Link

The magazine for people with Spina Bifida and/or Hydrocephalus

June/July 1995

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ASSOCIATION FOR SPINA BIFIDA AND HYDROCEPHALUS

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New legal rights for carers on the way

THE NEEDS of carers will be assessed by social services departments after the Government backed a private member's bill in the Commons in April. Malcolm Wicks' Carers (Recognition and Services) Bill looks as if it will now become law.

Once the Bill has been enacted and implemented, the social services will be required to assess the needs of people caring for the disabled and the sick – at the same time as assessing those of the person being cared for.

Carers will include parents looking after disabled children and young people caring for older relatives, whose needs might include extra help in the home or respite care – a night or a holiday away.

The Department of Health says the Bill put existing good practice on the statute books and that the Government has provided an extra £30 million in the community care budget this year to support carers.

Mr Wicks, Labour MP for Croydon NW, said he had promoted the legislation with the Carers National Association because he feared that cash-strapped councils had been leaving people to care for their sick and disabled relatives unaided. The existence of a carer was also being used as an excuse to withdraw services for the cared-for person.

One example he gave was a disabled woman who lost her home and bath help when she got married, although her husband was also disabled.

Mr Wicks said there were at least 6.8 million carers in Britain, of whom an estimated 1.5 million provided care for 20 hours a week or more.

THE Bill was supported by Conservative MPs, including Lady Olga Maitland (Sutton and Cheam) who said it was often taken for granted that parents would care for disabled children unstintingly and with unflagging energy.

Junior Health Minister John Bowis, expressing Government support for the Bill, said it was not good enough for social services departments to use the arrival of a carer as an excuse to withdraw services. Labour health spokesman David Hinchliffe urged ministers to ensure that local authorities had sufficient resources to deliver the measure; it would be wrong to build up hopes and then not deliver the goods at local level.

■ **Many *Link* readers, we know, have strong views on this issue.** ***If you want to share them through the magazine, please contact Liz Cawthorne, the editor, tel: 01733-555988.***

Contents

ASBAH is a registered charity

Cover: HRH The Duchess of Gloucester at our START launch at the House of Commons, see pages 14 -16.

New fieldworkers

East Sussex and part of West Sussex

SALLY Valentine, a self-employed counsellor and holistic masseur using essential oils, is the new fieldworker for a large part of East Sussex and part of West Sussex.

Sally, aged 37, started her part-time job with ASBAH on 24 April.

A former BT telephonist before leaving to have a family, Sally is also a volunteer counsellor for Tourette Syndrome – a neuro-biochemical brain disorder which results in tics, blinking and making noises.

Sally has worked with people with a range of disabilities and regards the ASBAH job as adding to her skills on the "journey of life."

She said: "I'm learning more and more. I try to look at the person, not the disability and look forward to meeting people in their own homes."

Northamptonshire and Leicestershire

A FORMER speech therapist, trained counsellor and journalist is the new fieldworker for Northants and Leics.

Cathy Harrell, aged 42, started working for ASBAH 20 hours a week on 10 April.

Cathy, who has a disability from birth which resulted in having her right leg amputated when she was two years old, is married and has a daughter. The Harrell family live in Leicester.

A speech therapist for 13 years, Cathy then trained to be a counsellor and a few years ago qualified as a journalist on a RADAR bursary at a college in Sheffield.

She hopes to combine her fieldworker post with some freelance journalism.

Cathy said: "I am very much looking forward to working with the families in my area."

Bromley, Bexley and Croydon

DIANE Morgan will replace Margaret Holmes as fieldworker for Bromley, Croydon and Bexley in June.

Diane lives in Sydenham, on the border of Bromley and Lewisham, and is looking forward to meeting families in her area.

She was previously working for Kingston Social Services in the adult learning department as a part-time care manager.

Before that, she took three years off to have a child. She has also been a deputy manager at a residential home for children with learning and physical disabilities for Wandsworth Social Services.

Diane, aged 36, said: "In the job I've just left, much of my work was office based and I had very little contact with clients.

"The ASBAH job is a lot nearer to where I live and it's something new for me. The emphasis is on client contact which I am looking forward to."

North Yorkshire and Cleveland

A NURSE, who has just completed her final exams for a three-year honours degree course, is the new fieldworker for North Yorkshire and Cleveland.

Geraldine Potuszynskyj, 33, starts her 15-hour-a-week job with ASBAH on 5 June 1995.

Part of Geraldine's patch was previously covered by Christine Osman, but part of it has never been covered by an ASBAH fieldworker.

Geraldine, aged 33, will be based at her home in Otley, although she lives quite near the Northern Regional Office at Five Oaks.

She said: "I've always been in a caring role. I've been a nurse since I was 18.

"I really wanted to branch out into the community, and the job with ASBAH gives me more responsibility and the opportunity to get involved."

Geraldine has two children and plans to continue as a part-time nurse at Wharfedale General Hospital. She is currently awaiting the results of a joint degree course in psychology and media studies, taken at Trinity and All Saints College, Leeds.

Avon

INTERVIEWS were due to take place in mid-June for a part-time fieldwork post in Avon.

National ASBAH is grateful to Bristol ASBAH for helping to fund this post.

Correction

The half-time fieldwork post now filled by Sally Valentine is half-funded by Sussex ASBAH, not 25% as mentioned in the last *Link*.

John takes the cloth

JOHN Naudé, mobility adviser at national centre for more than six years, has left ASBAH to train to be a vicar.

He says ASBAH has taught him a lot about disability and about his own prejudice against disabled people from the days when he mixed only with the "sports elite" through wheelchair basketball.

Working at ASBAH has developed his teaching and counselling skills and helped him to recognise that disability is a political issue.

"In the past, I always felt a pressure to walk and be like an able-bodied person which in theory would make me more accepted in society," he said.

"But I now realise it is society which puts up the barriers against disabled people.

"If I had equal access with non-disabled people then my value and participation in society would be so much greater. Therefore, we need Government to reduce discrimination by giving us equal civil rights."

However, despite his satisfaction in helping people with spina bifida and/or hydrocephalus accept and value themselves as disabled people, he has been moving gradually towards taking a more active role in the Church of England.

The shift goes back to his mid-20s when a TV documentary on the Church's negative attitudes to disabled people made him cry.

John, a former pupil of Lord Mayor Treloar College, said: "I couldn't understand why I was crying and wondered what was going on. I felt God was saying 'This is where I want you to go.'

Then the idea faded until just over two years ago when his local vicar held a meeting for people interested in becoming involved full-time in the Church. John said: "At that point I felt a shove and I ought to check this out."

He went to see an official at Peterborough Cathedral , then his own vicar and church wardens. He then had to write a 35-page personal 'faith audit' describing the spiritual 'highs and lows' of his life.

In the next stage of the selection process, John was interviewed by two Church officials who did not know him and finally the Bishop, who recommended him to attend a three-day selection conference.

The conference proved to be exhausting with a round of rigorous personality tests, interviews and continual observation by six selectors.

John said: "In a way I found all the hard work reassuring because I knew that, if I was rejected, I probably wasn't right for the job."

But he was accepted into the ministry and plans to commute to Ridley College, Cambridge, from his home in Peterborough.

John said: "I believe who I am is the result of my relationship with God, and I want others to recognise that they are acceptable to God as they are – that they don't have to be super-nice, have money, or even be able-bodied!"

"I believe Christianity should give people the freedom to discover who they are as they are, and it is the Church's job to encourage people to leave behind the things which separate them from God."

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How to complain to NHS trusts

WHO do you complain to when faced with a problem with an NHS trust? And does the usual complaints procedure still apply?

The evidence uncovered in the April issue of *Community Care* by Paul Burgess, welfare rights officer for Lancashire County Council, seems to suggest that the buck stops at the trust chief executive.

His article was prompted by a radio report of a woman who had been telephoned by the hospital in which her father was a patient and 'told to collect him the next day or he would be out on the street.'

Mr Burgess writes: "Conduct of this kind in the age of the Patients' Charter sounds so outrageous as to be unbelievable, except that the parliamentary ombudsman, William Reid, has produced excoriating reports when he has found similar examples."

The Commons select committee on the ombudsman says trusts are covered by the NHS Hospital Complaints Procedure Act but, if so, who does one complain to?

Mr Burgess says one of the problems centres around ensuring that frontline staff have an early opportunity to put things right, but to enable patients to move the complaint upwards quickly if they are not satisfied.

"The select committee was concerned to see the chief executives of the trusts actually signing the replies to complainants, and accepting responsibility visibly for what goes on. They were not happy that the chief executive merely had responsibility for ensuring the complaints system was in place."

The conclusion from all this seems to be that patients should write to the chief executive if they are unhappy and, if they are still dissatisfied, the health service ombudsman.

Continence service axed

AN ADVISORY service whose helpline and advocacy assisted people in all parts of Britain for 15 years has been axed.

The Northern Region Continence Advisory Service, based at the Dene Centre in Newcastle, has closed after a round of health authority cuts.

The service was set up and run by national continence adviser, Helen White, who sprang from a health visitor background with a special interest in continence management.

ASBAH continence adviser, Mary White, said: "Sadly, this excellent service has fallen victim to health authority cuts. The effects of the loss of the service, its helpline and advocacy aspects will be felt all over the country

"Adult services for disabled people nationwide are scarce and I am saddened by Newcastle health authority's decision to deprive our client group still more."

Fun in the New Forest

A FUN challenge which aims to give wheelchair users the opportunity of countryside access and enjoyment of the open air takes place in the New Forest, Hampshire, this autumn.

The New Forest Wheelchair Challenge, organised by the Disabled Drivers' Association (DDA) on Saturday and Sunday, 16 /17 September 1995, is open to users of electric wheelchairs, scooters and manually propelled chairs or all kinds, accompanied by walkers (pushing if desired) or cyclists as required.

Four, six, 10, 15, 20 or 40 miles can be covered in the one or two days, along trackways through beautiful forest and across open heathland.

Additionally, if they wish, participants can use the challenge as an opportunity to raise money for the Disabled Drivers' Association or a charity of their choice.

Entry forms for the New Forest Challenge are available from Dr Mike Bruton, DDA, 14 Belmont Park Road, Maidenhead, Berks, SL6 6HT. Tel: 01628 26767.

The event is part of the moves being made by the Disabled Drivers' Association, the Fieldfare Trust (a Sheffield-based charity working with sponsorship from British Telecom under the *Countryside for All* campaigning banner), the Ramblers' Association, the National Trust and many others towards opening up the countryside for disabled access.

Booklets to help bereaved relatives

THREE new booklets have been published to meet the needs of the wider family when a pregnancy is terminated following the diagnosis of abnormality.

Help for Fathers, Help for Grandparents and ***Talking to Children*** have been produced by the charity SATFA – Support Around Termination for Abnormality.

The new booklets are available from SATFA at £1.00 a copy. ***SATFA can be contacted at 29-30 Soho Square, London, W1V 6JB. The helpline telephone number is 0171-439 6124.***

FORESIGHT NOT HINDSIGHT

SPINA BIFIDA WEEK

31st JULY - 6th AUGUST 1995

FOR the second year running, ASBAH will be joining forces with a vitamins manufacturer to present national Spina Bifida Week.

The national week – being held from 31 July to 6 August – is being organised by the Larkhall Natural Health Group, makers of Cantassium 400 mcg folic acid tablets, who give us 10p from each pack sold.

It will focus once again on the abysmal lack of awareness of the benefits to the unborn babies of their mothers taking folic acid tablets from before conception until the 12th week of pregnancy.

A diet rich in folic acid plus a daily tablet supplement greatly reduce the risk of pregnancies being affected by spina bifida and related defects like anencephaly – providing the supplements are taken before women become pregnant.

Women with previously affected pregnancies, or with a history of spina bifida in the family, should ask their doctors for high-dose folic acid, which is available only on prescription.

A nationwide Gallup survey of 1,300 women carried out for Cantassium in the first week of April this year showed that, while two-thirds of women questioned had heard of folic acid, only one in four knew why it was beneficial.

Many of these women thought it helped them combat PMT, feeling tired and colds and flu. Half of the women overall did not why they should be taking folic acid. This increased to a 60% level of ignorance in the 16-24 age group.

Only one in four mothers knew about the benefits of taking folic acid.

The Gallup survey reinforces a mid-1994 survey of 603 women attending their first appointment at an ante-natal clinic in Leeds which showed that only 18.7% had increased folic acid intake before conception, compared with 2.4% the previous year.

The Leeds survey showed that 30% of the women involved were increasing intake after the critical period when the neural tube has closed (on day 26-27 of embryonic life, or 12-13 days after the first missed period).

The Leeds survey – carried out by a team of scientific researchers led by Dr Chris Schorah – took place over four months in the middle of last year. ASBAH is helping to pay for a follow-up survey in Leeds this year, this time introducing a number of socio-economic indicators.

Help & Advice

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

London, Surrey, Kent, Sussex

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

Lincs, Cambs, Leics, Notts, Northants, Norfolk, Suffolk, Essex, Herts, Beds

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

Northern Ireland

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

Northumberland, Durham, Cleveland, N Yorks, S Yorks, W Yorks, Tyne & Wear, Humberside

North East Region Office, Five Oaks, Ben Rhydding Drive, Ilkley, W Yorks LS29 8BD. Tel (01943) 609468. Regional Co-ordinator: Joan Pheasant NNC.

Rest of England and Wales

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

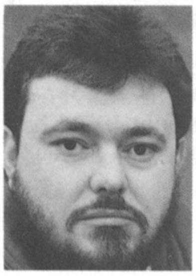
ASBAH welcomes the support of its commercial partners.

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

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

Darke at the cinema

by Paul Darke



YOU know which film I don't like – *The Raging Moon* – and why I don't like it (see my article in the last *Link*). In this issue it is time for a discussion of the film I like.

My favourite film many would consider to be equally offensive towards people with disabilities: Mel Brooks' *Young Frankenstein*. It is masterpiece from 1974 that, above all else, makes me laugh out loud every time I see it; which by the use of video means regularly. I'd say it just pips my second favourite film (all Marx Brothers' films) by a whisker. I suppose I like it because it is offensive (though only superficially): it appears to make fun of hunchbacks, amputees, visually impaired and blind people, and even people with learning difficulties. But I admire it because it has an awareness about disability representation that has not been seen since. Not even in any written film analysis.

Mel Brooks' films are all spoofs of one thing or another, and the success or failure of a spoof is based upon its knowledge of the conventions of the very thing that it is spoofing. Brooks' awareness of how disability has been used in old Boris Karloff, Bela Lugosi and Lon Chaney movies is so astute that he plays with those representations to turn them in on themselves to both highlight the conventions and then play with them. The use of old blind men as saintly sages was fairly common in the 1930s. They were tragic figures whilst also being wise and worldly. Brooks shows what a narrow and ridiculous view of old blind people this is by having the very same character in his film spoof – *Young Frankenstein* – be a bumbling fool, who thinks he's full of wisdom, who smashes, burns and torments his monster visitor. On the surface just another stereotype? No. Brooks is using one stereotype to ridicule another one; in this case two negatives making a positive.

Brooks' treatment of the characters who are hunchback or have an amputated limb is exactly the same. But the crowning glory is in his treatment of the monster with a learning difficulty. Here he criticises the way in which normal society is happy to accept abnormal people but only if they conform to a normalising social programme or medical treatment (and don't we know about that!). What Brooks is showing the viewer is the fascist nature of the able-bodied norms which constrict not only the disabled but the able-bodied as well; and making us laugh at the same time. As my mother liked *The Raging Moon* because it reassured her in her views, I am sure *Young Frankenstein* does the same for me: it abhors convention and the conventional (whilst being intentionally vulgar). And I bet my mother hated it.

New video on pressure sores

A NEW video on the prevention of pressure sores, which was screened on BBC TV in early April, is now available and supported by an advice leaflet.

Don't Get Sore – Get Moving, produced by the Department of Health, is aimed at people who are not health care professionals but who are caring for patients directly in a range of settings.

It is also for people vulnerable to pressure sores who wish to be involved in their own care.

The video portrays every day situations, with patients and their carers talking about their own experiences of how pressure sores are caused and how they can be prevented.

It was screened on BBC Select – the BBC's open access early information service – at 5am on Friday, 7 April.

Copies of the video can be purchased (£35.50 including VAT) or rented (£13.50 including VAT for five days) from CFL Vision, PO Box 35, West Yorkshire, LS23 7EX. Tel: 01937-541010. The accompanying booklet – Your Guide to Pressure Sores – can be obtained separately, from the Health Literature Line on freephone 0800-555777.

Your views on wheelchairs needed

A DISABLED woman, who has started a campaign to raise standards in wheelchairs, wants to hear from other users.

After raising complaints about her electric wheelchair with the manufacturer, Mary Richards was invited to send her own ideas on design, manufacture and cost of wheelchairs. As a result of her own complaint and others she has received, Mrs Richards mounted the *Our Legs!* campaign. She is now working with manufacturers to get improvements.

Views, complaints – or even praise for good design or manufacture – should be sent to: ***Mrs Richards, 81 Leeming Lane North, Mansfield Woodhouse, Mansfield, Nottinghamshire, NG19 9HP. Tel/fax: 01623-654247.***

THERE is little published information on childbirth for women with spina bifida. It is not a topic included in obstetric training as it is felt that most obstetricians do not see enough women with any particular disability. In response to requests for much more information, the magazine* Disability, Pregnancy & Parenthood International *approached a consultant obstetrician who had been particularly recommended by one mum with spina bifida.* Disability, Pregnancy & Parenthood (DPPI) *allowed us to reprint the consultant's article along with two case studies of mums who have spina bifida. (Turn to page 12 for more details of* DPPI*).

Childbirth and spina bifida – a consultant's view

By Charles Wright, consultant obstetrician and gynaecologist, Hillingdon Hospital, Uxbridge, Middlesex

I HAVE probably seen less than a dozen women with spina bifida in my career to date and I have been struck by how most of the women who come to me have a very positive attitude: they've considered childbirth and parenthood more seriously than most non-disabled women and their attitude seems to be that they are dealing with all other aspects of adult life, so they expect to be able to deal with pregnancy.

In obstetric terms I go along with this attitude: there is no reason to be anything other than positive as their chances of having straightforward pregnancies and deliveries are very high.

The main point for me to check with a woman who has spina bifida would be her thorax: what her chest expansion is like when she is breathing. The reason for this is that, according to the severity of spina bifida and the resultant spinal deformity, chest expansion can be quite limited. Since pregnancy for all women entails a loss of space for the diaphragm to expand fully, it is obviously a concern that, for some women with spina bifida, this could be too much for them.

However, almost all of the women I have seen seem to be particularly fit (including an Olympic swimmer!) so chest expansion in pregnancy has been no problem for them. Everything else (eg the shape of the pelvis) as obstetricians we are trained to deal with and most problems are surmountable, so I do not feel any particular concerns.

The most common questions that a woman and/or her partner puts to me are:

Will the child have spina bifida? (Perhaps).

Will I be able to deliver normally? (Wait and see). One can rarely tell from the outset of pregnancy as it depends entirely on the way the baby develops inside that particular mother's pelvis – just as for any other woman. In my experience most women do deliver normally – there may be obstetric reasons for a Caesarean section that emerge during pregnancy or, more rarely, during labour but these are only a little more likely for women with spina bifida.

As for particular tests/special precautions during pregnancy, I find most women who come to me know more about spina bifida than I do – they've read about vitamin supplements and folic acid prior to conception so I rarely need to discuss this. In pregnancy, as with all other women, they are offered a number of tests including one to detect spina bifida in the foetus. Their options are the same as everyone else. I do not see them as being extra problematic and encourage them to come and see me as often as they like out of the scheduled appointments. They tend to be very aware of their bladder hygiene so increased infections during pregnancy are not a problem that I particularly expect.

What determines whether a vaginal delivery will be possible are the same factors as for any other woman: the position of the baby in the pelvis at the end of pregnancy. If the spinal deformity is such that it prevents the baby from engaging itself in the head-down position then, even if the pelvis is normal, a Caesarean section will be necessary.

During pregnancy I do arrange for women with spina bifida to see a specialist in anaesthesia so that they can discuss the options for labour and Caesarean sections. People often wonder whether their spinal deformity will mean that they cannot have epidural or spinal anaesthesia. The answer is that it obviously depends on the individual woman but, as a general rule, epidurals are possible as long as the segments of the spine are clearly visible. If they are not, spinal anaesthesia is usually still possible even if the kyphoscoliosis (spinal curvature) is quite marked.

Continued on page 12

Women who have had babies talk about their experiences

Karen Hall from Bedfordshire

I WAS 29 when my husband and I decided we wanted to have a child. My family were not very keen and tried to dissuade me saying that I wouldn't be able to cope. We went ahead and found that all the health professionals were very supportive. Looking back I didn't have enough information at the right time. For example, I knew nothing about the advice to take folic acid supplements until my obstetrician told me at 24 weeks of pregnancy. I did experience breathing difficulties from the middle of pregnancy and my husband had to give up work to be at home with me, but the discomfort did not get any worse after that.

We weren't told of any ante-natal classes because it was assumed that they would be inaccessible. I wish they had. My husband bought lots of mother and baby type magazines and we read through these together and found them very helpful.

I was told quite early on that because of the size of my pelvis I would need a Caesarean section to deliver the baby and also that an epidural would not be possible because of my spina bifida. This was disappointing as it meant that Ronald was delivered under a general anaesthetic so neither my husband or I were "there" to greet him immediately. I went into hospital 24 hours early for the Caesarean at 37 weeks of pregnancy. Everything was fine until after the birth.

I was in hospital for a week during which time I was in my wheelchair from early in the morning to late at night. The bathroom was inaccessible with a high-sided bath with no handles – no way could I negotiate this with my Caesarean scar!

The midwives left all my care to my husband. On the day I was due to go home it was discovered that there was an infection in the scar. No one had checked it the whole week I had been in hospital not even since it had been uncovered. They wanted to keep me in hospital for a further 10 days but since they just didn't have the accessible facilities I insisted on going home.

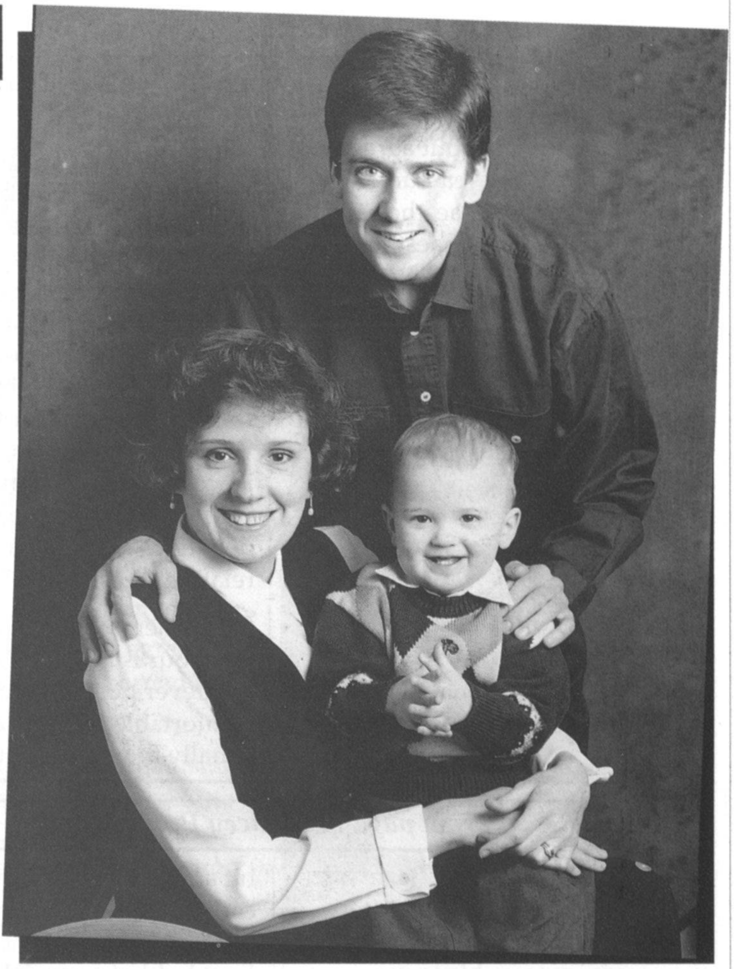
I had seven courses of antibiotics over the next six months. My husband also discovered that I had developed pressure sores while in hospital as a result of sitting down in my wheelchair all day.

So what would I do different next time?

I would make sure that I had more information in advance; I would be more assertive about getting my scar checked once it was uncovered; I would make sure that I had regular times out of my wheelchair, lying in bed to avoid the pressure sores – and I would try and get more sleep once the baby had been born!

Karen Hall, aged 32, and husband Ian at home with two-year-old Ronald.

Tracey Proudlock from London



Tracey Proudlock, aged 29, husband Liam and their 16-month-old son, Billy.

I HAD no problems with my breathing during pregnancy but did find that pregnancy posed an extra strain on my urinary tract and I became much more prone to infections from four months on.

The antenatal staff did not seem to know much about women who catheterise so I had to seek out advice myself from a urologist who put me in contact with a continence adviser.

She did a complete review of my continence management, something which I had not done in the five years that I had been self-catheterising. She took me step-by-step through the entire procedure, pointing out how risk of infection could be minimised at every stage. I found this very useful. However, because of the risk that urinary tract infections may start early labours, I was advised by my obstetrician to have a low prophylactic (preventative) dose of antibiotics continuously from seven months of pregnancy. I was not entirely happy about this but was assured that the particular drugs had been checked as safe in pregnancy and would not affect my baby or my ability to breast feed.

The other major problem I had in pregnancy was very intense and localised back pain. The doctors just ascribed it to pregnancy and could not offer much in the way of relief. It was very disabling as I could not sit, which meant I could not drive the car. The only relief came if I could lie on my side. The pain disappeared immediately after the birth but I wish I had had more advice on managing the pain.

I found the doctors all to be very open-minded about how I would cope in delivery. Their attitude was "Let's just see how it goes" but I was quite anxious that delivery would not be normal. This was really exacerbated by other mothers who would say things like "Your baby can't have much space in there" or (because I use a wheelchair) "There won't be any gravity to let the baby drop down."

So I was convinced that I would have problems in labour and right up to the moment when his head popped out I was sure I would not cope because I had not been able to attend any National Childbirth Trust classes (all inaccessible to a wheelchair user) and because my body was different. Also I had been told quite early on by the doctors that because the vertebrae in my lumbar region were not clearly defined, an epidural would not be possible. My fear was that my baby would have to be delivered while I was totally unconscious under a general anaesthetic.

In fact, although I went overdue a few (anxious) days, my labour started spontaneously and, with the help of a little Pethidine to ease the pain, I had a pretty normal labour. I lay on my side for much of the time as I found that this eased the pain of the contractions. At one point I remembered what the active birth books had said about gravity helping to progress labour so I asked my husband to pull me up onto my knees. This was quite a difficult and tiring position for me. When the midwife revealed on examination that I was only 7 cm dilated I was a bit disheartened (I had hoped that I would be further) and threw myself onto my back and stayed there for the rest of the labour. They pulled the backrest off the bed and put lots of pillows behind me so that I was sitting up. My husband and the midwife held my knees up and out. This helped me focus downwards.

The second stage was quite long and the midwife was concerned that the baby might be getting tired and offered to do a tiny perineal cut – I agreed and our son slipped out in a flash.

Postnatally, I stayed for the two days that most women are allowed in my particular hospital. My husband was around most of the time to help with bathing. The

continued on page 12

From page 9. A consultant's view – Charles Wright

It does depend on the experience of the anaesthetist as to whether he will feel confident about agreeing to an elective Caesarean under spinal or epidural anaesthesia, instead of a general anaesthetic.

We are fortunate in having someone who is very experienced and thus women with spina bifida are offered the same range of choices as other women, with most favouring the local rather than general anaesthetic so they can remain conscious as the baby is delivered.

Other forms of medical pain relief are generally safe in labour, although I have to say that most of the women I have seen seem to have a higher tolerance of pain and do not seem to need medical forms of pain relief as often as other women.

Perhaps this is because of their determined and positive attitude, perhaps it is because they have had to tolerate higher levels previously and have adapted or perhaps it is partly a result of the neurological damage caused by the spina bifida minimising the transmission of pain signals. Whatever the reason, my experience has been that most of the women who have had vaginal deliveries seem to have had relatively easy labours.

Our general policy with all women in labour is that they should try whatever position feels comfortable and this applies equally to women with spina bifida. Some of those who have a more marked curvature of the spine have found actual delivery on their sides easier.

I do not treat them as higher risk and would not expect to be present during labour although I am of course available should the need arise. They may be likely to have more problems in labour but midwives and obstetricians are trained to handle these and many can be anticipated before the day of labour arrives so there is rarely any cause for concern.

On the whole my experience of women with spina bifida has been very positive and it is very rewarding to witness their happiness and fulfilment when the baby is born.

From page 11. Tracey Proudlock

showers, although new, were of the stand-up variety with a step-up cubicle and no anti-slip mats so they were inaccessible to me.

During labour, the doctor had advised that an in-dwelling catheter be inserted which I was reluctant about as I do not normally have one and was concerned that it might affect my continence management after the birth. After the birth the doctor said: "We'll leave it in" and, although I protested initially, I was very glad of this decision in retrospect. What I had not realised was how much fluid your body does pass after birth and, had it not been for the in-dwelling catheter, I would have been needing to get up and go to the toilet every hour or two.

When I got home and started to self-catheterise again, I did experience problems inserting the catheter. Neither the health visitor, the community midwife, nor the GP could help me and I spent a very uncomfortable eight hours until the antenatal doctor came up with the answer. After a vaginal delivery everything shifts a little bit and, instead of inserting the catheter into the urethra, it was hitting the back of the vagina wall. I got hold of a special small mirror that hooks onto the toilet so that I could see everything more clearly and the insertion of the catheter ceased to be a problem. I wish my continence adviser had thought of warning me about this in advance!

One final point is about breast feeding. Everyone seems to think you are such a martyr nowadays if you choose to breast feed but I actually wonder whether disabled women should get even more support to breast feed since it is so much easier. There were often times when I just didn't have the physical energy to get up, and making up bottles would have been a real effort whereas breast feeding seemed so convenient. It also encouraged me to take care of myself: eating well and having a regular sit-down.

In retrospect, I wish I could have been calmer about the whole experience. Each day of the pregnancy I felt as if I were the only pregnant woman in the world!

About DPPI

DISABILITY, Pregnancy and Parenthood International (DPPI) is a non-profit quarterly journal aimed at everyone interested in promoting better awareness and support of disabled people in pregnancy and parenthood. It aims to inform health and social work professionals, disabled people who are already parents and those who wish to become parents, and organisations concerned with disability and/or pregnancy and parenthood. It includes news of professional good practice and pioneering projects, useful new research, books and audio-visual resources, and the expertise and experience of veteran disabled parents themselves.

Annual rate for institutional and professional subscribers: £20.00 (UK); £25.00 (outside UK). Subsidised rate for individual subscribers: £12.00 (UK); £14.00 (outside UK). ***To subscribe: send your name, address and payment (cheques payable to Arrowhead Publications) to: Arrowhead Publications, 1 Chiswick Staithe, London, W4 3TP. Please state if you prefer to receive DPPI on audio cassettes).***

The LINK diary

This and That!

THE SKY'S the limit for amputee Ray Gainer who has been offered a specially-designed leg to allow him to bag his commercial pilot's licence.

Ray's "flying" leg is being made for the *This Is Your Life* personality – featured in the last *Link* – by a robotics expert. The pair met recently while Ray was doing some flying tests in the United States of America.

The robotics expert flew in specially from Seattle after being contacted by a doctor Ray knows at the Texas Medical Centre – which is situated close to Euston, where Ray was flying.

No charge was made for the consultation and, once Ray was back home in Liverpool, further information on the new leg was exchanged by fax machine.

The new leg will cost around $10,000 and Ray *(pictured below)* is now setting about trying to raise the cash.

He aims to return to the United States this autumn to have the new leg fitted and take his final flying test – even if it means sacrificing his part in this year's European Wheelchair Tennis Tour.

"My sports are important but so is my leg and so is my flying. A lot of people have backed me for this course and I'll get it as long as I can get this leg made."

While in the States for a fortnight in April, Ray did a lot of flying – including a fun trip on NASA's space shuttle simulator.

During the commercial pilot tests, Ray took full control of the plane while his examiner went over areas which needed refreshing.

Ray, 34, said: "The biggest problem was my leg because I couldn't get it to work as I wanted. I could still fly but I know I could do better with a better leg."

However, even though he is making the commercial pilot's licence his number one objective this year, Ray still intends competing in two major British wheelchair tennis championships – at Sheffield and Warrington.

He is being sponsored in both these events by his sports club, but has been less successful in gaining the £800 sponsorship needed to enter the European wheelchair tennis circuit which run from the end of June to August.

Disappointed, Ray said: "I've sent off 150 letters and CVs of my achievements but have not received one reply. I've tried really hard to get some backing and it gets you down when you don't even get an acknowledgement."

But, never one to give up, Ray is still hopeful that an offer of sponsorship will come through in time.

LC

SUPPORT is needed for this year's parachute jump to raise money for ASBAH and local associations.

Last year's highly successful National Parachute Jump raised £31,345 – split between ASBAH and The Children's Society.

In addition, Sussex ASBAH – the only local association agreeing to take part last year – earned itself £2,333.

This year ASBAH is organising its own jump at four parachute centres in Cambridgeshire, Northamptonshire, Suffolk and Kent.

Local associations or individuals wishing to take part in this year's event – planned for the weekend of 23 and 24 September – should write or phone NOW for full details and sponsorship forms.

Appeals manager Roy Johnston said: "Once any costs have been covered, local associations could receive the bulk of the funds raised by them at their nearest parachute centre."

John Rogers (left), key volunteer organiser, Roy Johnston, ASBAH appeals manager and David Hoyle of The Children's Society with proceeds from last year's parachute jump. Picture taken outside the Royal Marines Museum, Southsea. Photo courtesy of The News Portsmouth.

Roy is also looking for people willing to be contacts for Ipswich and Northampton.

For more details of the parachute jump, contact Roy Johnston at national centre on 01733-555988.

Commons launch for our needs assessment & training service

ASBAH has pledged its support to social workers throughout England, Wales and Northern Ireland – in a bid to get effective community care to everybody with spina bifida and/or hydrocephalus.

The support comes in the form of an expert helping hand from START, our new needs-led assessment and training service which was launched at a reception in the House of Commons, held in the presence of our patron, HRH The Duchess of Gloucester.

Government ministers – including John Bowis (Health) and Eric Forth (Education) – MPs, peers, heads of several national voluntary agencies, professional colleges and local government institutions gathered for the event on 15 May.

They heard how START will help social services departments as they carry out their lead-role duty to assess the needs of people with spina bifida and/or hydrocephalus who are struggling to make their own way in the world – often against a background of swingeing cuts in department budgets.

"The world young people are entering today is extremely hard and certainly highly competitive, particularly for those with a disability," ASBAH vice-chairman Austin Crowther said at the launch.

"Spina bifida and hydrocephalus can be very severe and complex disabilities, requiring careful assessment of abilities to form an essential foundation for progress. Our experience so far is that many community care assessments are superficial and ineffective."

Mr Crowther said ASBAH was not yet ready to deliver a verdict on the ability of social services nationwide to deliver community care to disabled people – as "the jury is still out."

Many social workers do not have the expertise in these disabilities which would enable them to carry out effective assessments of need. This is where START comes in.

Rising phoenix-like from the closure last year of our Five Oaks assessment and training centre in West Yorkshire and led still by Joan Pheasant, START will fill in gaps in knowledge, and help social services departments and health services work out the most effective ways to help ASBAH's service-users become more independent.

START will travel the country taking part in assessments and running its own training courses. Because the service is backed by ASBAH's general charitable income, prices have been pitched at levels that social services can afford.

To coincide with the launch, over 1,500 specially-prepared information packs were posted to social services directors. There were enough copies to land on the desks of all their key staff involved with disabled people.

Mr John Bowis *(pictured above)*, the Health Minister responsible for community care, welcomed the professional input that ASBAH was offering to put into the assessment process. He said this would be "a tremendous benefit" to people charged with carrying out the assessments.

"Your reputation ranks high at the Department of Health because of what you have achieved. You are also a dynamic organisation and we have had a dynamic presentation from you today, and that is right and proper," said Mr Bowis.

START -
THE COM

**INQUIRIES about START were received fron
even before launch day at the House of Co**

**STARTS offers an expert helping hand to so
tackling problems faced by ASBAH's service-u
as much indepence as possible. Its st[illegible] help
effective assessment of individual nee[illegible] in or
level of support required.**

**One inquiry was about a young man who ha
at sall well on a work-training scheme.**

**Joan Pheasant, START manager, said: "In th
the young man was having problems because
not understand his disability and so tasks were
in a way which he could not grasp readily.
culties coping with his personal care."**

**The result was that START was commissioned
assessment and suggest ways of easing the pr**

**Another inquiry concerned a young couple, bot
who are living with one set of parents.**

**Joan said: "We have been asked to assess the
find out the level of independence they can
would be required to maintain this."**

MAKING CARE IN MUNITY A REALITY

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oth with disabilities,

e couple in order to achieve, and what

Sometimes, START is called upon to liaise with both parents and local authorities as an independent source of expertise. "We give independent advice on the disabled person's abilities and work out strategies to enable them to cope," said Joan.

This may include cases in which a child is put on the 'at risk' register by social workers if they consider a parent cannot look after the child.

"We observe the parent and child over the assessment period and compile a report on our observations to enable the courts to decide about the future care of the child."

Individual assessments can also be made of children with behavioural problems. In these, START calls in psychologists and other professionals to assist. Depending on the outcome of these assessments, START arranges courses for the families and/or individuals involved.

At first, START is being offered to social services departments. Later, the service may be extended to schools, health authorities and possibly fund-holding GPs requiring a practical life skills assessment alongside a medical report.

For more details, contact: START, Five Oaks, Ben Rhydding Drive, Ilkley, West Yorkshire, LS29 8BD. Tel: 01943-609468.

What is an OT?

by Rose Hinchliffe
Occupational Therapist
START team

WHEN someone asks me what I do, I find myself inwardly squirming.

When I say the words "occupational therapist", I either get a blank look or "so you can help people find jobs" response or – the one that makes me squirm most – "you make baskets and stuff fluffy bunnies."

I cannot tell you how delighted I am when someone has an accurate understanding of what I do – in this case usually because they have had, or know someone who has had, occupational therapy.

So what is occupational therapy? Even with three years training and almost six years experience, I still find it hard to explain in a nutshell just what it is, but here is how it is defined in a textbook:–

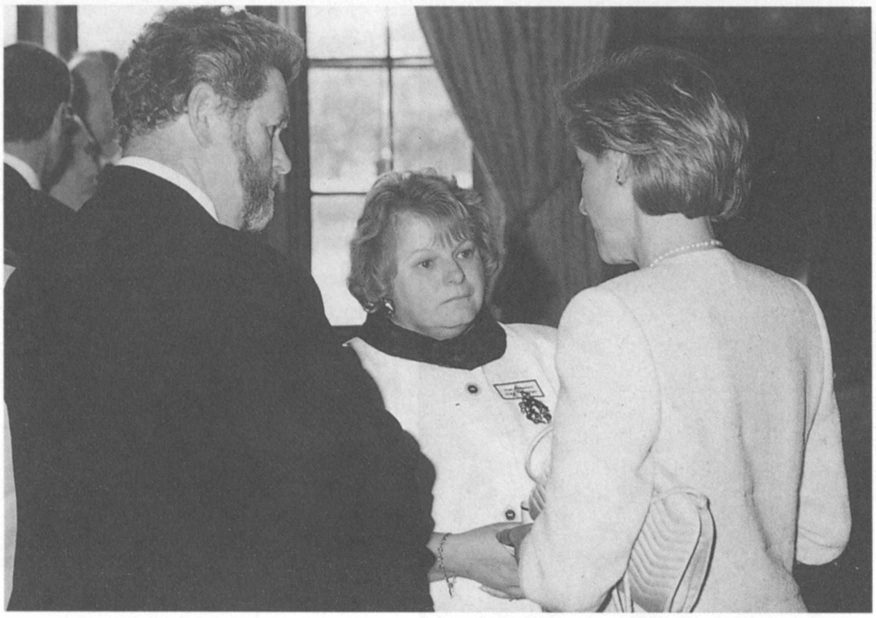
"Occupational therapy is the treatment of people with physical and psychiatric illness or disability using specific activities to enable the individual to reach their maximum level of function and independence in all aspects of life."

Rose Hinchliffe

Quite a mouthful, don't you think, but what does it mean?

more on page 16

TS: TONY BRITTON AND LIZ CAWTHORNE PICTURES: CHRIS LOWNDES



ASBAH's patron HRH The Duchess of Gloucester, GCVO, talks to START manager, Joan Pheasant, (centre) and Austin Crowther, ASBAH vice-chairman, at the launch of ASBAH's Service Team for Assessment, Rehabilitation and Training at the House of Commons, London on 15 May.

From page 15 – Rose Hinchliffe, our own occupational therapist

Basically, more than anything else, the activities selected must be tailored to suit an individual.

For example, a young mother who has had a spinal injury and now has to use a wheelchair. Perhaps it would be really important to her to be able to prepare meals for the family independently.

So the occupational therapist (OT) would work with the mother in preparing a programme so that, as well as adapting and learning to prepare meals working from a wheelchair, she would improve her wheelchair skills in a confined space and, most importantly, look at her kitchen for adaption and advice.

Or an elderly man who has had a stroke and, as a result, has reduced use in one of his arms. Even though lots of activities in the kitchen would benefit his affected arm, he may not be motivated because his wife does the cooking.

You find OTs in a variety of situations – hospitals, social services, days centres – working with different types of people of all ages, from children to adults to the elderly.

So what has an OT got to offer someone with spina bifida and/ or hydrocephalus? First of all assessments – not just of their physical needs but of their psychological and social needs. OTs can advise on treatment for specific problems such as transferring skills and the provision of specialist equipment and advice and information on adaption to the home.

The OT should discuss all these things with the individual and their carer(s).

A simple example would be a young person with spina bifida, who is a wheelchair user and has just moved into his or her own flat. The person might be totally independent except for a step up to the front door which he or she cannot manage.

A community OT, usually through referral to social services, would visit this person in their own home and identify from assessment that their only problem is access and, after discussion with the person concerned, recommend a suitable wheelchair ramp.

Once the ramp has been installed, the person is now physically able to gain access – psychologically they do not have to depend on anyone else, and socially they have the choice to go out.

If an OT ever does ask you to make baskets and stuff fluffy bunnies, it is for a purpose – perhaps as a finger-strengthening exercise or to increase someone's concentration. Whatever an occupational therapist suggests , it should be related to their everyday life.

So, if you ever come across an OT, make their day. Don't mention baskets and fluffy bunnies but say "ah ... you look at an individual's physical, psychological and social needs." A word of warning, however. You will probably have to pick them up off the floor as they have fainted in surprise!

A BROCHURE about training courses offered by START has been inserted into this edition of Link. There are three courses in the immediate future. To book a place on any of the courses, please use the form, or contact: Joan Pheasant, START manager, Five Oaks, Ben Rhydding Drive, Ilkley, West Yorks LS29 8BD, tel: 01943-609468.

Hydrocephalus Network
News

SUMMER 1995

ASSOCIATION FOR SPINA BIFIDA AND HYDROCEPHALUS

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

The Hydrocephalus Study Day planned for November has been postponed until the Spring, now that the study day on Wednesday 21 June, "Understanding Hydrocephalus" has been opened to parents. If you want further information please contact Rebecca Sewell, Eastern Regional Office, ASBAH House, Peterborough, tel: 01733-555988.

The first of a series of articles on hydrocephalus for *HN News* by Dr Roger Bayston

Hydrocephalus: what it is and what causes it

By Dr Roger Bayston
M Med Sci MRC Path
ASBAH's Honorary Consultant in Hydrocephalus

THE TERM "hydrocephalus" is from two Greek words meaning "water in the head." In fact the "water" is cerebrospinal fluid (CSF), a clear liquid which is produced all the time in the cavities or ventricles inside the brain. It passes from one ventricle to the next (four in all) through narrow pathways, then circulates around the surface of the brain – a little also goes down the spinal cord – and is absorbed back into the bloodstream. The absorption takes place through specialised veins inside the skull which have a sieve-like surface. Though much slower than the circulation of the blood, the CSF is constantly being produced, circulated and reabsorbed.

Hydrocephalus can result when either too much CSF is produced (very rare), or when it is prevented from circulating or being reabsorbed. As in these circumstances CSF is constantly produced but cannot get out, it accumulates and causes raised pressure inside the brain. The ventricles swell and the brain tissue is stretched and squashed. The skull bones in babies and young children are not fixed together as they are in later life, and the pressure causes the head to increase in size. However it is important to

continued on page ii

Reminder ....

Rosemary Batchelor, ASBAH's disabled living co-ordinator, would like to remind parents that anyone with hydrocephalus showing signs of shunt blockage should be taken to their neurosurgeon and not the local hospital.

She said: "We are getting an increasing number of calls telling us of cases where people with shunt blockages are admitted to local hospitals and then having to be transferred to a neurological centre."

....

Hydrocephalus: what it is and what causes it

By Dr Roger Bayston

from page i

realise that hydrocephalus can also arise in older children and in adults. A later article will deal with the effects of hydrocephalus on those who have it.

A number of conditions can give rise to hydrocephalus. Uncommonly it can be due to a genetic disorder, in which case other members of the family are usually affected.

Non-genetic causes are more common. In babies who are born with hydrocephalus the condition is said to be congenital, and it must be realised that this means simply that it is present at birth, and not that it is hereditary. In congenital hydrocephalus the actual cause is usually impossible to determine but it is assumed to be due to events during the baby's development before birth, such as damage to local blood supply or infection. A known cause of congenital hydrocephalus, uncommon in this country, is toxoplasmosis.

About 20 years ago the commonest form of hydrocephalus was that associated with spina bifida. At least 80% of people with spina bifida have some degree of hydrocephalus though it is not always in need of treatment. Here the interference with CSF flow is due to abnormalities of the brain structure at the back of the head which develop at an early stage of the pregnancy. This is often called the Arnold-Chiari malformation.

In recent years far fewer babies have been born with spina bifida, and the largest number of cases of hydrocephalus in infancy occur in babies born prematurely, due sometimes to maternal ill health or smoking. Even very small babies can now be made to survive, but their vital functions, normally taken care of during pregnancy by the mother, have to be controlled artificially. Unavoidable rapid changes in blood pressure can cause bleeding in the brain, and the blood from this haemorrhage blocks the sieve-like absorption system leading to post-haemorrhagic hydrocephalus. Brain haemorrhage in adults (stroke) is similar and can also lead to hydrocephalus in survivors. Head injury sometimes has the same effect.

Another way in which the CSF pathways can be blocked is by debris and pus in acute infections of the membranes surrounding the brain (meningitis). This can arise in previously healthy babies if they are unlucky enough to develop a serious bloodstream infection soon after birth, but it can happen to anyone in any age group. Fortunately, meningitis is not common and one major cause, haemophilus, has been greatly reduced by the introduction of the HIB vaccine.

Other types of hydrocephalus can be due to obstruction by cysts in the ventricles. Dandy-Walker cysts, which block the fourth ventricle at the base of the brain, are an example of these swellings.

Brain tumours can obstruct the CSF flow, either by their bulk or by causing brain swelling. In adults, blockage of one of the connecting pathways between the ventricles (aqueduct stenosis) can cause the onset of hydrocephalus. Two other conditions, benign intracranial hypertension (not very benign for those who have it) in which the CSF pressure is raised, and normal pressure hydrocephalus in which, as the name suggests, the CSF pressure is not raised and which is probably not hydrocephalus at all, are also seen in adults.

Finally, hydrocephalus is often classified as either communicating or non-communicating. In the first type, the problem is usually failure to absorb the CSF at the end of the system, whereas in the second there is blockage of the CSF pathways within the ventricular system.

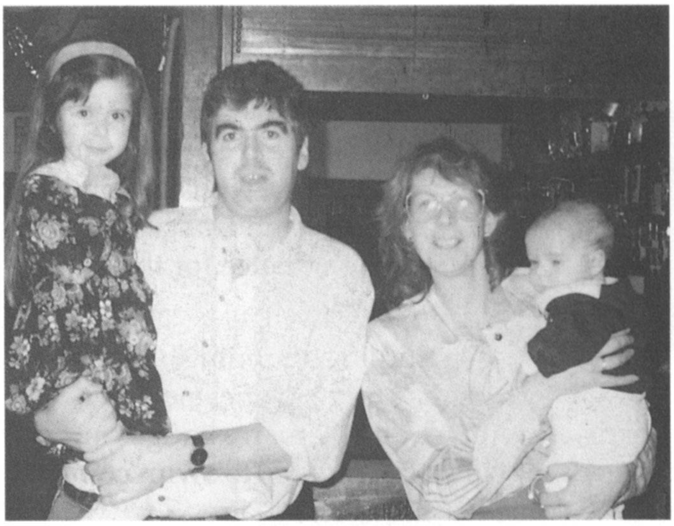
In later articles I shall be describing the treatment of hydrocephalus and its possible complications; the effects which hydrocephalus has on the structure and function of the brain and the ways in which this affects the person who has the condition.

Dr Bayston is based at City Hospital, Nottingham.

The first of a series of articles on hydrocephalus for *HN News* by Dr Roger Bayston

No fear of flying

Fear of Flying, the article in the New Year issue of *HN News* on whether children with hydrocephalus should travel on aeroplanes, prompted a response from a family in Bolton, Lancashire. Liz Cawthorne reports.



The Watkins family – Jennifer, Keith, Marilyn and baby Thomas

SEVEN-year-old Jennifer Watkins, who had her first hydrocephalus shunt fitted when she was five months old, has flown many times with parents Keith and Marilyn to take holidays in Spain.

Her parents, both now aged 40, had taken advice about flying from specialists in this country who told them there was no need to worry as the pressure-controlled cabin should not affect the shunt.

As a baby, Jennifer used to fall asleep as soon as the plane had taken off. As she got older, Mr Watkins recalls his daughter feeling a little uncomfortable as the plane descended, but this problem was usually overcome by giving her sweets to suck.

It was during a fortnight's holiday in Majorca, when Jennifer was three years old, that the nightmare of every parent of a child with hydrocephalus arose.

What started out being a suspected cold, was actually a blocked shunt.

Mr Watkins, from Bolton, Lancashire, explained: "Jennifer had had a cold before we arrived, but on the first day we'd gone out for a meal and she virtually keeled over. We stayed in the apartment for a couple of days and she started vomiting, so we called the doctor. He thought it was a virus and gave her something for it.

"On the Wednesday she perked up a bit and was OK for a couple of days.

"Then she relapsed and had pains in her head and on the Saturday we had to call the doctor again who wanted her to be checked in hospital."

They were rushed by ambulance to a private hospital in Palma which Mr Watkins describes as "immaculate." After studying the results of the x-rays, doctors said they were going to operate.

Mrs Watkins wanted Jennifer to go home but the family was advised against this because of the danger of any further delay.

Mr Watkins said: "We relented and they whisked Jennifer away to a children's hospital five minutes away and operated that afternoon.

"At about 6pm they wheeled her back out and said the bottom of the tube had been blocked but was now clear and fluid was beginning to drip through."

The couple's holiday apartment was 50 miles from the hospital so they were moved by holiday company Thomsons to a nearby hotel.

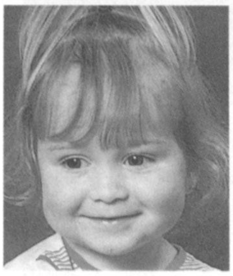
As the end of their holiday approached, the family were hopeful they would return home on the booked flight. But it wasn't to be.

Mr Watkins explained: "Jennifer came out on the Friday morning and we were due to fly home on the Saturday evening. Then, at 10pm on the Friday, she woke up crying and screaming and we had to take a taxi to fly back to the hospital."

A neurosurgeon was called to the hospital who, after examining Jennifer, said there was definitely a problem with the shunt and it would have to be removed.

more on page iv

South African dancer



LAST year, Charlotte Bellamy, from South Africa, (*pictured left*) won a trophy at the East Rand Dance Festival in the set dance for three-year-olds.

And in swimming, Charlotte has three proficiency awards, five meter and 10 metre badges and a young diver badge. She wants to swim competitively like her big sister, Claire.

Charlotte, now four, goes to playgroup as South African children do not go to school until they are seven. She has ballet and swimming lessons.

The Association for Spina Bifida and Hydrocephalus in South Africa produces a newsletter for members. The contact address is: **PO Box 17109, Congella, 4013, Natal.**

Reader's letter

We have just returned from America and I felt I must write to you following your article *Fear of Flying*.

My daughter Vicki, who is 13 years old and was born with hydrocephalus, seemed to suffer no ill effects from the flight, not even 'popping ears'! In total, it was her fourth trip on a plane.

Vicki had a particularly bad year last year and had to have four revisions of her shunt due to blockage. We were a little apprehensive about taking her but we very much in need of a holiday, and did so on the advice of her specialists.

I realise this might not agree with everyone's experience, but we had no problems.

Mrs J Arnott, Blackpool, Lancs

No fear of flying from page iii

"By that time we were down in the dumps as all we wanted to do was to go home."

Jennifer was in intensive care for three days and the family remained in Majorca for another week or so.

She was released from hospital two Wednesdays later and a flight was booked on the Friday night.

An ambulance arrived at the hotel at 5.40pm to take the family to the airport, but they were told by Thomsons they did not have authority to leave Spain.

Nevertheless, they went on to the airport, got through Customs and into the departure lounge only to find the flight had been delayed by seven hours. Once on the aircraft, they were again told, this time by a stewardess, that they did not have clearance to leave.

Clearance was eventually obtained and, after a trouble-free flight, the family arrived in Britain to be transported home by car.

Their consultant in the UK read through the Jennifer's notes written by the Spanish doctors. Although the new shunt was not one the British consultant would have chosen, everything looked fine.

The family returned to Majorca the following April to put their previous experience behind them.

Mr Watkins said: "If anything ever goes wrong again, we'll know what to look for. One of the most annoying things was the Spanish authorities not being able to get Jennifer's records from her hospital in Britain when they faxed through to them. All they received was an acknowledgement of their fax!"

"The Spanish, on the other hand, gave us copies of everything they had done to take back with us."

Mr and Mrs Watkins only go on holiday to countries like Spain which they consider offer good medical care.

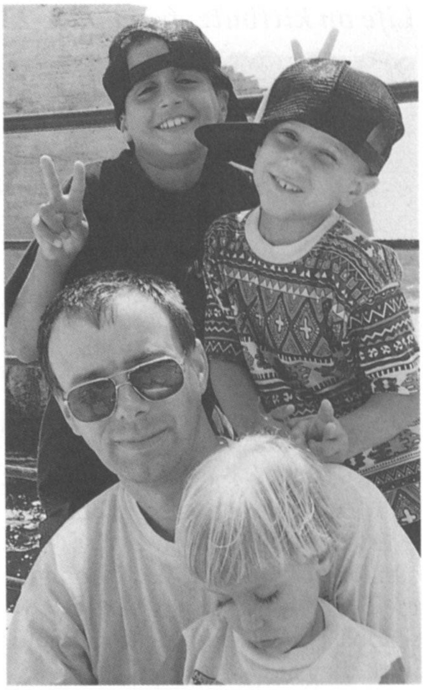
"We wouldn't go to Greece or the Far East and I wouldn't like to drive through France and get stuck with a medical problem in the middle of nowhere.

"In Spain, once the authorities decide to get moving, they are out of this world. We also had a great deal of back up from the insurance company, and Thomson's staff were superb."

Note: *If you are going abroad, our Information Department, with plenty of notice, can find your nearest neurological centre.*

Life on kibbutz

Link reader Simon Robins and his wife Ayelet and three children live on a kibbutz in Israel. Their youngest daughter Dolev has hydrocephalus. Simon describes their communal lifestyle and how they have coped bringing up a sometimes seriously ill child.



Dad Simon with sons Eder and Lotem, and daughter Dolev, who has hydrocephalus

OUR story starts in the summer of 1978 when I went to a kibbutz in Israel as a volunteer. I stayed at Kibbutz Neve Eitan, which is very close to the Jordanian border and a few miles south of the Sea of Galilee. I met my future wife, Ayelet, during these months. She was born on the kibbutz.

We lived in England for a year but in 1980 we decided to return to Israel and to the kibbutz.

We are both teachers – I teach English as a foreign language at the kibbutz regional high school and Ayelet is a primary school teacher.

In 1982 we got married and now have three children – two sons, Eder, aged 11, and Lotem, eight, and a four-year-old daughter, Dolev, who has hydrocephalus.

There were a lot of problems in Ayelet's third pregnancy. She was going to have twins but in the 26th week it was discovered she had too much amniotic fluid. She taken to hospital immediately and in the 28th week the doctors decided that a Caesarean was necessary.

One baby sadly died after two weeks. By that time the other baby, Dolev, had been diagnosed as having hydrocephalus. She was transferred to a central hospital in Haifa where she received a shunt. Dolev's weight at this time was just one kilo. The doctor said that she was the smallest baby in Israel to receive a shunt.

Dolev finally came home after nearly four months of intensive care.

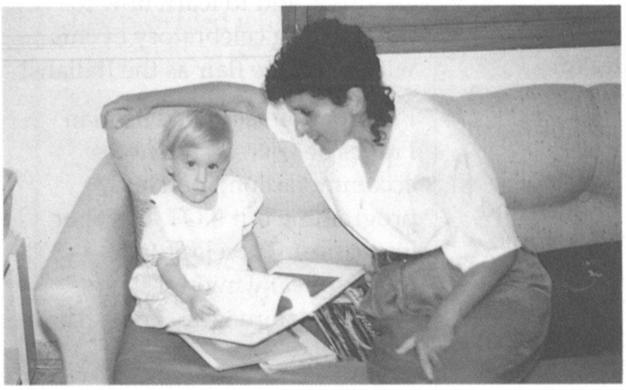
At that time Ayelet and I translated an American booklet about hydrocephalus for parents into Hebrew, as a way of thanking the doctors for what they had done for us and to help other parents in Israel know more about hydrocephalus and its treatment.

Dolev has not been very lucky since then.

She has been through some 10 additional shunt-related operations since the first one. She has had two shunts and an external shunt. Her present shunt has been functioning perfectly for nearly two years now – touch wood.

In one of her last operations Dolev received some infected blood. As a result she has hepatitis C. After consulting various experts including Professor Mowat in London, Dolev started receiving injections of Interferon in April 1994. She had to have three injections a week for a year. These have proved successful and the dosage has now been doubled.

Dolev has a tendency to have epileptic attacks and although she receives medication for this, she still has one occasionally. The doctors do not know what triggers them but one theory is that Dolev may have scar tissue on her brain as a result of all the shunt-related operations and that this is the trigger. However, nobody really knows for sure.



Mum Ayelet and Dolev in the family home on the kibbutz

Dolev has to catch up with her peers. She was born very prematurely and has spent a lot of time in hospital. She has occupational therapy on a regular basis and is making excellent progress. Dolev is very outward-going, talkative and makes people laugh. Her motor development is slightly behind but mentally she is fine.

Dolev now receives some physiotherapy almost every day from a kibbutz member who receives guidance from a professional physiotherapist. Dolev goes to a regular kindergarten and takes part in all of the activities.

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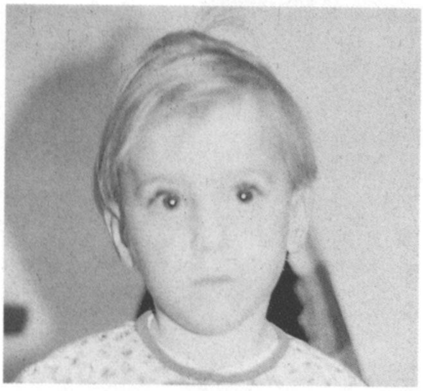
Life on kittbutz, from page 23



Daughter Dolev

Even though we live on a kibbutz, every day life is in some ways similar to any other place. You go to your job and the children go to school. The children sleep at home until they are 18 years old.

On the other hand, there are many features of kibbutz life which could be regarded as very unusual.

All kibbutz members receive the same income from the kibbutz no matter what their job or responsibilities are.

Those who work outside the kibbutz give their salaries to the kibbutz and receive the same allowance as everyone else.

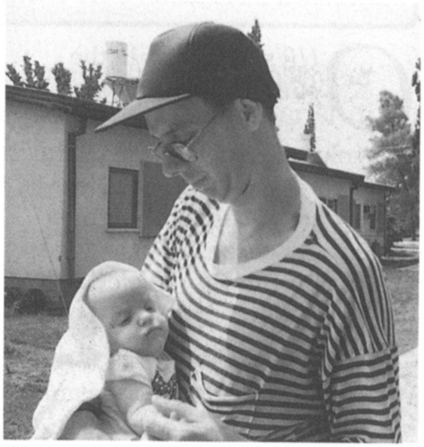
The kibbutz provides a number of services for its members. Meals are usually eaten in the communal dining room although people sometimes eat supper at home. Laundry is done centrally and collected by members a few days later.

People past 'retirement age' (60-65 years) continue working. People work for as long as they can, wherever they can make a contribution.

Health and education are expenses which are paid for by the kibbutz and not by the individual.

Living on a kibbutz is an advantage when a family member has serious health problems. Ayelet and I have both been able to continue with our teaching careers. Every-day problems, such as paying the rent or buying the next meal, do not exist because we live on a kibbutz.

On the other hand, if your child is seriously ill, then this is essentially a family problem and you, the parents, have to deal with it alone – like anywhere else, I suppose.



Simon and Dolev as a baby outside their home on the kibbutz

A chance to learn, celebrate and share experiences with fellow Europeans

THE following projects, run by Mobility International, are aimed at anyone who is interested in attending.

❍ **An international conference on civil rights and independent living, from 27 August-2 September at the Sonnenberg Centre near Braunschweig, central Germany.**

The conference will look at: developments in social legislation for people in Europe; the United Nations Standard Rules for Equalisation of Opportunities and what can be achieved at European level.

Working languages: English and German. *For more details contact: Gerd Meister, Internationaler Haus Sonnenberg, Bankplatz 8, Postfach 2654 D-38016 Braunschweig, Germany. Tel: + 49 531 49242. Fax + 49 531 42512.*

❍ **A big sports, artistic and cultural festival** with music, dancing, eating and drinking, **at the end of November in Milan, Italy.**

Called *Festeggiamo Insieme (Celebrate Together)*, the event will also be looking at good examples of integration in all these areas, so there will be a chance to make friends with people from other countries and to learn how to organise big celebratory events with the same flair as the Italians!

Particpation fee: 9,000 Belgian Francs per person (includes accommodation, food and programme but NOT travel or insurance). Travel refund +/- 35% for European Union residents. Working languages: English and Italien. Ref: EU-6-95.

❍ **A Question of Image – Using the Media, from 2-6 December, in Paris, France,** will look at how to change attitudes through the media.

There will be presentations from disabled journalists and workshop discussions on how to improve the media portrayal of people with disabilities.

Participation fee: 7,500 Belgian Francs (includes accommodation, food and programme but NOT travel or insurance). Travel award: +/- 40% (for European Union residents). Langauges: English and French. Ref: EU-8-95.

For further information about any of these events and projects, contact Mobility International, rue de Manchester 25, B-1070 Brussels, Belgium. Tel: +32 (0) 2 410 6297. Fax: +32 (0) 2 410 6874.

Sexuality and incontinence

AROUND three million people are likely to be regularly incontinent in the UK yet often sheer embarrassment stops many people from seeking help.

National Continence Day on 21 March – following on from last year's National Continence Week – aimed to raise awareness and encourage sufferers to seek help.

This year's event – Dry Days/Dry Nights – focused on the particular needs of ethnic minority groups, carers, child and adult night bed-wetting and the role of pharmacists.

For its part in the day, the Royal College of Nursing organised a conference on Disability, Continence and Sexuality in Special Needs Children for nurses who care and support families with special needs children.

Editor Liz Cawthorne joined the conference to find out what is needed to tackle this widespread but often embarrassing problem.

PARENTS as well as professionals face one of their greatest challenges in tackling the issues of incontinence and sexuality, says Phillipa Russell, director of the Council for Disabled Children.

As a signatory of the UN Convention of the Rights of the Child, the UK is obliged to ensure the survival, development, protection and participation of children with disabilities – allowing them full citizenship and the ability to enjoy life.

Family life has changed over the years. According to the Office of Population Censuses and Surveys, 360,000 youngsters aged 16 and under have significant disabilities in England and Wales; 189,000 have very severe disabilities and 5,500 children live in residential care and 16,000 children attend 52-week-a-year residential schools including emotionally disturbed children. Fourteen per cent of disabled children were regarded as having behavorial problems by their carers.

The theme – *Special Child, Special Parent?* – was pursued with examples given of over-protective parents who were constantly vigilant that their children did not miss out, resulting in the child not being allowed to grow up.

Mrs Russell said: "Sometimes your most important role is to stop the parent from being over-protective. The messages for the future are sharing concerns with the parents but also listening to the children, which requires special expertise and training."

Communication problems are often at their worst when it comes to talking about sexuality.

Mrs Russell gave some examples of teenagers, some with spina bifida, who had experienced this.

continued at foot of page 24

Charter for Continence

The Charter for Continence – launched on **National Continence Day** – presents the specific needs and rights of people with bladder or bowel problems. It outlines the resources available and the standards of care that can be expected.

As a person with bladder or bowel problems you have the right to:

- ❍ Be treated with sensitivity and understanding.
- ❍ Become continent if achievable.
- ❍ Receive a thorough individual assessment of your condition by a doctor or nurse knowledgeable in this aspect of care.
- ❍ Request specialist advice about continence care.
- ❍ Be provided with a clear explanation of your diagnosis.
- ❍ Participate in a full discussion of treatment options, their advantages and disadvantages.
- ❍ Be provided with full, impartial information on the range of products which are available and how to obtain them.
- ❍ Expect products to have clear instructions for use.
- ❍ Receive regular reviews of treatment and be given the opportunity to change treatments if your condition has changed.
- ❍ Be made aware of any treatments or products as they become available.
- ❍ Be provided with a personal contact point able to give you on-going advice and support.

Dry days, dry nights

THE GOVERNMENT'S Chief Nursing Officer, Yvonne Moores, dropped in on the Continence Day conference after attending the official press launch.

As part of its contribution, she said, the Department of Health had sent out window stickers to pharmacies with the *Dry Days/Dry Nights* logo and the message 'Ask your pharmacist for advice.'

There were also bookmarks giving the numbers for the adult and children's helplines produced in Urdu, Bengali, Hindi, Gujurati, Greek, Turkish, Vietnamese, Cantonese, Somali. The Welsh Office had some published in Welsh on one side, English on the other.

Mrs Moores said: "There are three million adults in England who have a problem with continence and half a million six to sixteen-year-olds who regularly bed-wet. This is a huge number but still most of those are not seeking help. Only one in six are coming forward and talking about it

"Seven out of 10 could be cured and the other three could have their lives improved."

Mrs Moores added: "One of the greatest myths about incontinence is that only older people have the problem and that nothing can be done about it."

The following new initiatives were also mentioned:

- Guidelines for boarding schools produced by ERIC - the Enuresis Resource and Information Centre.
- The focus this year on ethnic minorities.
- Raising awareness about the pharmacists' role.
- *The Charter for Continence*, produced by a coalition of voluntary organisations.

Mrs Moore said: "Last year's message was *Don't Suffer in Silence*. This year the message is *Let's Talk About It*. It's time to turn wet days and nights into dry days and nights."

Helpline numbers

TWO helpline phone numbers have been set up for people wanting information and advice about incontinence.

For adults, the number is 0191 213 0050 which is open Monday-Friday 9am-6pm.

For advice on childhood bed-wetting, call 0117 926 4920. This service operates Monday-Friday 9.30am-5.30pm.

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continued from page 23

Paul, 13, who has spina bifida, said: "My mum won't talk to me about sex. I think she feels sorry for me ... I think she feels I won't ever have a girlfriend."

Francis, 15, who has spina bifida and lives in residential care, said: "I'd like to know if I can ever have children ... I am not sure if I want them ... but I'd like to know."

At school there is a notion that no one is different, so issues like sexuality and continence among disabled pupils are not talked about.

Mrs Russell said: "If the child was black, nobody would think it didn't need other black people to talk about their culture etc, but it's not like that for disabled children."

The areas in which nurses can help are:

- Nursing – giving advice on nutrition, continence, etc.
- Teaching – giving practical guidance on care in the home.
- Educational assessment – what the child is going to need at nursery school.
- Respite-care advice.
- Support – advice and counselling.

When a group of parents with disabled children in Sheffield were interviewed, this is what they had to say about their healthcare professionals:

- Be treated at partners.
- Don't put us on trial.
- We resent being made to feel inferior.
- Don't forget, we have other demands being made on us.
- Could professionals consult each other.
- Try and be flexible - consult parents and children.
- Tell us if other professionals are going to be consulted. Don't work behind our backs.
- Keep appointments; don't be late.
- Remember our feelings.
- See us as people.
- Some of us have seen 15 different people.
- If things are wrong, say sorry.
- Don't fob us off with silly excuses.
- We wouldn't feel so angry if we were involved.

Being honest and entering an open debate with parents early on was the best policy – even if there were some painful things for them to face.

Mrs Russell said: "Parents and children don't want things to be decided before they are consulted."

If it is necessary to consult with others in order to decide how to tell parents something in the best way, Mrs Russell said, this should be explained to them beforehand.

Why sex education is crucial

CONTINENCE, sexuality and self esteem are three points on a triangle which are closely linked.

According to Maddie Blackburn, former ASBAH research fellow, continence and sexuality can be very difficult issues to face even by able-bodied people, let alone disabled people.

Maddie's research, carried out at the adult disability service at the Chelsea and Westminster Hospital in London, was based on interviews with 123 adults on sexual awareness and independence. She recently wrote it up for *Link*.

She recounted the experience of one young woman, who was a single parent with spina bifida yet living independently.

"The young woman said that her sex education was disastrous and the management of her incontinence had been non-existent until she became pregnant."

Although most of the adults interviewed had received some sex education, it was very specific to the non-disabled person. Images of disabled people were not shown as examples to the youngsters and, consequently, they felt excluded from the education system.

It was important that sex education fitted in to a person's cultural and religious framework and it should be graduated.

In her survey, Maddie found that most of the adults wanted more information about body development, contraception and child care.

Those taking part were asked what the words sexuality, friendship and relationships meant to them and in what way they wanted the information to be presented? Most said it should start with their parents but counselling and videos were extremely popular.

Maddie said: "There should be an opportunity to reinforce things over and over again, which is good for people with poor memory."

"Sex education should start at an early age so that the person doesn't grow up feeling dirty or with taboos.

"It is never too late to learn. People will come to you with problems and questions they have bottled up for 20 or 30 years.

"Because of technology they have survived but have never had their questions answered. The adult disability service provides a gamut of information and suggests where they can go for further help."

Video insight into the 'costs' of incontinence

Mary White

A 15-MINUTE video on Peter's life is the result of efforts by an ASBAH continence adviser to find out the 'costs' of double incontinence.

Mary White found that, over two years, Peter's incontinence cost £6,720 in pads, deodorants, clothes, travel to find advice and absence from work.

But the personal costs to him – in terms of self-esteem, acceptance by his peers and starting relationships – were far greater.

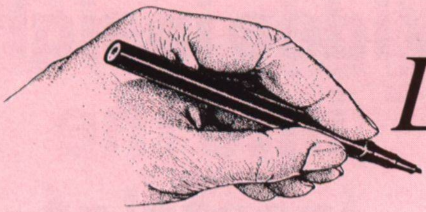
Peter's Story – launched nationally at the Royal College of Nursing's conference for *National Continence Day* – reveals the emotional trauma and tragedy of growing up with double incontinence – from feeling left out at school to attempts to have a sexual relationship with a woman at college.

The video will give confidence and hope to others affected by double incontinence, and will provide an insight - and a training tool - for professionals in health, education and social services.

The cost for Peter to have surgery so he could gain urinary control for the first time was £6,730 – shared by him and the NHS. Another £900, which was how much Peter's employer gave in terms of time off for the operation, brings the total cost to £7,810.

The video makes the point that the cost of surgery compared very favourably with the £6,720 previously spent on Peter's incontinence over two years, together with the incalculable costs to his personal well-being.

To order the video, send a cheque or postal order for £25.00 (payable to Derby & Distric ASBAH) to: Anthea Hewitt, Secretary, Derby & District ASBAH, St Merryn, 20 Burley Hill, Allestree, Derby, DE3 2ET.



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 WOULD, in response to Tracey Proudlock's letter (*Link*, last issue), like to say that independence (at least for me) isn't just being about PC, courageous and living a wholesome and healthy life.

It is (again for me) about getting what you want out of life. If what you want is a curry and a drink with your mates in the pub, then isn't the ability to get it just as much a demonstration of independent living?

Like everybody else on the planet, black, white, disabled or not, I do reserve the right to be a yob if I want to be. Equality is equality. You have to take the down side of that with the up.

If you want disabled people to be like other people, then you must expect them to be like all the other people and not just a single variety.

D Fulford-Brown
Wyton, Huntingdon.

DATES TO PUT IN YOUR DIARY

Saturday 1 July

Scoliosis Association (UK) meeting, south west region, Post-Graduate Medical Centre, Princess Elizabeth Orthopaedic Hospital, Wonford Road, Exeter, 11.45am-4.30pm. £3 person, inc refreshments (children under 15 free), payable by 16 June (cheques made out to Scoliosis Association (UK): *Mrs Monica Brennan, 70 Oxford Street, Burnham-on-Sea, Somerset TA8 1EW.*

2 - 3 July

Pathways '95 exhibition and festival directed towards increased enablement for disabled people, Westpoint Exhibition Centre, Exeter, 10am - 6pm both days.

Sunday, 9 July

Recreative Movement display afternoon, St Ivo Centre, St Ives, Cambs, in aid of Cambridge & District ASBAH. 2-5pm, admission £1.50 at door. (Ladies keep-fit inc wheelchair-users, keep fit to music, join-in sessions).

16 - 19 July 1995

Annual Mobility Roadshow and 'Ideas into Action', 7th international conference on mobility and transport for elderly and disabled people, Transport Research Laboratory, Crowthorne, Berkshire.

28 - 30 July

ASBAH weekend parenting course, 'Parents with disabilities and their families', Hereward College, Tile Hill, Coventry. Designed to give families a break, time to explore and learn, and to meet new friends. £25 each adult, children free. *Booking forms from Joan Pheasant, Five Oaks, Ben Rhydding Drive, Ilkley, West Yorkshire LS29 8BD, tel: 01943-609468.*

31 July - 6 August

National Spina Bifida Week. *Details: Tony Britton/Liz Cawthorne, ASBAH, 42 Park Road, Peterborough PE1 2UQ, tel: 01733-555988.*

Saturday, 16 September

ASBAH AGM, Peterborough. Speaker to be announced.

19 - 21 September

International Naidex, Wembley Exhibition and Conference Centre, London.

17- 27 September

Project Phoenix trip to Andalucia, study tour for disabled people. Cost about £780. Helpers eligible for some sponsorship but must make contribution towards own costs. *Details: 31a St Vincents Road, Westcliff-on-Sea, Essex SS0 7PP.*

1 - 7 October

ASBAH driving course, Nell Bank, Ilkley, West Yorkshire. Seven-day course including 10 hours driving instruction. *Details: Joan Pheasant, Five Oaks, Ben Rhydding Drive, Ilkley, West Yorks LS29 8BD, tel: 01943-609468*

13 - 17 November

ASBAH Lifeskills Course, five-day course, venue to be decided depending on where applications come from. *Details: Joan Pheasant, Five Oaks, Ben Rhydding Drive, Ilkley, West Yorkshire LS29 8BD, tel: 01943-609468.*

March 1996

ASBAH understanding behaviour course, three-day course to help families where a child with spina bifida and/or hydrocephalus shows behaviour problems. *Joan Pheasant, Five Oaks, Ben Rhydding Drive, Ilkley, West Yorks, tel: 01943-609468.*

HOLIDAY ACCOMMODATION

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

ISLE OF WIGHT ASBAH

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

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

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Fully equipped, completely wheelchair-accessible, two-bedroom bungalow. Sleeps six. Site near sea with access to New Forest, Bournemouth. Excellent site facilities 100 yards from chalet. *Details: Mr P Cash, tel: 01425-672055.*

LOOE, CORNWALL

Fully equipped, self-catering, two-bedroom bungalow. Sleeps six. Site near sea with easy access to beach, shop and camp facilities. Easily accessible for wheelchairs. *Details: Mr P Cash, tel: 01425-672055.*

SELSEY, SUSSEX (ASBAH)

Purpose-designed mobile home for wheelchairs. Sleeps six, colour TV, midi stereo system, payphone, ramp and veranda. Clubhouse, indoor swimming pool. *Details: Mrs B Nunn, tel: 01903-763473.*

ROMNEY SANDS, KENT

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WEYMOUTH BAY

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mary sol

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

MEMBERSHIP

INDIVIDUAL ASBAH membership – receive publications as well as voting rights at twice-yearly Council meetings. £17.50 a year (waived if you are on benefit). *Application form from: Company Secretary, ASBAH, 42 Park Road, Peterborough PE1 2UQ.*

TRAVEL PLANNING

PLAN your holiday, coach tour or trip abroad with Lincs Travel. 2% of value donated to ASBAH. *Pam Forster, Lincs Travel, 9 Stenner Road, Coningsby, Lincs LN4 4RP, tel: 01507-523833.*

LINK Rates

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Small adverts for the next issue of *LINK* (August) should be submitted by Wednesday, 14 June. Please send them to the Editor.

Display Rates on application, from the Publicity Manager.

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