Link

OCTOBER/NOVEMBER 1992 NO 142

Price 30 pence

The magazine for people with
Spina Bifida and/or Hydrocephalus

IN THIS ISSUE

BREAK FREE WITH YOUR WHEELCHAIR

DO WE NEED A REGIONAL REGISTER?

THE BRAIN TELESCOPE - A FLEXIBLE FRIEND

ASSOCIATION FOR SPINA BIFIDA AND HYDROCEPHALUS

ASSOCIATION FOR SPINA BIFIDA AND HYDROCEPHALUS

ASBAH House, 42 Park Road, Peterborough PE1 2UQ
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ASSOCIATION FOR SPINA BIFIDA AND HYDROCEPHALUS

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OCT/NOV 1992
ISSUE NO 142

CONTENTS

▲ Update 4
▲ Neuroendoscopy 7
▲ Letter from America.. 8
▲ Your wheelchair 10
▲ Writer's Block 12
▲ Spina Bifida Register 14
▲ Competition Results 16
▲ Out & About 17
▲ Reviews 18
▲ Seminars/Small Ads 19

The magazine for people with spina bifida and/or hydrocephalus

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Will the Minister change his mind?

ASBAH will be using evidence gained from our questionnaire on Attendance Allowance and under 2s, to try to persuade the Department of Social Security to make back payments of this benefit to our clients.

We had a magnificent response to the questionnaire after it was published in the August/September issue of LINK.

Assistant fieldwork manager Mary Malcolm, has asked us to thank all those who completed the forms:

"I am delighted that people have taken the trouble to respond and hope that we are able to take the end result to the Minister at the Department of Social Security. We hope that the DSS will look at the situation again and agree to ex-gratia payments for all clients affected."

We would like to thank Hannah Harris, Welfare Rights Officer of Mencap for her efforts and support.

There is still time to return forms to ASBAH if you have not already done so.

LINK will keep readers up to date with any developments.

LINK price changes

Readers are reminded that as from 1 November new subscription rates will apply:

- Subscription rates - £4.80 UK, £15 Airmail, £7.50 Europe and Surface Mail
- Cover price 80p (including p&p).
- Bulk order, of 6 or more, 45p per copy + p&p + VAT
- Orders of 2-5 (inclusive), 80p per copy (including p&p)
- This is the first UK subscription price rise since 1985

Lifeskills success

Pictured left and on the cover are three participants at ASBAH's recent Lifeskills Development Course in Somerset. Thirty students attended, from all over the country, to develop new wheelchair and other independent living skills. More pictures on centre pages.

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Taking tea at the Palace

Putting on the style almost a million light years away from their usual, daily round - but two members of ASBAH's staff behaved as to the manor born!

Joan Pheasant, Five Oaks Centre manager, and disabled living adviser Leonie Holgate pose for a picture after gracing a Buckingham Palace garden party in July.

Joan and Leonie had earlier taken iced coffee and cakes on the Palace lawns before joining up with ASBAH chairman Patrick Daunt and executive committee member Michael Booth for glimpses of the royal family.


Leonie & Joan, stepping out.

They mingled with the Queen and Prince Philip, the Duke and Duchess of Kent and Princess Alexandra but, like thousands of other ordinary citizens enjoying the sights and sounds of this special event, never quite got to shake their hands.

On the way out, eagle-eyed Leonie spotted two uninvited guests left to their own devices, completely ignored by the security men - two little pigeons nodding off in a nest on the stone path leading into the forecourt!

Changing faces in Northern Ireland

June Kerr, ASBAH's co-ordinator in Northern Ireland, retired from her post on 30 September. Since a car accident two years ago, Mrs Kerr has continued to suffer pain from her injuries and as a result, has only been able to return to work part-time. But she hopes that she will now be able to concentrate full-time on having further treatment and making a complete recovery. Described by ASBAH's executive director Andrew Russell as "an outstanding manager, whose kindness, wisdom and dynamism are appreciated by all her colleagues", June certainly takes all good wishes for a speedy return to full health, from her many friends in ASBAH.

Taking over the position of co-ordinator, from 1 October, is June's colleague Meta Harvey. Mrs Harvey has been a part-time education adviser at the Northern Ireland office since April 1991, having previously worked as a teacher in both mainstream and special education. She was still working part-time in teaching but has given this up to work full-time as ASBAH's co-ordinator and was busy learning her new job when we spoke to her in September: "I am looking forward to working with a super team. All the groundwork has been done by June and she has given me a sound foundation to work from so that we can continue to provide the same quality of service for our clients. I would also like to foster our existing close links with local Associations".

During its first six months in operation, the Northern Ireland office saw its caseload double from 300 to 600 - showing the clear need for the help their fieldworkers, continence and education advisers could provide. Although the number of clients continues to grow it has "steadied down". Many of the new cases are new-born babies - reflecting the relatively high incidence of spina bifida in the Province.

For the future, ASBAH is working on various approaches to help us fund our Northern Ireland operations, including co-ordinated approaches to the business community and seeking funding from the statutory authorities.


June Kerr


Meta Harvey

As seen on TV

In November, ASBAH member Helen Vaughan will be appearing on the Channel 4 programme 'Same Difference', as a mother who decided to continue with her pregnancy knowing that her baby would be born with a disability. And when you've seen the film you can read the story, as Helen (whose daughter Holly is one year old on 2 October) will be writing about her experiences for the next issue of LINK - don't miss it!

Buying and selling equipment

The first issue of a low-key 'Exchange and Mart'-type publication, specialising in equipment for disabled people, was due to be sent out to subscribers on 29 September.

Called 'The Disability Equipment Register', it is an introduction service aimed at putting people who have equipment in touch with those who want it.

"Every disabled person knows how expensive new equipment can be, yet there are hundreds of items lying around, which could benefit someone else. It can be as difficult to find a buyer as to find the item you need.

The Register brings these two needs together, without the need to spend a fortune on expensive advertising", said proprietor John Selby.

Updated lists will be sent out about twice a month, with a year's subscription costing £12 or less for shorter periods.

The Disability Equipment Register, 4 Chatterton Road, Yate, Bristol NS17 4BJ, tel 0454 318818.

The Triple Test

This screening test, primarily to identify pregnancies at a high risk of Down's Syndrome, can also indicate whether there is a high risk of some other abnormalities, including spina bifida and anencephaly, before more invasive diagnostic procedures are considered. The Triple Test is a blood test which measures "markers" in the blood serum. Mothers-to-be who are concerned about Down's Syndrome as well as spina bifida may wish to discuss this test with their GP. There are only a few hospitals offering this test on the National Health. Some GPs and consultants are registered with the service and can provide the testing packs. Results take 7-10 days and the test is best carried out between 16-18 weeks of pregnancy for spina bifida and anencephaly detection. The AFP test, which is more widely available on the NHS, will indicate equally well whether there is a high risk of spina bifida alone.

Down's Syndrome Screening Service, Institute of Epidemiology,
34 Hyde Terrace, Leeds LS2 9LN.
Telephone: 0532 344013.

PACTS become operational

In his keynote address at the Papworth Trust's 75 year celebrations this summer, Parliamentary Under Secretary of State for Employment Viscount Ullswater talked about developments in employment services: "Locally based teams called 'Placing Assessment and Counselling Teams' (PACTS) will provide practical help for both employers and individuals, including help with special aids and adaptations to premises.

Viscount Ullswater and Lady Masham

PACTs will combine the work of Disablement Resettlement Officers, the Disablement Advisory Service and the assessment role recently undertaken by the Employment Rehabilitation Service. Specialist staff working in the PACTs will be called Disability Employment Advisers. PACTS can help people with disabilities to find and keep jobs in open employment."

Viscount Ullswater said that all PACTs would be operational by October.

---NEWS IN BRIEF---

21st Century Schools

'Education into the Next Century' is the grand title of a booklet produced by the Department for Education. It outlines the Government's proposals for education set out in the White Paper entitled Choice and Diversity: A New Framework for Schools. The White paper was published in the summer and forms the basis of an Education Bill being put to Parliament this autumn. *Copies of the booklet are available from: Freepost (BS523/81), Bristol BS3 3YY or Freephone 0800 211 112.*

Four go coast to coast

Another walk across England has been completed for ASBAH. This time the 200 mile trek from the Irish to the North Sea was inspired by James Wing - a toddler from Norwich who has hydrocephalus. James' godfather Carl Mook organised the walk with three friends and together they raised almost £2,000 which will be spent on fieldwork in the Norwich area.

Write a letter, make a friend

Write Away is a penpal club for young people with special needs, using whatever means of communication they feel most comfortable with - conventional pen and paper, braille or audio cassette. For a membership fee of £2, youngsters from five to 18-years-old are sent a folder with pen, paper and envelopes and the name of a specially selected penpal.

Write Away, PO Box 175, New Ash Green, Dartford DA3 8PQ. Telephone: 081 961 5876.

Lifeskills - lost property

Left behind on Lifeskills course: 1 Pair girls Boogie Jeans, height 114cms, from Tammy Girl. 1 pair men's underpants (plum), large. 1 pair men's underpants (black/white stripe), medium. 1 pair rosebud knickers, medium, hips 38-40. 1 flannel (grey/blue)

Please contact Lynn Thomas on 0733 555988.

Happy ending for holiday romance

Five years ago Kirstine Kemp, a member of Kent ASBAH, went on holiday to Yugoslavia and Steve Martin went as a carer. Romance blossomed and in August they became Mr & Mrs Kemp Martin. Steve works in car parts sales but he is a St John Brigade Officer and his aim is to become a paramedic with the ambulance service. Kirstine works part time in a supermarket and also does voluntary work for Canterbury Hi Tec. She is taking a sign language course and her ambition is to work with deaf people.

Enjoying life in the mainstream

Support Assistant Barbara Webb wanted to share her experience of supporting a child with spina bifida in mainstream education: "After reading a copy of LINK, I feel I must write about Nicholas who is ten years old. I have worked with him in a mainstream school, as his special support assistant since he was five. I accompanied Nicholas on a recent school journey, youth hostelling for five days. Together we managed the splints, catheterisation and night pads etc. He enjoyed the independence of being away from his family. The picture shows him rock climbing and he also managed abseiling, showing great courage and determination. Nicholas enjoys the full support of his fellow pupils. I hope this letter and photograph will provide encouragement to others."

Waiting to hear from you

Cormac Burns is 19-years-old and would like a female penfriend, preferably from the Northern Ireland area. Cormac, who has hydrocephalus and spina bifida, is interested in weight training and socialising. He is currently attending a YTP course and hopes to work as a clerical assistant.

Letters to Cormac should be sent to him c/o LINK at ASBAH House, 42 Park Road, Peterborough PE1 2UQ - we will forward them to hm in NI.

NEUROENDOSCOPY

ITS ROLE IN THE MANAGEMENT OF HYDROCEPHALUS

Paul May, consultant paediatric neurosurgeon, Royal Liverpool Children's Hospital, Alder Hey, examines the advances in neuroendoscopy.

Endoscopy of the nervous system has been practised for many years. The major restrictions to its development, however, have been technical and over the last five years there has been a major advance in the fibre-optic and visual technology, allowing a renewed interest in the applications of endoscopy of the central nervous system.

The rigid neuroscope (brain telescope) has been used for years for the direct inspection of large ventricular cavities and for the retrieval of free floating ventricular catheters and, in some situations, the coagulation of choroid plexus which has been shown in some cases to reduce the need for a shunt in young babies.

The recent development of a fibre-optic flexible and very small neuroendoscope (brain telescope) has allowed the development of much more invasive and complicated techniques within the hydroencephalic brain, performed through a small burr-hole incision.

This technique, particularly of flexible neuroendoscopy, has gained much support and interest in the United States. Coupled with a laser, it is possible to perform small operations within the head with the brain telescope.

Its value in the treatment of hydrocephalus lies in several categories. It is sometimes possible to create communications between the ventricular system and the CSF spaces on the outside of the brain, therefore obviating the need for an indwelling shunt system. This is particularly useful in cases where the obstruction is at the aqueduct of Sylvius and in which the third ventricle is very enlarged.

Some authors have reported the ability to control the hydrocephalus without the need of a shunt in 80% of children over the age of two, with aqueduct as the cause of their hydrocephalus.

In other situations, there may be isolated loculi or separate compartments of CSF within the child's brain and it is possible, with the flexible endoscope, to move around inside the brain joining up these cavities and converting multiple shunt systems to a single shunt system, therefore reducing the risks of complications and infection.

It is also possible to remove small tumours from inside the ventricular system and to biopsy tumours and areas of abnormality from within the ventricular system without needing to open the skull and search for these lesions under direct vision.

The system is a complicated and expensive one and, at present, the flexible endoscope is under evaluation at the Royal Liverpool Children's Hospital. Its role and value remain to be evaluated properly and it is still really in the experimental phase.

The advent of a fibre-optic laser has greatly increased the capacity of these flexible brain telescopes to perform intracranial procedures. However, the minimum cost of one of these new laser systems is around £40,000, with the setting up of the endoscope and camera systems costing approximately £25,000.

There is, as they say, nothing new under the sun and certainly endoscopy has been around for some time. However, with the change in the technology available to us now, I think that the development of flexible neuroendoscopy coupled with fibre-optic laser could possibly make significant changes to the management of some of the pathological processes relating to hydrocephalus.

I will keep readers informed of future developments.

LETTER FROM AMERICA. . .

★ ★

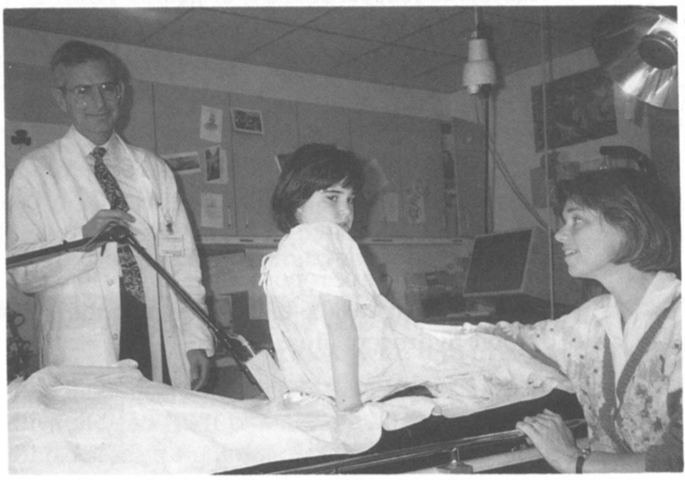
Mary White, ASBAH continence adviser (winner of the Smith & Nephew/Florence Nightingale Scholarship) writes about her trip.

"To be offered a Smith & Nephew/ Florence Nightingale Scholarship is an opportunity that can surely only happen once in a lifetime.

That was the verdict of my family as we sat around the kitchen table discussing whether or not it was right for me to accept the offer and pass out of their young lives for six weeks. We all agreed that it was a wonderful opportunity for me and that it would be good for ASBAH but it was they, the children, who would have to make sacrifices. There was so little hesitation that I has the distinct feeling that they might even welcome the prospect of six weeks without their nagging mother. Already the poem, which was to hang on the kitchen wall during my absence, was taking shape in my mind. Subtle reminders and do's and don'ts.

The itinerary was a nightmare to organise but I did try to write letters and make phone calls while continuing with the rest of my work. With six weeks to go, I had my flights booked and hotels arranged but my visits were far from organised. I had visions of the whole process collapsing like a house of cards. Panic set in.

That when when Lynn Thomas, DLS's marvellous secretary, stepped in. 'Give the whole file to me", she said. I did as I was told with great relief. Two days later, she phoned to say that she was making contact with my hosts and that arrangements were well in hand. Four days later, I visited the office and she had a map of the USA spread out on her desk with my trip plotted. Phone calls came in, while I was there, from Boston and Canada confirming my visits and the availability of consultants. One week later, she presented me with four copies of my final itinerary, showing flights, hotels, contact telephone numbers and fax numbers. It all seemed so easy when she was organising me and how well she did; all my travel plans worked, all the hotel bookings were in order and, best of all, everyone expected me and knew just who I was. Thanks to Lynn and her colleague Rolanda.



Dr Stuart Bauer carrying out urodynamics on Jacqueline at Boston Children's Hospital

The trip began at Boston Children's Hospital where I met Dr Stuart Bauer, a paediatric urologist of international repute. He was very welcoming and had organised a programme, during which we went to see a hospital school outside Boston which caters for young students needing medical or social care.

From Boston, I flew to Dallas where I was to contribute to an independence training course for young adults and their parents. The course was fully funded by Agent Orange, a government fund for Vietnam Veterans and their children. This was immediately followed by the annual conference of the Spina Bifida Association of America at which ASBAH's former executive director Moyna Gilbertson was to be the keynote speaker. I, too, was an invited guest, contributing to the Nurses Forum. Moyna was, of course, a great hit and people patiently queued to have a word with her afterwards. A few of us set off to explore Dallas by night and were amused to see one the leading lights of the American Association, who is herself in a wheelchair, being persuaded to ride in a circular contraption which was spun at high speed. Game girl that she is, she omitted to tell the organiser that she has an artificial leg. He stood back and spun the wheel joyfully but, within seconds, his face had 'litigation' written all over it for her leg flew off, scattering the crowd in all directions! She thoroughly enjoyed the joke.

From Dallas, I went to Houston and spent a few enjoyable days with Dr Jeffrey Woodside at Texas University Hospital. He showed me his magnificent urodynamic treatment/continence clinic which advertises itself locally as offering 'one-stop shopping'. By this, they mean investigation and treatment in one session. He also took me to the best eating places in the city and I left him considerably heavier.

From Houston, I went on to Atlanta to spend time with Dr Don Lollar, educational psychologist. He showed me the Sheperd Spina Injuries Centre and I was able to observe the physical and psychological management of traumatised patients.

While in Atlanta, I took time off to visit a friend I made at the national conference. She is Jean Brown, an impressive clinical nurse specialist from Shriner's Hospital, Greenville, South Carolina. Shriner's Hospitals are financed by the Freemasons and provide a very high standard of care in wonderful surroundings. They make no charge and so, for the first time, I met parents who did not have to worry about the cost of treatment. I met many members of the Baptist community and enjoyed their hospitality. Jean and I exchanged ideas, slides and videos and her husband Jim was quite unable to understand why we were having such a lovely time.

My next port of call was John Hopkins University Hospital, Baltimore, where I saw an out-patients department - the marble hall of which cost $4m - and some impressive surgery by Dr John Gerhard, who learned his craft at Liverpool's Alder Hey Hospital. Again, the mercenary face of American health care reared its head and I was made aware of the great anxiety parents face when confronted with bills for health care.

Independence Day saw me in Washington as the guest of Agent Orange co-ordinator Babette Polzer and her husband Eddie. A concert on the Capitol lawns with Henry Mancini and James Galway, followed by fireworks and more wonderful food. Would I ever me able to waddle home to the UK?

My final visit was with Dr Barry Shandling, professor of paediatric surgery, Toronto, who - with his engineer Bob Gilmour - devised the continence enema catheter system. Toronto is a fine city and I felt that Canadians probably enjoy the best of the British and American cultures. They have a national health system which is staggering under the weight of ever-increasing costs, just like ours. Again, I was wined and dined and, as Barry Shandling is something of a gourmet, this was serious business. I had Japanese food beautifully served, delicate and colourful. Barry chose the menu and said; "Why don't you just enjoy it, my dear, and I will tell you what you have eaten afterwards". Very worrying, I thought.

As my journey neared its end, I realised that it is quite wrong for us to believe that our cousins on the other side of the Atlantic are more advanced than we are. In many ways, we are ahead and there is little doubt that our system of health care is much more socially aware and just. The US system is selective in that it caters for the very rich and the poor but not the average middle-income family. For these families. the strain and pressure of medical bills is never-ending.

Back home in Derbyshire, the climbing roses were past their best and the Clematis flowers had died. Our mongrel dog, Teddy, could not believe it was really me and the rabbit and guinea pig came out to see what all the fuss was about. The house looked well, no broken windows or signs of fire and, as the children ran to meet me, they all looked several inches taller, fit and well.

Who is indispensable? — not I."

While I Am Away

Please, try to remember while I am away,
The things that concern me, the things that I say.
Remember your pets and all that they need,
Keep them warm, loved and clean - their housing, their feed.

No food in the lounge! Don't leave that in the hall!
Keep your feet off the furniture and off the wall!
Have you tidied your room - no clothes lying about?
Have all all cleaned your teeth today - or is that grout?

Have you been in the shower, cut your nails, washed your hair?
What are you doing today - what should you wear?
Have you practised your music and done your homework?
These things are important and not things to shirk.

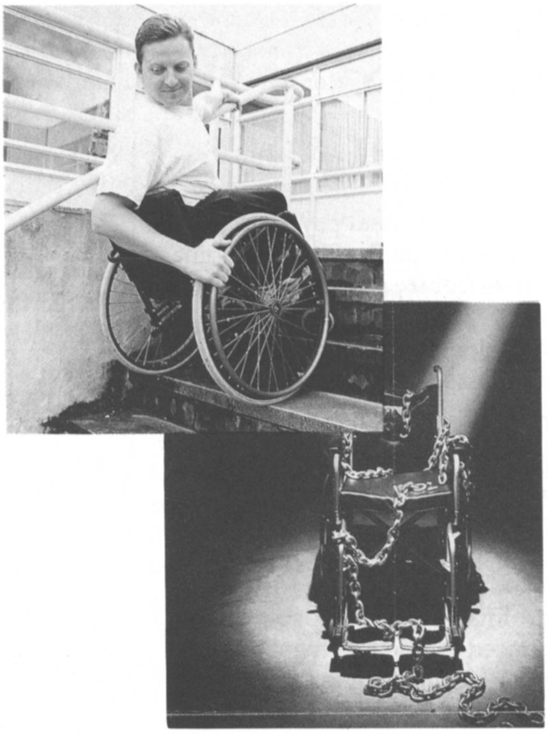
The love of my family, my friends and my home,
Will do much to sustain me, wherever I roam,
Be good to each other - that's important to me,
Be kind and considerate - display loyalty.

At the end of my journey, the day I return,
We will all be together - for this I will yearn.
The need to escape you, occasionally known,
Will be long forgotten when I feel alone.

So try to remember while I am away,
The good things I do, the kind things I say,
Think not of the worst side of me - only the best.

How do you see your wheelchair?

John Naude, ASBAH mobility adviser and a wheelchair user *(right)*, poses the question and urges wheelchair users to **think positive**.

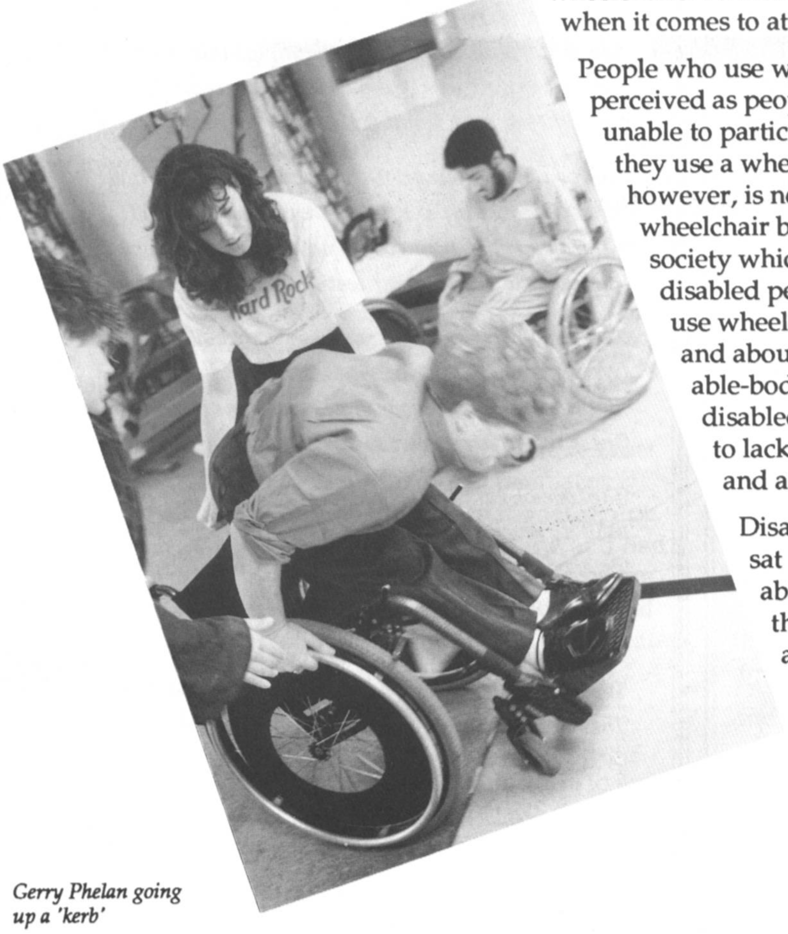


Does the phrase "Wheelchair bound" or "confined to a wheelchair" sound familiar? Do we see the wheelchair as something negative, something we would never want anyone to have to use? This was understandably the case in the 'old days' when wheelchairs were basically a chair on wheels and the person using it would use it from room to room (usually pushed). It then 'progressed' to being used outside, to being pushed around the park, to be taken for a "walk". When we see old pictures, we see people being pushed with a blanket over their lap. They have no control over where they are going. They are seen as passive and helpless objects.

Surely, though, we have changed, we no longer see wheelchairs or the user, as something negative, as sitting passively in the chair, to be pushed and patted on the head. The thing that has changed most is the technical side of wheelchairs. I am afraid that not a lot has changed when it comes to attitudes. Why is this so?

People who use wheelchairs have been perceived as people who are unable to cope or unable to participate fully in society, because they use a wheelchair. The problem, however, is not the disability or the wheelchair but attitudes of an able-bodied society which has discriminated against disabled people. Therefore, people who use wheelchairs are not able to get out and about to 'integrate' because an able-bodied society has not enabled disabled people to participate - due to lack of access, public transport and attitudes.

Disabled people have in the past sat and accepted the image that able-bodied people have given them. This also applies to using a wheelchair. Because wheelchairs have been seen as something to sit in and be pushed, they have not been seen as a piece of equipment which will enable someone to become mobile. The wheelchairs which have been provided by



Gerry Phelan going up a 'kerb'

How do you see your wheelchair?

the health service are, therefore, cumbersome, heavy, immobile and institutionalised. Until recently, they have not seen wheelchairs as equipment to enable and have continued to provide the grey monstrosities which 'beg' someone to push them.

Wheelchair users need to throw away the image of being shackled and bound to their wheelchairs and should not feel "confined" to it. It is not the wheelchair which does the confining but the lack of access which keeps a disabled person trapped.

We need to challenge the idea that a walking person is perceived as being superior or more acceptable than a person who uses a wheelchair. They are no better or more acceptable than disabled people. We need to recognise the differences and acknowledge them and to no longer accept the images that disabled people have put upon them.

We should refuse to see a wheelchair as something negative but see it as a piece of equipment which *enables* movement.

Lucy White moving forward on her back wheels

This does mean taking control of the wheelchair, to push it yourself and *not* be pushed. By being pushed we continue to portray the image of being helpless and passive. Throw away the chains of being confined or bound to your wheelchair, and use your wheelchair as a positive piece of equipment which can enable you to get from A to B.

John was amongst those helping ASBAH members to take control of their wheelchairs at the recent LIFESKILLS course,held in Taunton, pictured on these pages. Participants were taught to backwheel balance to enable them to get up and down kerbs independently.

Ian Driscoll backwheel balancing

Writer's Block

In the wake of moves to place greater emphasis on written exams, Pat Danks sets out the alternative ways in which children can record what they learn.

Billy rubbed the paper with his finger, trying to blot out the mistake he had made. An ugly smudge appeared, then a hole. He spun round in frustration and pinched the girl sitting next to him. He knew he was in trouble again as her cries reached the teacher's ears.

Billy was known as a low-achieving, disruptive child, without motivation, who hated school and everything about it. In the eyes of staff and children alike, a real nuisance.

Children who struggle with the skill of writing, who perhaps have poor reading ability, have a difficult time. Our society, culture and school system, still rely heavily on the written word. Both the traditional method of teaching, 'chalk and talk', and the more active approach of projects, work-cards and workbooks, create numerous difficulties for those unable to make a statement in the written form.

These children are often misunderstood and pre-judged as unable to concentrate and conceptualise. This becomes a self-fulfilling prophecy as they become disruptive in an attempt to impress their peers. Through constant failure they often lack self-esteem, fully aware that their efforts are poor and messy. At worst, they take every opportunity to avoid school, regularly truanting.

Obviously the teacher must observe and recognise all the needs of the child, making every attempt to address the problems of reading and writing skills through whatever remedial programmes they consider suitable. But in the meantime the child must not be allowed to spend five per cent of time on task involvement and 95 per cent trying to record what he has done, the failure of which overshadows his task achievement. While learning is valuable, whether or not it has been recorded, the lack of recording ability may block children's learning and, together with low teacher expectation, create a cycle of under-achievement.

In order to address this problem and assist the child to enlightenment and the learning reinforcement that recording provides, we must:-

✻ Help the child to see the relevance in recording one's ideas, discoveries and results.

✻ Experiment with the child any suggested methods. Discuss the advantages and disadvantages.

✻ At first, give highly motivating tasks which contain a built-in recording system ie making a graph of passing traffic using plastic vehicles.

Teachers should also develop an awareness of the wide variety of ways in which the learner can make a statement. We must be as inventive as possible to assist motivation, making certain that the child sees a relevance in the task and recording method to be used.

Alternative ways of recording include:-

● *Computers:*

The introduction of these into the classroom has provided teachers with an ideal recording facility. Together with the word-processor, word check programmes and print-outs they have vastly improved the statement procedure. But access for children is limited because of financial restraints.

● *Tape-recorders:*

Classroom or small pocket recorders can be used quite simply. They improve listening skills. A child can use headphones to follow instructions and to eliminate distraction and heighten attending ability. Children love to hear themselves on tape. It encourages talk about task method, extends language abilities and activities ie interviewing classroom visitors, telling stories and relating experiences. Taping proves instant feedback and reinforces learning.

● *Symbolic representation:*

✻ The movement of blocks, cars, plastic objects etc. For example, the use of doll's house furniture and bendy people for teaching or assessing a child's knowledge of prepositions ie: "Stand the man behind the chair", "Put the baby in the cot".

✻ The choice of an object from a presented selection.

✻ Using a collection of items for classification, numeracy, language and science activities.

✻ Plastic numbers and letters, word cards or symbols if a written or numerical answer is needed.

● *Pictorial representation:*

One picture is said to be worth a thousand words. There are inumerable opportunities for this type of recording, ranging from sceintific discoveries, personal surveys, language and numerical skills to pictures which share experiences. For example:

✻ Photography: including cine and polaroid - for recording visits, drama, models, or activities for later discussion.

- ✳ Drawing: children's own work.
- ✳ Pictures: supplied or collected.
- ✳ Rubbing techniques.

● *Situation representation:*

Action dolls and apparatus, play people, doll's houses, model railways, roads, airfields and garages. This method is useful for statement-making or assessments during one-to-one or small group activities and play sessions, the teaching of placement, cause and effect, and life situations, particularly those that the child finds difficult to talk about.

● *Miscellaneous means:*

Clay, art/collage, drama, social role-playing, mime, movement/ expressive dance and puppetry. The last two suggest methods of making statements about the more abstract, such as the demonstration of fear, emotional matters, relationships and moral judgments.

Although most of these means of recording are generally used in all infant classrooms at some time, it is suggested that they should be available in the older child's learning situation, planned for and built upon if there is a known problem. These methods of recording tend to be looked upon as childish, but considering the restraints of writing, they can be presented in the context of higher interest work. After all, when older secondary school children carry out practical experiments in science, design and technology etc, often their experiment is laid out, labelled or diagrammed. The civil service and weather men present us with information in this way all the time. Why can't this respectability be carried over to other work if the children have a problem?

Max drew eight men. He said it was a pop group. He was asked to draw a guitar for each man. After using a mapping technique to check he found that he had three guitars left. The children discussed how many more guitars there were than men, were there less or more men etc.

Tony used a Language Master. He had a short concentration span, was disruptive, but loved machines. A successful morning's work.

Matthew was given 30 blocks to make as many 5s as he could. He placed tickets underneath. This did not say what he wanted to say so he asked for symbol cards and put together 6 x 5 = 30. He then glued this to a piece of paper displaying it with pride. "Can I take it home Miss?" What a change from the usual lethargic boy.

Seeing changes of attitude in a child who is not used to achieving but is given repeated opportunities to do so can be an exciting event. How much more rewarding to discover a child's potential previously hidden through disruption or withdrawal.

Ian was a 10-year-old farm boy. He hated school, was quiet, sullen, had no friends and was considered to have a very low ability. His parents said he was bright and motivated at home. He could mend the tractor engine alone and carry out many other farm tasks that needed motivation, strategies and skills. After a term of Science 5-13 activities, in which he worked practically, he was requested to record his discoveries using a variety of active recording methods. The effect was amazing. He showed a perception far beyond expectation. Because we had eliminated the frustration of writing he grew in confidence. Gradually over months this positive attitude spilt over into all activities. His writing skills actually improved with the new motivation. He made friends and enjoyed life. His farm work was essentially practical. His family relationships were relaxed and the adult expectation high. He felt a useful, loved member of the family. This we had transferred to the school situation, fostered it and been rewarded.

Because many junior and secondary age group children still have to master many basic concepts, it is no disgrace to search out and use in a methodical way practical schemes of work which give opportunity to reach the required targets, followed by active recording methods which allow the children to learn, reinforce and show their abilities.

Pat Danks is a retired teacher and freelance writer. She taught for 17 years, 12 of them in special education.

This article was first published in Special Children April 1992 and is reprinted courtesy of that magazine.

Plea for a regional register of spina bifida patients

A urologist's point of view

Mr P D E Mouriquand, MD, Consultant in Paediatric Urology at Addenbrooke's Hospital Cambridge and Associate Lecturer at Cambridge University, argues that a regional register of spina bifida patients is needed to ensure that each one receives early assessment, proper treatment and regular follow-ups from the health service.

"Patients born with a myelomeningocele (spina bifida cystica) have five types of disorders, all related to the abnormal innervation (nerve supply) of the lower part of their body. These disorders have various degrees of severity and some children bearing this congenital anomaly have almost a normal life, whereas others are deeply disabled.

1 Paraplegia, or paralysis of the legs and lower part of the body, varies with the level of the spinal defect.

2 Skeletal deformities involving mainly the thorax, the spine and the lower limbs, may lead to pressure sores, joint dislocations and respiratory problems.

3 Abnormal circulation of the cerebrospinal fluid may lead to hydrocephalus, neurological troubles and cerebral retardation.

4 The paralysis of the bladder (neuropathic bladder) may threaten the urine drainage and the renal function and these patients are often incontinent.

5 Bowels are also paralysed and severe constipation with soiling is common.

The situation for these patients is therefore complex and involves several different specialities: Paediatric Neurology, Neurosurgery, Orthopaedic Surgery, Urology, Visceral Surgery, Special Nursing, Physiotherapy, and furthermore, Psychology. This complexity is easily measured by the weight of the patient's notes which has discouraged more than one consultant and which has led in too many cases to the abandonment of the patient or to the "wait and see" policy. A few rare centres in Europe have organised a proper follow-up of spina bifida patients and efficiently accompany these families along a very long tunnel. Their experience clearly shows that early assessment, proper treatment and regular follow-ups give these patients a long life in acceptable social conditions.

Renal problems, wetting and soiling are not a fatality, if the patient is taken in charge soon after birth and properly followed on an annual basis. Each patient requires a specific treatment which should be provided in each region by a team of specialists working closely together. This is why a Regional Register of Spina Bifida Patients should be set up to provide the essential follow-up that these patients deserve.

What can the urologist offer to these patients?

To answer that question, one should understand that the bladder is the keystone of the problem. The bladder normally has two essential functions: It is a reservoir which stores urine at low pressure between two micturitions; it is also an active reservoir, able to empty its contents at regular intervals, completely and without excessive pressure. These two functions imply the integrity of the neurological control of the lower urinary tract.

In spina bifida patients, the bladder and the urethral sphincter are paralysed and therefore these two essential functions are defective: the bladder often cannot store large volumes of urine at low pressure and the flow of urine coming from the kidneys is disturbed. Subsequently, the upper urinary tract is dilated and progressively the renal function slows down. (FIGURE 1b). The bladder often cannot empty completely. This leads to a permanent residue of urine in the bladder which is the cause of frequent urinary tract infections.

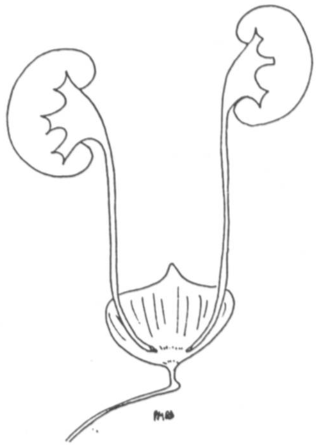


Figure 1 Normal Urinary Tract

High vesical (bladder) pressure and paralysed urethral sphincter often lead to urinary incontinence, which is a major burden for people with spina bifida and is the visible part of the iceberg. One could call this severe situation 'Bladder Failure' and indeed it threatens the patient's life as much as a 'Cardiac Failure' or a 'Renal Failure'.

One can now understand that the two essential targets to treat this 'Bladder Failure' are:

1 The preservation of the renal function and the upper urinary tract, which implies a free urine drainage at low pressure.

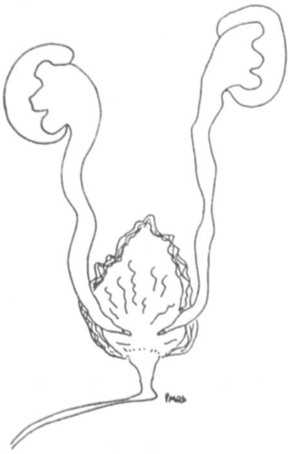


Figure 1b Neuropathic Bladder

2 The control of incontinence which implies the control of bladder emptying.

These targets can be reached if the bladder is big enough to store a large volume of urine at low pressure, if the bladder emptying is done completely, at regular intervals and if the bladder outlet resistance is sufficient to stop permanent urine dribbling.

What sort of procedures can be used to preserve the upper urinary tract and to control urinary incontinence?

For many years, the single answer to that question was to divert the flow of urine to the skin (non-continent urinary diversions). This radical solution is, nowadays, the last option chosen by the urologist because it is not very well accepted by young patients and because renal alterations are often not avoided.

The majority of urologists now try to keep and to use the urinary tract, to respect the patient's body image or, when necessary, prefer continent diversions to non-continent diversions. Thus, the main current therapeutic options can be summarised as follows:

1 *To preserve the upper urinary tract* the major treatment is to allow regular, complete and low pressure emptying of the bladder. This can be achieved by inserting a catheter in the bladder at regular intervals (clean intermittent catheterisation) and very often the patient does it himself without difficulty (self intermittent catheterisation). However when intravesical pressures (bladder pressures) are too high or when bladder capacity is too poor, it is sometimes necessary to augment (make larger) the capacity of the bladder by using a piece of bowel or a piece of stomach.

2 *To provide dryness* implies achieving an optimal balance between bladder pressure and bladder outlet resistance. Sometimes (25% of the cases), regular and complete bladder emptying is sufficient to get dryness but very often, complementary procedures are required in association with intermittent catheterisation: augmentation of the bladder, medical treatment aiming at stopping uncontrolled bladder contractions or augmentations of bladder outlet resistance, are the three main means we have to obtain dryness.

How does the urologist choose the right treatment?

The urologist must choose between two options:

- *to keep the urethra intact* and thus to allow bladder emptying through the natural route, or
- *to bypass the urethra* by diverting the urine through a continent or non-continent device.

This choice is of paramount importance and is related to the intellectual and orthopaedic status and to the sex of the patient. Spina bifida children are often unmindful of their problems and may not understand the necessity of emptying their bladders properly. Some devices to obtain dryness may be too complex and may cause severe disturbances to the whole urinary tract if they are not handled correctly. Paraplegic patients in a wheelchair often have difficult access to their urethral meatus (opening). This problem is increased by the lack of abduction (inability to open the legs), by the frequent obesity and by the unfortunate lack of dexterity of these patients.

When the intelligence quotient and or orthopaedic status are poor, bladder emptying through the natural tract is not desirable and a continent diversion is generally the option indicated. A continent conduit, made with a piece of bowel (appendix or small bowel) connects the bladder to the abdominal skin. The patient can then easily empty his bladder by inserting a catheter, through the continent conduit, every four hours.

On the other hand, if the patient has a good intelligence quotient or a good orthopaedic status, bladder emptying through the normal urinary tract is recommended.

In females, the first option is Clean Intermittent Catheterisation (CIC), which is often associated with complementary procedures aimed at increasing bladder outlet resistance: one of them - the urethral lengthening - represents a major surgical improvement and allows many females to achieve dryness.

Continued on Page 16

Continued from Previous Page

In males, CIC is more difficult because the length and the shape of the urethra are different and because it is not so well accepted, especially after puberty. Therefore, the use of a artificial urinary sphincter represents a possible option, although many complications are reported.

None of these treatments are perfect and complications are not uncommon but the comfort of these children is dramatically improved and their social integration becomes possible. It is extremely satisfactory to see the psychological transformation of these patients when they become dry.

Improved techniques in continent urinary diversions are published regularly, showing that these techniques are usually reliable and safe, when performed in specialised centres.

These are the main aspects of the urological treatment, but major progress is also recorded in other fields, such as faecal incontinence, where a new technique - the ACE (Antegrade Continence Enema) - seems to give excellent results to avoid constipation and soiling.

I will not discuss here the numerous treatments offered by neurosurgeons and orthopaedic surgeons to improve these patients' quality of life but I would like to insist on the essential co-operation between patients, parents and specialists to provide a good regional service. ASBAH is the sort of organisation which should arrange the link between us and this implies the creation of a Register of Spina Bifida Patients in each region. A register implies the computerisation of each patient with a detailed medical record which could be circulated among the specialists involved.

There is no place for the "wait and see" policy in the follow-up and treatment of spina bifida patients."

LINK No. 142 10/92

CALENDAR COMPETITION

Success again for Frank

Congratulations to artist Frank Rook, from Barnsley, South Yorkshire, whose work will feature once again in the annual Sunrise Medical calendar.

His painting 'Yorkshire Rape Field' was picked to adorn the 1993 calendar for the page marking May and June by a panel of judges at the Business Design Centre, Islington, in September. Judges included Katie Boyle, Alf Morris MP and RADAR director Bert Massie.

Frank with competition organiser Moira Buchanan

Katie Boyle remarked that it was the "luminous" quality of Frank's painting which impressed the judges. Frank (37), who has spina bifida, also has a painting in this year's Sunrise Medical calendar - the first produced by the company following invitations to six voluntary organisations to submit members' work.

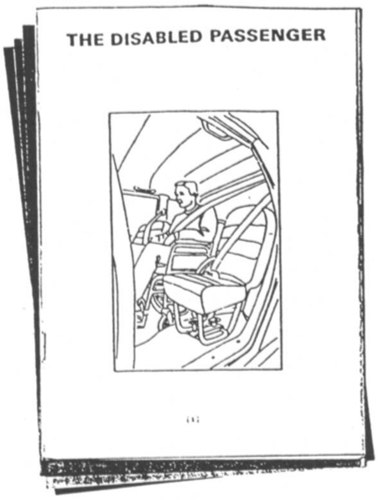
The same six organisations were invited to collect entries again this year, selecting two for final judging. They were ASBAH, Arthritis Care, The Stroke Association, Muscular Dystrophy Group, Multiple Sclerosis and the Spinal Injuries Association, and each group has a page reserved for it. Overall winner, whose vivid miniature painting 'Poppy Field with Corn' will grace next year's cover was Katy Etherington, aged 19, who has muscular dystrophy.

Commiserations to Sallian Smith, from Cliftonville, Margate, whose 'Foxgloves' tapestry was the ASBAH runner-up, and to all other ASBAH members who sent work initially to ASBAH House. Sunrise Medical marketing director Julian Cobbledick said the calendar this year has been seen in over 40 countries. It was a showcase for gifted artists and a caring company, and he was happy to be building on the success of this year's calendar.

CALENDAR COMPETITION

Information pack for disabled passengers

A information pack aimed at helping disabled passengers choose the right kind of vehicle to meet their mobility needs has been compiled by the Mobility Information Service. The pack contains a typed booklet covering such topics as gaining access to basic cars, through to selecting specialised transport, sources of funding and a list of assessment centres. Also included are road test leaflets which look at rear-entry vehicles for wheelchair users. The pack costs £2.50 including post and packing.



The Mobility Information Service,
National Mobility Centre, Unit 2a
Atcham Estate, Shrewsbury SY4
4UG. Telephone 0743 761889.

Getting the best from your wheelchair

This is the title of a new booklet published by RADAR. The 62-page booklet, which costs £1 including postage, describes techniques to enable users to get safe and full use of their wheelchair. There is advice on coping with uneven ground and kerbs, getting through narrow doorways and wheelchair maintenance.

RADAR, 25 Mortimer Street, London
W1N 8AB. Telephone 071 637 5400.

Orange badge concerns

The new Orange Badge for disabled drivers, requiring a photo to be fixed to it, will make it more dangerous for disabled children, says Dorset mother Mrs Elizabeth Fisher.

Mrs Fisher, who uses the badge when driving her 10-year-old disabled son Joel, says: "It gives any passer-by the name and picture of the child. If I get separated from my son while out shopping, it makes him susceptible to approaches from strangers".

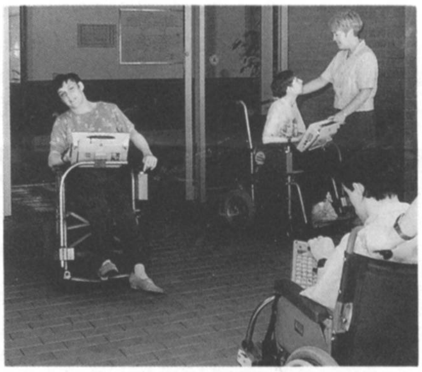
Mike Bruton, executive director of the Disabled Drivers Association, says the new badge has been designed so that the picture is *not* visible to passers-by - but still fixed to the card so that it can be shown on a challenge from a traffic warden. It folds like an-old fashioned triptych in a church, he said. "We made this point strongly in discussions about the card," he added.

Mrs Fisher felt that little thought appeared to have been given to the protection of children, and she would raise the matter with her MP.

Opening more doors

When the winners of the Holiday Care Awards are announced in November they can look forward to receiving an extra prize, thanks to Besam - manufacturers of automatic doors.

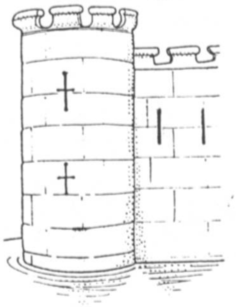
Each winner of the separate categories, to recognise achievements in meeting the needs of all potential customers, will be able to have an automatic door fitted to their establishment, which should further improve accessibility for their guests.



Automatic doors fitted to a new study block at Portland College.

Access to our heritage

As a growing number of historic buildings are becoming accessible to wheelchair users, a new guide has been published by RADAR with details of the provisions for disabled visitors in hundreds of historic houses, churches, castles and halls around the country. Parking arrangements, the availability of wheelchairs for loan, accessible toilets and assistance available from staff are included.



Some history on the buildings themselves is also given, along with information on any other attractions, such as gardens, gift shops and restaurants.

The guide costs £3 and is available from RADAR, address as left.

BOOK REVIEWS

Acts of Defiance, by Jack Ashley. £17.99. Reinhardt Books.

In the Parliamentary history of our times Jack Ashley's name is associated with many of the great moral crusades.

The MP for Stoke-on-Trent South for 26 years, until his retirement at the General Election, Jack took lead roles in many campaigns to bring disability and victimisation out of the shadows - thalidomide, Opren, battered wives, rape victims, and soldiers tormented by bullies, were among them.

What made Jack's contributions so unique in the Parliamentary process was that he inhabits a world of silence, losing his hearing after a relatively trivial operation on a perforated ear drum, in 1967.

He is totally deaf, but without the absence of noise one might imagine. Jack is hounded by tinnitus to this day, which at times drives him to distraction. At one time the combination threatened to overwhelm him.

Jack, Lord Ashley of Stoke since the election, tells his story in illuminating detail and with a lack of cant, in his autobiography 'Acts of Defiance'. This is a publishing event not to be missed.

Tony Britton, Publicity Manager.

Making the Right Start - A practical manual to help break the news to families when their baby has been born with a disability. £7.50 from Opened Eye Publications, 7 Aspen Wood, Godley, Hyde, Cheshire.

'Making the Right Start' is a highly readable practical manual which can only be useful to anyone who finds themselves in the position of having to break bad news to Parents. Sheila Jupp is a consultant clinical psychologist and, from extensive interviews with both parents and professionals, she has been able to formulate sound practical guidelines for those who are confronted with the prospect of conveying such information. Clearly, it has been parents' experiences which have provided the impetus for this manual: "Most parents remember in detail, years later, exactly how the news-breaker handled the situation. Many can recall phrases that have haunted them, sometimes for decades, and yet few hospitals seem to have any policy at all or give any guidance whatsoever, for those who are handed the task of letting them know".

This manual could help to rectify this situation. The feelings and behaviour of parents who have been told of their baby's disability are examined and here are guidelines for the professional on where and when to tell and how and what to say. The need for sensitivity and respect are emphasised and there is a useful practice checklist which underlines the need for parents to be told in a private location with their baby present. How information is absorbed is examined and there are guidelines for professionals on how to check whether they are giving facts clearly and in an understandable way.

Sheila Jupp's contribution in this area is very welcome and should be recommended reading for any medical staff who have to impart upsetting information - not just paediatricians and midwives.

Rachel Stanworth, DLS Manager.

FILM REVIEWS

Release Me. A video directed by Frances M Lea, copies available from 97A Florence Road, Finsbury Park, London N4 4DL. £10 to rent, £50 to buy.

A very good video which looks at the attitudes of the 'care staff' and 'relatives' towards a relationship between two people who have a learning disability. The film is 25 minutes long and is acted by people with a learning disability. It won the best acting award at the Tel Aviv festival and is also being shown at festivals in other countries, including: America, Australia and Ireland.

It should not be seen as a film which is only for those with a learning disability, however. It looks at the attitudes to sexuality and would be useful for professionals, carers and teachers who want to use if for workshops etc.

John Naude, DLA.

EXHIBITIONS AND WORKSHOPS IN NOVEMBER

EDUCATION

THE London Special Needs Exhibition is the largest annual event in the UK devoted entirely to special educational needs. Organised by the Educational Publishers Council and the National Association for Special Education Needs (of which ASBAH is a member) it provides an opportunity for parents, teachers and advisers to keep in touch with developments in this field.

Admission to the exhibition of publishing, equipment and technology is FREE. A series of seminars are run in conjunction with the exhibition, covering maths, spelling, handwriting, IT, behaviour etc. The cost of attending each seminar is £5, bookable in advance.

The exhibition takes place on Wednesday and Thursday 4 and 5 November at The Cumberland Hotel, Marble Arch, London.

EPC Exhibitions
Telephone 071 580 6321

HOUSING

ON Thursday 5 November RADAR is running the first of a series of regional workshops to explore the problems and possibilities in meeting the housing needs of disabled people. This workshop on Housing and Community Care will be held in Cambridge.

Rachel Scott, Conference Officer, RADAR, 25 Mortimer Street, London W1N 8AB.

ADVERTISING

FOR THE USE OF LOCAL ASSOCIATIONS

Rates: £3 for 30 words max; £4.25 for 30-45 words; £5.50 for 45-60 words.
Cheques and postal orders should be made payable to 'ASBAH'.

Small adverts for the next issue of Link (January) should be submitted by Friday, 6 November. Please send them to: The Editor, ASBAH House, 42 Park Road, Peterborough PE1 2UQ.

HOLIDAY ACCOMMODATION

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ISLE OF WIGHT

Isle of Wight ASBAH has a fully equipped, wheelchair accessible, two-bedroom holiday chalet. Sleeps 6 plus cot. Clubhouse, indoor heated pool, shop, etc. Site overlooks sea. Own transport advisable. Details: Mrs P Burden, 36 Sherbourne Avenue, Binstead, Ryde, Isle of Wight PO33 3PX. (Tel: 0983 564604).

HAVE A WINTER BREAK at Westgate on Sea, Kent, in our fully CH bungalow. Sleeps 8 plus cot, fully equipped kitchen for disabled use, no steps, bath hoist. Low prices for November to March. Greenwich Association, apply Eileen Walsh for full details. (Tel: 081 856 5880).

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