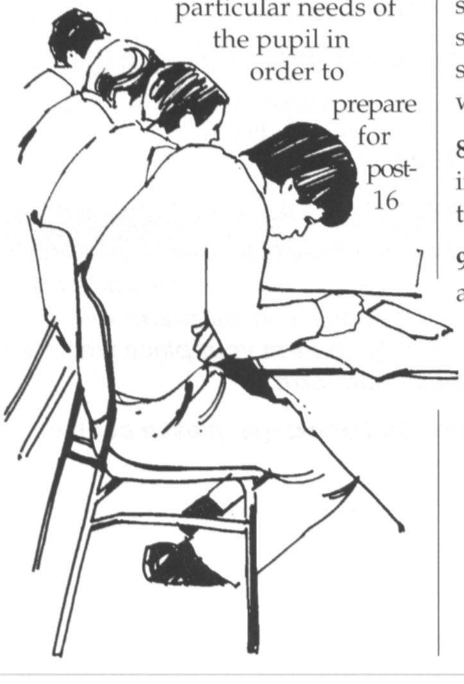
ASBAH aims to ensure that:

1. Every person with spina bifida and/or hydrocephalus will have equal opportunities in, and access to, the education provided for all able-bodied members of society.

2. There is commitment by central and local government to the provision of education accessible for all.

3. Any person with a physical or sensory disability, learning difficulty, emotional or behavioural problem, receives an education specifically related to meeting his or her individual needs and aspirations.

4. Pupils with spina bifida and/or hydrocephalus have the right to continuing education beyond the age of 16 and any curriculum should reflect the particular needs of the pupil in order to prepare for post-16 education, training and employment.



5. Local education authorities and other relevant authorities provide suitable pre-school and nursery provision which takes into account a child's special educational needs, and the appropriate funding authority makes resources available for this purpose.

6. Local education authorities, Higher Education corporations, Further Education corporations and other relevant bodies provide suitable access to universities, colleges of Further Education and other educational establishments for disabled students and make available suitable courses to meet individual vocational needs.

7. Higher Education and Further Education funding councils make appropriate resources available to LEAs for this purpose, including specific allocations or learning support facilities for individual students or groups of students with disabilities or difficulties.

8. Individuals are as fully involved as possible in choosing their own education provision.

9. Individual home/school liaison and co-operation are developed by parents and professionals.

POLICY

(A) ASBAH's policy on individual assessment which may include making a Statement of Special Educational Needs

1. ASBAH believes that parents should be encouraged to seek an assessment for their child with spina bifida and/or hydrocephalus for the following reasons:

(a) To identify special educational needs.

(b) To outline the special educational provision required.

(c) To state the appropriate type of schooling required.

(d) To identify and enumerate other specific non-educational provisions required.

(e) To identify the needs of children with regard to the special support services they may require.

2. ASBAH believes that the assessment process should commence as early as is practicable.

3. All possible information and assistance should be given to parents at every stage of the Assessment and the Statementing processes when required, especially when appeals are necessary.

4. The views of parents, and the views of children where ascertainable, must be taken into account in the preparation of the Statement.

5. The contents of a Statement should be related to the needs of the individual as assessed, and the appropriate funding authority should make available resources for this purpose.

6. Statements must be reviewed at least annually and at other times as and when changes in circumstances dictate.

(B) ASBAH's Policy on Integration

Wherever possible, children with special educational needs should be integrated into mainstream schools. As stated in the 1981 Education Act, children should be integrated as far as is reasonably practicable, taking into account the views of the child (where they are ascertainable), the parent and the school providing the education. ASBAH believes that all children should receive education on disability and its implications.

(C) ASBAH's Policy on Resourcing

ASBAH will work to improve the levels of resourcing, both by LEAs and central government, for children with special educational needs. ASBAH believes that resources should meet completely the provisions necessary for the physical, educational and social needs of all pupils with disabilities. This involves:

1. Appropriate staffing levels and patterns, to be accompanied by professional support and in-service training for all staff involved, including disability equality training.

2. Availability of suitable equipment and materials.

3. Suitable modification of educational buildings and the provision of transport where necessary.

4. Full input of relevant support services from other agencies, with particular reference to therapists, educational and clinical psychologists.

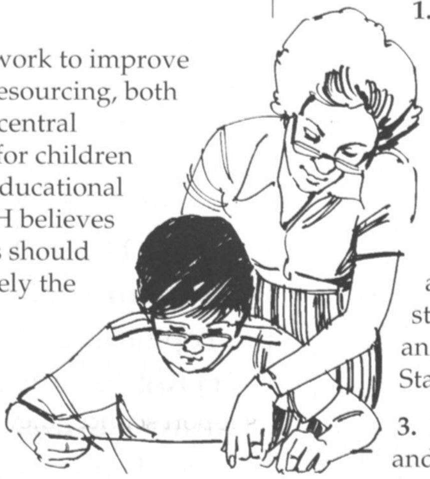
5. Support for the development of pre-school services.

6. Availability of resources for effective post-16 education and training.

7. Availability of resources for 19+ education, training and employment.

(D) ASBAH's Policy on Support

The Association, insofar as its resources allow, will offer:



1. Guidance and advice on education provision and resources that must appropriately be made available by LEAs and schools.

2. Assistance with assessment and statementing processes and the issuing of a Statement.

3. Information, assistance and support to parents of pre-school children with spina bifida and/or hydrocephalus.

4. Information, assistance and support during transition from pre-school to school-based services and Further and Higher Education establishments.

5. The support necessary to achieve and maintain individual independence.

6. Professional support and in-service training to all staff working with pupils who have spina bifida and/or hydrocephalus.

January 1994

Any reader who has been experiencing difficulty in obtaining a grant for further education from the Further Education Funding Council, please contact Peter Walker, Education Adviser, ASBAH House, 42 Park Road, Peterborough PE1 2UQ, tel 0733-555988.

Changes for the better in Northern Ireland?

PLANS to improve the educational statementing process for almost 7,000 children with special needs in Northern Ireland have been welcomed by ASBAH.

The Northern Ireland Office has announced that it wants to cut delays in issuing statements, boost parental choice of schools and set up an an independent body to deal with complaints.

"We would welcome improvements to the present system and look forward to more detailed information becoming available", said Karen Sharma, ASBAH's education adviser in the Province.

One of the biggest causes of anxiety for parents and teachers has been delays in assessing pupils and issuing meaningful statements.

"Often, by the time a final statement is issued, the accompanying advice is out of date and frequently inaccurate. Provision recommended may no longer be appropriate", said Mrs Sharma.

"Time lost at this stage, particularly when dealing with young children, could cause irreparable delay to the child's development and progress".

ASBAH remains concerned that government may be paying lip-service to the ideal of parental choice if local boards are allowed to plead "efficient use of resources" as a reason to deny the school of choice.

And parents will only be able to appeal against special educational provision and the named school - not against the description of special needs.

"In my experience, the description of needs in the statement has often been unsatisfactory, inaccurate or ridiculously vague", added Mrs Sharma.

THE HARDEST DECISION

by Jane Daly

'I'm sorry to have to tell you that a serious abnormality has been detected in your baby'.

With increasingly sophisticated prenatal tests more and more parents each year are faced with this devastating news. Over two thousand couples choose to end the pregnancy rather than continue to term. Jackie and David made that decision when their second child, a daughter, was diagnosed with severe spina bifida and hydrocephalus.

"I knew by the way that they were looking and pointing at the screen that there was a problem and they were about to say something. For a second I just didn't believe them. I was angry that it hadn't been picked up before, at the last scan. They said that the prognosis was dreadful. We did it for her *really. I'd looked after a baby on the paediatric ward who had died after a few days with spina bifida and hydrocephalus."*

Most parents experience a combination of shock, disbelief and anger as they come to terms with the diagnosis. There is an unbearable sadness at the loss of the normal baby that was hoped for and the dreams for the future as well as guilt concerning the reasons for the baby's problems. Family and friends often have strong opinions surrounding termination, and health professionals, who find the subject equally difficult, may try to hurry the parents into a decision with little or no counselling. Julia Samuel, a bereavement counsellor at a large hospital, says; "I have found that the parents who take longer to make up their minds are better prepared to deal with their grief afterwards. They have given themselves time to work through all the arguments, and may therefore be more confident that they have made the decision that is right for them."

"We saw the consultant for a six week check, which was a very brief meeting and that was that. There is a one in twenty chance of it repeating. We started trying for another baby almost straight away. It sort of becomes an obsession after something like that has happened."

Jackie continues:*We were left together for a few minutes then the sister came in. She asked if I'd ever looked after anybody undergoing a termination because she knew I was a midwife. They kind of assumed I was going to have a termination. I went to see my consultant at the antenatal clinic the next morning. He asked me if I wanted to come in that day and I said no, I wanted to come in the the next day. It felt too quick - I'm glad I waited."*

Faced with an abnormal scan or test results many parents feel that they would like to discuss termination with someone who has had a similar experience before making a decision. SATFA (Support after Termination for Abnormality) is a charity which exists to support parents during

SATFA

Support after termination for abnormality
29-30 Soho Square, LONDON W1V 6JB. Tel: 071-439-6124 or 0245-467097

SATFA is a support group run by women and couples who have experienced a termination of pregnancy because an abnormality was diagnosed in their baby.

Parents of a baby with an abnormality can feel very alone. They may think that no one can possibly understand their feelings. It is quite natural for them to wonder if the tragedy could have been avoided, to blame themselves and sometimes the hospital staff and to feel that they could have done something to prevent it happening.

They may feel less alone if they talk to other people who have lost a baby in a similar way and who can understand how they feel.

SATFA can put parents in touch with someone local with whom they can talk.

this period, and after the termination - should that be the chosen route.

Termination often means an induced labour as this is considered safer for the mother after fourteen to eighteen weeks of pregnancy (depending on the consultant). Parents may feel very anxious about what will happen when the baby is delivered, worrying that they will not be able to cope with seeing the deformities. With sensitive care by the hospital staff many couples feel supported enough to both see and hold their baby. It is routine procedure on most units to take photographs.

"Every midwife who looked after me asked if I wanted to see her after she was born. I said 'Yes, if she looks normal'. But when it came to it they just whisked her away. Most of the time I didn't have a midwife. When I wanted to push we rang the bell and nobody came so David went out and dragged somebody in. I was terrified of delivering without a midwife there."

"I went home within two hours, I couldn't wait to get out. As soon as I got home I said to David that I did want to see the baby - maybe the next morning. He rang the hospital and asked when the post mortem was being done. They said that it already had been done. I couldn't believe it. I wish I'd said no to the post mortem and then I could have seen her."

> **"I had Christopher around and my Mum wasn't very well so I pulled myself together for their sakes, but when no one was around I just cried. I couldn't handle talking about it."**

Many couples feel guilty grieving for their baby when the decision to end the pregnancy was theirs. These feelings of guilt, failure and loss are complex and contradictory - yet grieving for a baby after termination for abnormality is right and necessary. Bereavement counselling, when it is available, can help parents take the first steps in coming to terms with their baby's death. Julia Samuel offers the following description of her role; "In a way, I believe the most useful role of a counsellor is just being there. For parents to know that once a week there is the time to really express what they feel, to focus on the reality of their loss. The simple procedure of being listened to and understood is in itself helpful. The unacceptable 'bad feelings' are hopefully accepted and respected by me, which in time helps the parents accept them too."

> **"It was the right decision at that time. The only thing I feel angry about now is the way I was treated. It was kind of, go to hospital, have it done, and go home and forget about it."**

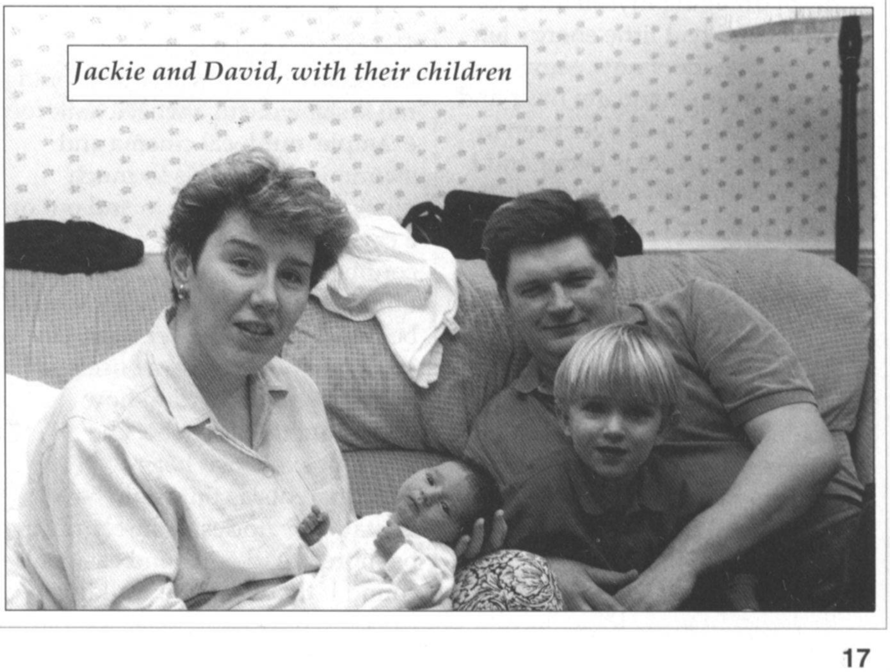
The Compassionate Friends

Membership of The Compassionate Friends is open to all parents who have suffered loss of a child, of any age in any way. The national committee (all bereaved parents and including regional representation) meets five or six times a year. The AGM is held during a residential weekend, when talks, discussions and group meetings also take place. There is a network of County Contacts, across the UK, who co-ordinate enquires received, put parents in touch with each other, and liaise with local TCF committees to organise meetings.

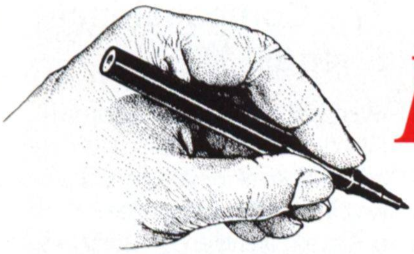
The Compassionate Friends produces a **range of leaflets** and a quarterly **Newsletter** containing many articles and letters written by members. Two issues are sent free to newly-bereaved members, and thereafter an annual subscription covers printing and postage. The Newsletter is also available on audio cassette.

The Compassionate Friends has accumulated an extensive **Postal Library** of books on bereavement which parents and those working in the caring fields may borrow. Journals, articles, video and audio cassettes are also available.

TCF National Office, 53 North Street,
Bristol BS3 1EN. Tel 0272 539 639
(Helpline); 0272 665 202 (Admin)



Jackie and David, with their children



Letters

I WAS very sad to read David Fulford-Brown's letter (Oct/Nov LINK) as he seems to feel that people should walk whatever the cost. He also doubted that he would have gained his BA if he'd been a wheelchair user - I find that very upsetting as many wheelchair users have been to university and beyond. I do feel, however, that it is likely to be more difficult for disabled people to get into higher education - but this has less to do with being disabled and access and everything to do with inequality of opportunity. Special schools do not place highly academic achievement and many higher education establishments have poor facilities for disabled people. The problems lie, not with the disabled person having a wheelchair, but with society that denies that person access to its mainstream.

I walked with great and increasing difficulty for many years. I was very unfit and exhausted for the effort of dragging myself around on sticks and had little energy left for anything else. I now use a lightweight chair and am fitter and healthier than I have ever been in my life. My posture is better and I am so much more comfortable - yes, I depend on my chair, but I am much more independent because of it and I resent David telling me that I have chosen the "soft option".

Instead of putting my energies into struggling to walk, I now put them into trying to change my environment and people's attitude to disability through my involvement with the disability movement.

David says that is is an "able-bodied person's world" and is "step oriented" - it needn't be - the world is made up of many people, non-disabled and disabled. I'd like to see all disabled people involved with their local organisations of disabled people and start challenging, through access groups etc, for rights to be part of every section of society and maybe one day our world will be properly accessible to all and using a wheelchair will be seen as just another way of getting around.

Ms Liz Cox, London

I AM writing to comment on two of the articles in the Oct/Nov issue of LINK.

First of all, in reply to David Fulford-Brown, I agree with him that some walking must be an enormous asset. I have tried very hard to encourage my daughter to walk. It opens up so much more to her. She can get on and off a bus and so has independence there. She can go upstairs and can go into many places where she could not if she were in a wheelchair, for example our local cinema and swimming pool. It is so much quicker for her to get in and out of a car and into buildings. If she was confined to a wheelchair most of our and her friends' houses would be unnegotiable on her own. One could alter one's own house but not everyone else's and how restricting that must be. She couldn't even visit her grandparents as they only have upstairs lavatories. It surely must be more broadening and easier all round if there is some walking.

Secondly I'd like to comment on the sibling article. None of the families involved was at the teenage stage; apart from one, they were all fairly young. Our family is quite different, our spina bifida daughter is extremely jealous of her able bodied siblings - one older and one younger - and spends the whole time dwelling on the unfairness of it all. She is argumentative, unhelpful and quite awful to them both - she hardly says a civil word to them. They try very hard but eventually they are provoked beyond everything into an argument. You didn't have any thoughts by children between 14 and 19. I wonder what they would be. When they were younger they took it all as part of life but now they know their friends don't have the problems and so does my handicapped daughter. Surely there must be other families where things are difficult, where incontinence causes acute embarrassment, where a lot of aggression is brought on because the disabled child is intelligent and angry?

In LINK everything is always going well with wonderful results and no problems. I realise you don't want to have negative articles to worry people but I find it depressing that no one ever seems to have our problems and we are obviously going wrong.

Let's hear a little more about the horrors that aren't easily dealt with.

R F Flowerby, Surrey

MAY I add some comments to John Naudé's letter in the December/January issue of LINK?

Whilst agreeing whole heartedly that the wheelchair is a very positive piece of equipment which should be acknowledged as such, and therefore not a failure if it has to be used for total or partial mobility, some part-time walkers may benefit more from the use of a battery operated 1.4 mph mobility aid. This encourages the continuity of walking, alongside a very efficient and practical mobility; giving greater outdoor freedom and conservation of energy, so leading to an active and fulfilling life style.

Considering David Fulford-Brown's comments about walking, may I point out that to me as a paediatric physiotherapist, the most important criterion is whether the child's walking is functional. That is - in or out of callipers, are they able to stand free, without support and only require elbow crutches/sticks to aid the movement of their legs to walk?

Children who are wholly dependent on walking aids, especially the rollator, tend to lean on the aid hard with their hands, and are therefore in danger of not encouraging the natural development of hand skills, which in many incidences, are already immature in nature.

Both getting into the upright position "to stand", and moving, "to walk", are very important steps in a child's development and should be encouraged at the correct chronological age - this experience affects both physical and mental development, helping to develop spatial concepts, body image and orientation.

Through the growing period "standing" and "walking" exercises provide stimulation to bone growth and density and encourage good posture of the spine. For a child with spina bifida these exercises will be as important a part of their physical education as free expression and wheelchair activities.

We have known adults who have found that to "stand" or "walk" for a short time each day makes them "feel better" as it improves their digestion, circulation and lung expansion.

Mary Barton MCSP, Disabled Living Adviser, Five Oaks

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