Link

AUGUST 1990 NO 129
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The magazine for people with Spina Bifida and/or Hydrocephalus

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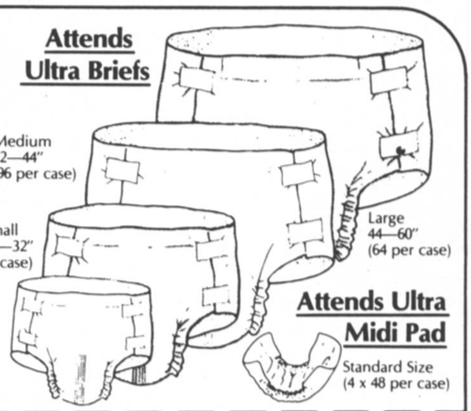

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ASSOCIATION FOR SPINA BIFIDA AND
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HERE we are, in the bustling city of Peterborough not far from its Norman cathedral, working out how best we can improve our services in the years ahead.

After our move this summer from the traffic-clogged, fume-laden and siren-shrieking streets of London, where National Office spent its first 24 years, staff are working well in their brand-new offices with their extra space. The building is smart and functional. The city centre is quieter, and just 10 minutes drive from the countryside.

Under the guidance of an energetic executive committee, ASBAH continues to look for ways in which it can improve its front line services - the network of dedicated fieldworkers and counsellors. Apart from some cautious consolidation in the North East, we have not been able to do as much as we would like this year. In some parts of the country, our fieldworkers are still stretched far too thinly.

The employment of extra fieldworkers and counsellors, where they can be securely funded, is one way of improving coverage. The opening of regional offices, with a start already made at 'ASBAH East' in Camberwell, is another way of making sure that the precious time of our fieldworkers is better managed. Recruiting regional co-ordinators who can bring a fieldwork expertise into the job will mean we are not taking on just another layer of managers. Again, this is a fairly slow process but one which is actively in hand.

Our disabled living advisory department, with its pool of specialist knowledge, continues to spark us all to do better and provides a constant stream of inspiration for people with disabilities and those who job it is to work with them. We continue to fight prejudice in the fields of housing, education and employment.

Independence training, both at our Five Oaks activities centre in Yorkshire and by means of special courses such as our Mobility Weeks, remains another major task and source of fulfilment.

Next month, National Office will welcome an extra special visitor when our patron, HRH The Duchess of Gloucester, officially opens the building on September 11. On this occasion, Her Royal Highness has expressed a particular wish to meet staff.

COVER – Pictured in front of the new headquarters are disabled living adviser John Naude and secretaries Kate Stilwell (left) and Trish Jones.

New look for 'Link'

A new publicity team at national office is going through all our publications and has already produced a new Hydrocephalus Support Group newsletter, a new 'Lift' magazine for our younger readers... and now a new 'Link'.

If you like them, then do feel free to contribute ideas, articles and photographs. If you don't, as with everything we are doing, do let us know what you think we are doing wrong. We'd love to hear from you.

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Net Gain

Tennis fan Jayant Mistry, who has spina bifida, took a break from play when the Princess of Wales officially opened a new indoor tennis centre in Nottingham earlier this summer. *Photo: Ross Kinnaird, Empics.*

Birthday Honours

WE ARE delighted to record that the president of ASBAH, Dr Jeffrey Tate, has been made a Commander of the Order of the British Empire (CBE) in the Queen's Birthday Honours, and that John Hawkshaw, treasurer of the Leeds and Bradford Association, will receive the British Empire Medal.

For Dr Tate, the 47-year-old principal conductor of the Royal Opera House, Covent Garden, and of the English Chamber Orchestra, it was his first award from the Queen.

"I was delighted to receive the CBE, which is the highest branch of the order below that of a knighthood", Dr Tate told Link.

"I've noticed many people have started putting in on their correspondence to me, but I expect the novelty will wear off soon and it will become like part of the furniture."

A profile of Dr Tate appears elsewhere in the magazine.

Members of ASBAH can meet Dr Tate when he presides at the association's annual general meeting in London on Friday, 12 October. The meeting will be held in the Cowdray Hall of the Royal College of Nursing at 10.30am for 11. Wheelchair access is through the entrance on Henrietta Place.

John Hawkshaw (41) has been honoured for his services to sheltered employment for the disabled.

He is raw materials controller at Remploy's amalgamated packaging factory in Millshaw, Leeds.

Mr Hawkshaw works tirelessly on behalf of other disabled people in their search for employment. He is a member of Leeds Disabled Forum and a community representative on Leeds Equal Opportunities Committee.

Arts Training

A CENTRE for Disability and the Arts has been opened by Leicester University, with the aim of encouraging people with disabilities to pursue an interest in the arts at a serious and sustained level, either as participators or as audience. It also provides opportunities to study aspects of the arts at a theoretical level.

The centre offers training in special art education to professionals such as music and gallery staff, teachers, community workers and nurses who work with disabled people. The centre will challenge prejudices against using disabled people in the arts, and its programme is designed to offered educational ooportunties to people with physical, sensory or learning difficulties.

Details, Dr E Hartley, Adult Education, Leicester University, tel 0533-522455.

MOBILITY WEEK SUCCESS

A water pistol fight, drama sessions, or meeting a "gorgeous boy" might not seem to have much to do with mobility but then an ASBAH Mobility Week is about a whole range of experiences...

WHAT A GIVEAWAY

For 19 of the lucky students, the big surprise of the week was going home with a brand-new lightweight wheelchair - theirs to keep, thanks to the generosity of the Association of Wheelchair Children and the manufacturers, Remploy.

Remploy gave 19 of their lightweight, robust 'Roller' wheelchairs to the youngsters they thought would benefit most from them.

This came about when course instructor Owen McGee, a physiotherapst and chairman of the Wheelchair Children group, thought it would be a shame for children who had done so well using the new chairs to go back to their old, often unsuiitable, models. So he simply handed them over!

WORKING HARD, PLAYING HARD

Of course the week was designed to improve wheelchair skills, including backwheel balancing, going up and down kerbs and stairs, and maintenance. But, besides the hard work this involves, both children and staff shared in the fun of a week away from home.

There may have been gripes from those who didn't like the food or, in one case, their pillows, but these were outweighed by the pleasures of meeting friends from previous years, and making new ones.

As you might expect with any group of young people, the most popular class proved to be that on sex education; at least one enterprising individual tried to infiltrate this for a second session when he should have been elsewhere.

The evening drama session - described as "brilliant" by one young girl - could also be seen as a way of increasing mobility: can you touch your elbow against someone else's ankle, both of you in wheelchairs? They certainly did.

During the action-packed course, our young participants, aged between 11 and 16, had talks and discussions on matters ranging from diet to personal assertiveness and personal hygiene to 'what is spina bifida?' Their evenings at the Ludwig Guttmann Sports Centre next to the world-famous Stoke Mandeville Hospital spinal injuries centre at Aylesbury were filled. They played badminton, they swam, they cued up on for thre green baize to play snooker, had a make-up demonstration and danced the night away at a end-of-course disco.

By the way, that water pistol fight we mentioned was part of the competitions held on the last morning!

MAKING IT HAPPEN

This first Mobility Week of 1990 was organised by ASBAH'S disabled living services team who, along with specially-engaged professionals, spent the whole week with the youngsters. and put in days of preparation to make sure everything ran smoothly.

"It was brilliant, a really pleasant although tiring experience for everyone involved," said disabled living services manager Rachel Stanworth.

But, as each week costs about £8,000 to organise, it would not have been possible to keep the cost to students so low without generous help from a number of trusts.

This year, ASBAH has been fortunate in securing help with fundings from: The Queen's Silver Jubilee Trust, Glaxo UK, The Enid Linder Foundation and Sainsbury's Family Trust. Their generous support enabled the cost to students to be kept as low as £75 for the whole week and, in several cases, this charge was covered by local associations and other supporters.

Fieldworker, Alan Langshaw with Tony White.

Physio Access

HEALTH authorities throughout Britain have been urged to ensure that all people have open access to physiotherapy services to cut the queues of patients needing urgent treatment.

In a joint report the Royal College of General Practitioners and the Chartered Society of Physiotherapy, complain that open access to hospital or community-based phsyiotherapy services is not available in a significant minority of authorities.

As a result, people often have to wait months to see a consultant before being referred for treatment. GPs and physiotherapists say this can cause unnecessary suffering and loss of income through sick leave from work, and ultimately lead to longer and more costly treatment.

The report, 'Relationships between General Practitioners and Chartered Physiotherapists' explores ways in which the two professions can work closer together.

CALLING ALL NURSES

Can you spare some time from 22-27 October? If so, you could be one of the volunteer helpers on our 'over 16s' mobility week.This course will be held at the Hereward College, Coventry, but will be similar to the Aylesbury one.

If you would like to join in and help a most worthwhile cause, please contact Trish Jones on 0733 555988.

Special Pen Pals Club

A PENPAL club for young people with special needs, using whatever means of communication they feel most comfortable with, has been given the patronage of blind MP David Blunkett.

It's called 'Write Away' and has been registered as a charity by its founders - Nicolle Levine, a teacher of children with special needs, and music therapist Hilary Wainer.

Young people are encouraged to break through the barrier of any sense of isolation by corresponding through their own chosen means of communication: conventional pen and paper, braille and electronic calculators. For those who find written information difficult, audio-cassettes will be provided. And, if members prefer drawing a picture, this too will be welcomed.

To join, young people (and adult helpers) fill in a registration form. Upon receipt of a token £1 membership fee, penfriends are matched according to the criteria stated on the form, and are sent their new penfriend's name in a 'Write Away' folder containing a pen, paper and envelopes.

The first 500 youngsters to register will be given a £2 book of 'smile' stamps.

David Blunkett writes: "For young people with a learning difficulty or with a disability, isolation and being cut off from the community and the society around them can be a very real problem. Our contribution to helping people building confidence, social skills and friendship can be through the development of a penfriend."

At present the club covers London and the South East but will expand to include all of the UK from next year.

Details from 'Write Away', PO Box 175, New Ash Green, Dartford, Kent DA3 8PQ. Tel 081-452 3330.

'LINK' readers are cordially invited to attend the

24th Annual General Meeting

of the

Association for Spina Bifida and Hydrocephalus.

It will be held on

Friday, 12 October 1990

in the Cowdray Hall
of the Royal College of Nursing,
Cavendish Square, London W1

at 10.30 am for 11 am.

We are delighted to announce that our president, Dr Jeffrey Tate CBE, has agreed to preside. We hope that he will address the meeting at the conclusion of the formal business of the AGM.

Wheelchair access to the Cowdray Hall can be gained by entering the Royal College through its entrance on Henrietta Place.

LIFE ASSURANCE FOR YOU

A life assurance policy specially for people with disabilities has been designed by Fish Insurance. The policy, called Disablecare, does not require a medical report or examination, though you do need to give some medical details.

Further information from: M J Fish & Co Ltd, FREEPOST, Preston PR2 2BR. Telephone 0772 724442.

CYCLE FOR STACEY

SELLAFIELD'S Snowball charity committee has bought a £1,400 powered Pony II cycle - so that nine-year-old Stacey Brown, of Whitehaven, who has spina bifida, can get out to play like her friends

The bike was given to ASBAH after a request was made to the charity committee by fieldworker Moira Foggo. ASBAH has in turn loaned it to Stacey, who outgrew another Pony bike which had been given by the West Cumberland Hospital.

"The Pony bike gives Stacey her independence," said her father Barry, who is an electrical engineer at Sellafield."When she plays out after school, she doesn't need to have any assistance.

"And, when we go on holiday, we usually go to caravan sites and we never see Stacey because she goes off with her younger sister, Alana."

ON THE MOVE

A new head office for the British Colostomy Association has opened at 15 Station Road, Reading, tel 0734-391537.

And the Disabled Drivers Motor Club has moved to Cottingham Way, Thraxton, Northants NN14 4PL, tel 08016-4724.

FOOT FAULT

SOME £12 million every year is spent by the NHS on surgical or orthopaedic boots and shoes. Yet one in six people prescribed this footwear would rather go barefoot than wear it.

If the shoes are prescribed for people who really need them, where does the problem lie? It is in the present system, says the Disabled Living Foundation.

Very specific prescription guidelines mean that housebound people get outdoor shoes. Outdated manufacturing specifications result in shoes which look horrible and are too heavy. People tire of complaining and accept shoes, which they then do not use. Children's shoes take too long to arrive and look quite unlike those worn by able-bodied friends. This embarrasses the wearer.

The DLF claims that unworn prescribed footwear can cost the NHS about £2 million every year.

The DLF, the Chartered Society of Physiotherapy, the King's Fund and the Society of Chiropodists, actively encouraged by the Department of Health, have formed a working party to look at the issues.

It will construct quality guidelines for the provision of footwear to recommend to health authorities. The working party does not set out to 'save' the wasted millions, but to ensure that every boot or shoe is truly fit to be worn.

The working party would like to hear from anyone who has had a problem with prescribed footwear and invites detailed accounts of current good practice in prescribing and monitoring procedures which have led to improved consumer satisfaction.

Further details from Ginny Jenkins, Clothing and Footwear Adviser, Disabled Living Foundation, 380-384 Harrow Road, London W9 2HU, tel 071-289 6111.

SPORTING INSPIRATION

A KEEN interest in sport and helping others led Ashley Coldrick, who has spina bifida, to meet the Queen when she presented him with an award at Portland Training College at Mansfield, Notts, this summer.

Eighteen-year-old Ashley was presented with the college's Douglas Lea Memorial Trophy for his inspiration and encouragement to other young disabled athletes.

A keen basketball player, he played in the national team when in lived in Hampshire and took part in the National Games at Stoke Mandeville, where he also won the 100 metres wheelchair sprint championship four times. As a teenager, he has played many sports from discus and shot-put to slalom and archery but, since moving home to Matlock, he has concentrated on basketball.

Ashley receives his trophy from the Queen

At the Portland Training College, where he has just finished a further education course, he was made basketball coach and his team have played able-bodied youth groups in the area though, as Ashley told us: "We lend them wheelchairs for the matches against us".

BOWLING FOR BRITAIN

Two ASBAH members in Birmingham have been chosen to represent Britain in the ISOD Lawn Bowls Championships which, this year, are being held in the city. Eight countries will be taking part in the competition from 18-24 August.

Andrew Rock, aged 27, has been bowling for about five years now, "It was the sport I liked best" at a local sports club - The Wobblers and Wheelies. He has received several medals including a gold at Rugby, in May, for long indoor bowling. Andrew is currently training with the British squad and has received a grant from ASBAH's Professor Zachery Fund.

Barry Hussey is 26 years old and started bowling about 4 years ago when he joined the Birmingham Sports Club for the Disabled in Sutton Coldfield. Barry is a member of the Les Autres Association who help with his training. This will be the first time he has represented his country at bowls. He's been a runner-up in several major competitions before and hopes he can "go one better this time".

CONTACT REGISTER FOR DISABLED PARENTS

The National Childbirth Trust is a charitable organisation concerned with education for parenthood. One of the services they offer is a national contact register for disabled parents. The aim is to put people in similar situations in touch with one another and they have parents with spina bifida amongst almost 200 listed contacts. If you'd like to join the register ring Judy Vickery on tel: 071 622 4792.

HAVING A BABY?

In our book reviews section this month you'll find The Baby Challenge - a handbook on pregancy and childbirth for disabled women. If you're a disabled mum-to-be or have recently had a baby we'd like to hear about your experiences. Write to Link about the good and bad aspects of pregancy, delivery and living with a baby and the reactions you've had from health professionals and the general public.

Lucky enough to even the score

JEFFREY Tate says several times in conversation that he believes he has been extraordinarily lucky. He mentions various turning-points in his life when by chance he was in the right place at the right time and he ascribes his enormous success to these coincidences.

A less modest and less cheerful temperament would point out that in one respect he has been extraordinarily unlucky. He is severely disabled, with congenital curvature of the spine (kyphoscoliosis) and spina bifida. Because of the spinal curvature, his lungs are underdeveloped and he suffers shortness of breath. He also has a withered leg, which means he has to wear a leg extension; he walks lop-sidedly - and surprisingly fast - with a stick. Children point at him in the street and in Italy once a man came up to touch his hump, believing it would bring him fertility. He sits to conduct, one long arm waving above the podium, but occasionally, in moments of excitement, lurches to his feet. Once he fell off the podium but climbed back to finish the performance.

"I've always been so astonished that I'm actually doing it," he says about conducting, "that I've never had a chance to sort of feel grand about it." He originally trained as a doctor, at Cambridge and at St Thomas's Hospital, London, and qualified. But music was always an obsession - as a child, playing the piano and singing in the church choir; as a medic, organising a hospital music society and madrigal group. One of the great strokes of luck in his life was meeting the tenor John Kentish and his wife, who persuaded him to apply for a place to study coaching at the London Opera Centre. He succeeded - but then decided to carry on to qualify as a doctor.

He became Dr Tate in 1969, but hesitated on the brink of his career. Looking back, he says, he can see that his heart was never really in medicine: it was something he did to reassure his parents, who wanted him to be financially secure, and because he felt he owed a debt of gratitude to the medical profession. And, while he dithered, the Opera Centre wrote to say that they were still holding a place for him so "I'll give it a year," he thought, "just to get it out of my system," But as soon as he finished his training, Covent Garden offered him a post as répétiteur; Sir Georg Solti asked him to assist on his recording of Parsifal; soon other conductors - Sir Colin Davis, Rudolf Kempe, Carlos Kleiber, Pierre Boulez, Herbert von Karajan - wanted Tate as their assistant. In 1978 he was working as assistant director at the Cologne Opera, when some singers told him that the Göteborg Opera in Sweden was looking for someone to direct Carmen. Tate scratched his head to think of someone, till finally the friends insisted, "Couldn't you do it?"

He had never conducted an opera in public before. He was worried about his ability to manage physically (and indeed his shoe fell off at the first performance but he barely noticed): "As the music moved under my hands, I suddenly felt that I was doing something I had been waiting to do all my life." He was then 35. In the 12 years since, he has conducted at most of the world's great opera houses, and has recorded everything from grand opera to chamber music. He made his American debut at the New York Metropolitan Opera in 1980 when the conductor of Lulu fell ill, and Tate took over the performance without rehearsal. "It was a terrifying four hours," he recalls drily.

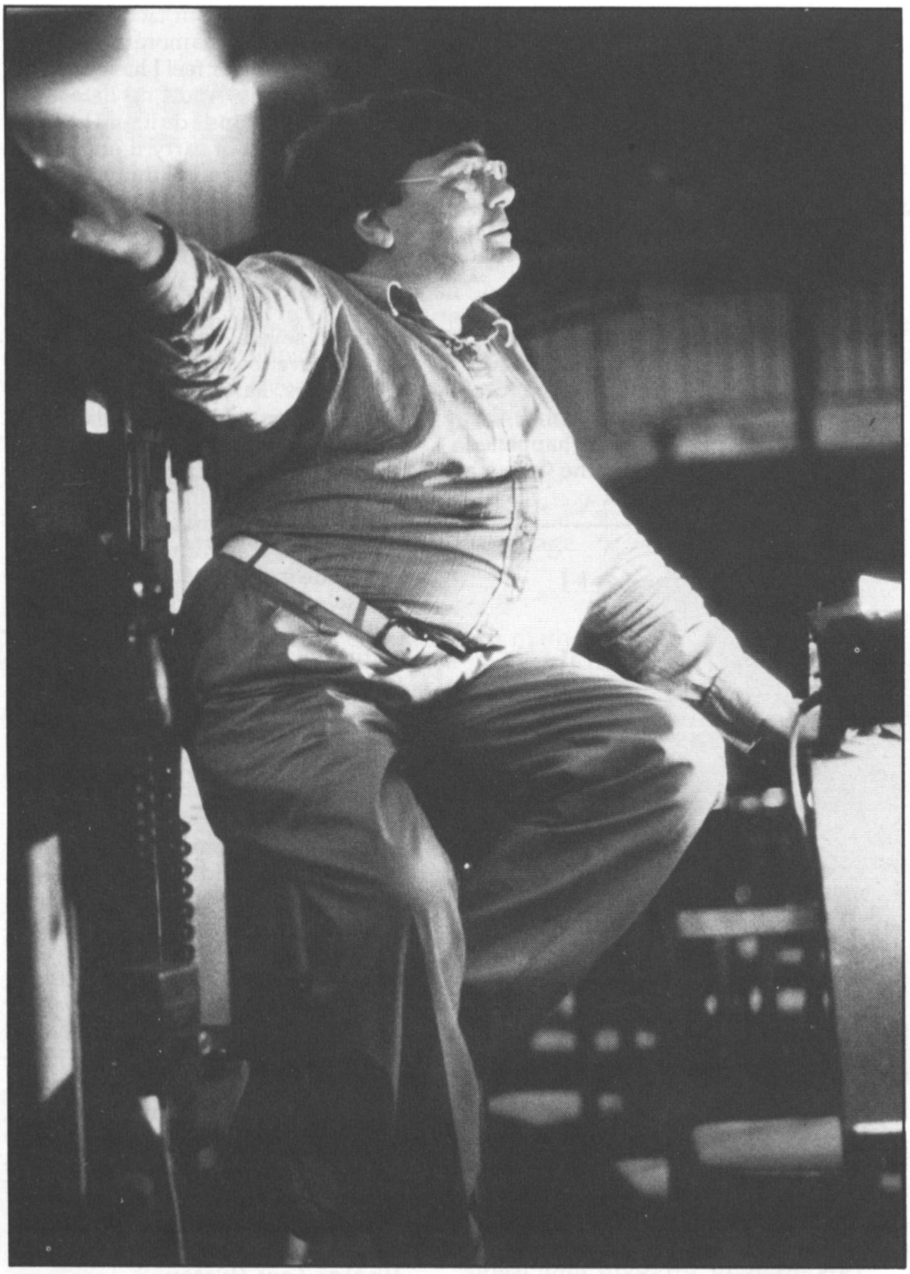
He sits to conduct, one long arm waving above the podium but, in moments of excitement, lurches to his feet.

He once had the embarrassing experience of Leonard Bernstein falling at his feet crying "Maestro!" (I was rather hoping to address Jeffrey Tate as Maestro myself, but he wouldn't have it. He hates the whole Maestro syndrome.) He made his Covent Garden debut in 1982 and has since conducted in Geneva, Hamburg, Munich, Salzburg, Paris, San Francisco. He is now Principal Conductor of the English Chamber Orchestra and of the Royal Opera, Covent Garden (where he is currently conducting Kiri te Kanawa in Arabella); he is Principal Guest Conductor of Orchestre National de France and of Geneva Opera, and next year becomes Musical Director of the Rotterdam Philharmonic. This year he was made a CBE.)

In case that all makes him sound too formidable, I should hasten to say that he is one of the most approachable, likeable, entertaining people you could ever hope to meet. He has an enormous circle of friends and an even larger orbit of people who would like to be his friends, among whom I include myself. His range of interests is extraordinary. He reads seriously and voraciously (a biography of Wittgenstein when I met him); loves looking at paintings, at architecture, at landscape; is expert in Meissen porcelain. He adores being driven at high speed, and when I gave him a lift to the Opera House kept urging me to whizz through bus lanes and no entry signs. He is a keen cook and dinner party host and lists his recreations in Who's Who as "church-crawling, with gastronomic interludes". In London, he lives in Camden but he also has apartments or "bases" in Geneva, Cologne, Paris and New York.

I was worried about how I would raise the subject of his disability, but in fact he raised it himself early on. Talking about a harrowing incident in his medical career (which I shall come to later), he said: "Most people who know me forget I'm disabled after the first half-hour or so." I am sure this is true for anyone meeting him socially or at work, but an interview is different - I was struck by how keen he was to relate questions back to his disability, to show how it colours every aspect of his personality, his sexuality, his musical career, his attitude to the world. I think he feels he has a duty to speak up for other disabled people: he mentioned that publishers often ask him to write his autobiography and he's never tempted, but he would like to write a book about "the positive and negative sides of disability".

But are there positive sides? "Ooh yes!" he says, amused by my bewilderment. "I think I'd be a desperately intolerant person if I weren't disabled. I would be very arrogant. I'm arrogant enough anyway, but it takes the edges off. I mean, I have



Jeffrey Tate

a great sympathy - not just a liberal sympathy but something deeper - for minorities, for people who are outcasts. And I can stand outside situations, and not feel involved - in a good way, as well as a bad way."

He doesn't seem at all arrogant now, and admits that he has mellowed since he became a conductor, but in his twenties apparently he had a scathing wit and a very sharp tongue. "I didn't think I was scathing - I would say I was candid, direct - but several people have said that is how I came across. And I think if I hadn't had the additional problems of coping with other people's attitudes to my disability, and had concentrated only on honing my mind, I would probably have honed it rather better, and I would have become very tiresome indeed. Very full of myself. Because I was a clever boy and that was my weapon."

He mellowed a lot when he became a repetiteur and worked with opera singers. The répétiteur's job is to teach singers their parts, but a good répétiteur is also part guru, part psychotherapist. Dealing with singers, he soon learned, required enormous tact and subtlety. "You can never just say 'That's appallingly flat'; you have to be diplomatic. And I think that was when I became a little more human."

I assumed the negative sides of disablement were to do with tiredness, but he said no, he was so used to living in his own body that he never even thought about it. He was outraged once at an airport, when an official insisted on putting him in a wheelchair. It is other people that are the problem: "Nowadays, the only negative moments for me are connected with children, when they look at you and laugh or point in the street. That still rankles; it hurts. And once or twice during my medical training, I was aware of patients looking at me doubtfully, perhaps thinking a better doctor, would have cured himself. You would like to look normal just to avoid that. But otherwise I've stopped caring."

There was never any one specific moment when he became aware of his being disabled. His mother took him to the doctor when he started walking because his feet seemed very flat, and tests then revealed the kyphoscoliosis and spina bifida. By the time he went to school (in Farnham, Surrey), he was wearing a leg brace, built-up shoe, and spinal corset, and there were two long stints in hospital when he was eight and 12. His parents were careful not to mollycoddle him, to make him independent, to let him pick himself up when he fell over and so on. But how harrowing it must have been for them! Jeffrey Tate admitted that he had never really thought about how it must have affected them - a surprising lacuna in such a thoughtful man. But the family attitude was stiff upper lip.

Disability, he says, is worst in childhood: "I'm so glad I'm not a child any more because of course as a child it is horrible. One is very isolated because one is different." He was precociously clever, bookish, musical, self-contained; he preferred the company of adults to children. Grammar school came as a shock. "It was only when: I entered the adolescent world of all boys together that I realised people might single me out as odd, and push me on one side."

And as early as 12 or 13 he began to realise something else about himself: that, sexually, he was attracted to men. "The most telling thing was that we took in a lodger - times being quite hard in the 1950s - a young assistant master from my school, and his brother came to stay with us sometimes and I was absolutely - I don't know - overwhelmed by this brother, who must have been about 30. I mean it was rather different to the normal sort of adolescent boy having a crush on another boy. It made me realise that perhaps there was an aspect of the adult male that attracted me. My best friend was the girl next door but I rather vainly took her out for two years, but I realised after a while that we weren't getting anywhere. She wanted, eventually, a husband with whom she could have children, but that didn't concern me. I wanted something else, a sport of spiritual thing - call it adolescent if you like - but the more independent, companion-like relationship that can exist between two men."

For the moment, though, he shelved that problem while he threw himself into his schoolwork, and music, and medical training. There were always new intellectual peaks to conquer, new exams to pass. And at medical school, just when he thought he had come to terms with his disability, he had two profoundly upsetting experiences. The first was when he took a routine medical for insurance purposes, and the insurance man said blithely, "Of course, we can't give you a life expectancy of more than about 52." (This is what Jeffrey Tate told me, though in two previous interviews he has said that the life expectancy given him was 48. He is 47 now). Then, a few days after this blow, he was assigned a patient to examine and "present" to the consultant. The patient was a woman in her early fifties, with severe scoliosis like his, who was dying of heart failure. And the reason for the heart failure was chronic bronchitis caused by the fact that her lungs were too small - as a result of her scoliosis. "And she was my patient and it was horrible . It stays with me to this day, the face of the dying woman, purply-pink, and gasping for breath, and I said to myself, 'Is that my fate?'"

And as he finished his medical training, and no longer saw exams and intellectual hurdles looming ahead, he was forced to think again about his private life. "It was the real problem of my twenties, I think. The purely physical side of one's life - if one is disabled and therefore not particularly attractive - is very difficult to organise." Emotionally, he feels, he could just as easily have been heterosexual, and he had several very intense emotional relationships with women, but physically he always preferred men. This too, he believes, was connected with his disability: "As a boy, I was very interested in physical perfection - and of one's own sex inevitably - because one was concerned about the way that one was. And therefore there was a sort of penchant, or fascination, with the idealised male form. I felt a sort of envy and the envy turned into attraction, I think. But I haven't really analysed this deeply enough; it isn't in that sense important enough to me; one is what one is."

It is striking that, while he talks readily about his disability, he is not happy talking about his homosexuality. Significantly, perhaps, he says that when he was trying to sort out his love life in his twenties, he resented the amount of time it took. He wanted to get settled in a relationship so that he could get on with his work. "I'm a very independent person who's made myself a very isolated person and therefore I don't readily give myself to anybody."

But in 1978 he met a German geologist, Klaus Kuhlemann, which he believes was one of the two great pivotal moments of his life (the other was meeting the Kentishes). It happened when he was working at the Cologne Opera but just about to go to Göteborg to conduct his first opera in public. He went out to dinner with a group of friends; Klaus was standing at the bar, and joined in their conversation, " and we talked and talked and talked, and exchanged phone numbers." But Tate was due to leave for Göteborg in two days - "and probably if I'd gone, I might well not have rung him - who knows?" But by chance (or subconscious volition?) he lost his passport and had to stay a few days more, and then he did ring Klaus up. They saw each other every day until Tate went to Sweden, and Klaus followed in time to see his first-ever performance as a conductor, and they've been together ever since. "Which is, you know, one of those sort of magical stories - that it all worked out at the right time, at the right place. I count myself very lucky."

> **"I no longer feel I have to storm all the bastions. I hate going into new situations"**

Klaus, he says, "is the least self-centred person I know - and is a good example for me," He also gave him the stability he needed to cope with his new career, "I doubt whether I would have had the courage and the strength to do what I did - especially in America, taking over Lulu - if I'd been on my own. I'm sure I would have pulled out through lack of self-confidence."

Lately, he says, his courage as a conductor has begun to fail, or perhaps he is growing tired. He dreads working with new orchestras, hesitates to work in new places; and in fact need never do so, because he has more than enough work. "I no longer feel I have to storm all the bastions. And I do hate going into new situations. I do it, and I usually manage to sort of carry it off, but the cost of it is enormous. I flutter so much beforehand. When I began, I was frightened enough, but maybe ignorance was bliss. Now sometimes I get really terrified.

He says several times that he believes he will never be in the very top rank of conductors. Partly this is because he came to it late, without formal training, and feels he is "running to catch up". He is still learning much of the symphonic repertoire. But also, he says, he perhaps lacks just that final edge of passion, of commitment. "Music in itself," he explains, "cannot be for me my whole life. I do get enormous fulfilment from it, but I cannot admit to getting total fulfilment from it. I like to try and be as complete as I can, and music is only one element. If I only had music, I think I'd become slightly dead, you know? Certain parts of me would become numb."

And indeed he says he may one day give it up. After all, he trained as a doctor, and gave that up. Now he is constrained by the need to earn his living, but he hopes that in a few years' time he will be able to afford a long sabbatical in which to study fine art, or write the book about coping with disability. Of course one hopes that he will go on, like his hero Klemperer, growing and growing as a conductor, but one can't help feeling with Jeffrey Tate that anything he ever does will be outstanding.

Story: *Lynn Barber*
Photo: *Tom Pilston*
Taken from *'The Independent on Sunday'*.

Support skills for maths

EARLIER this year, Professor Mahesh Sharma, one of America's leading authorities on numeracy learning difficulties, visited England to give a series of lectures. At a lecture hosted by the Dyslexia Institute entitled "Making Sense of Maths", he covered five areas dealing with the diagnosis and provision of remedial measures for those who have mathematical learning difficulties.

Professor Sharma's lecture covered levels of cognitive development, his theory of mathematics learning personality, the language of mathematics, levels of mastery of mathematical skills, and the pre-skills and support skills required by a child to learn maths

Below we print an edited extract from his talk dealing with the last of these factors and which is relevant to developing skills in children with hydrocephalus.

As Professor Sharma's introduction makes clear, many problems of mathematical learning have their roots in the pre-skills a child needs to acquire to master mathematics. Where a child is experiencing problems, identifying whether or not these 'anchoring skills' (as Professor Sharma calls them) are present is the first step to effective action.

"Without exaggeration, I can claim that most of you are better reading teachers than maths teachers. I make that claim because I know that you have more experience in the reading process. You read more, you have taken more courses, you read in your own leisure time, you take books to the beach. I don't know very many people who take mathematics books to the beach or who do mathematics in their leisure time.

When you are dealing with a child who has a reading problem, you don't just look for the cause of the reading problem in reading itself. You look for many things outside reading which might be contributing to the reading problem. You are aware of all the other skills outside the reading skills area which might be contributing to the child's difficulty. But, ordinarily, when it comes to mathematics remediation, most people look for the problem and the causes of learning problems in mathematics itself.

If the child is having difficulties with long division, you say 'Well,he is having difficulties because he doesn't remember his multiplication tables'. So you start working with multiplication tables. Then you discover the child is having trouble with addition tables, so you start working with them. Then you discover the child is having trouble with number conceptualisation so you start with that.

You work for a few weeks and then you realise that nothing is being achieved because you have come to the lowest possible level of mathematics teaching. So you throw your hands in the air and say 'Well, this child does not have an aptitude for mathematics learning. Either you are born with it, or you are not'.

Now notice that the cause and the remediation of the mathematics learning problem remains in the field of mathematics itself. If you were doing the same thing in reading, you would have looked at the visual memory, the auditory memory, the short-term memory, the attention span, the sequencing, and a whole lot of things. The same thing has to be done when we are thinking of remediation of mathematics learning problems.

We have to look for those pre-skills, those support skills, non-mathematical in nature, but which affect conceptualisation. There are some skills which are absolutely essential to this. If the pre-skills are present, mathematics learning is easier.

I call these pre-skills 'anchoring skills' because mathematical concepts get anchored if they are present. If they are not present, then the concept is learnt by a child and a few days later it is gone because the concept was not anchored to something. What are those pre-skills?

The first pre-skill necessary is the child's ability to follow sequential direction. Let's take an example. If I wanted to multiply 25 x 36, it is necessary to follow certain steps. The first decision you make is should I multiply 2 with 3 or 6 with 5. There are children who don't know whether they should multiply the ones digit first or the tens digit first. Then you multiply 5 x 6 and you get 30. Now you must make a decision where to put that zero, where you put that 3.

I have already followed about four directions and I have not yet completed one-quarter of the problem. To complete it, I must follow more than 16 sequential steps. Mathematics is a collection of a large number of procedures where I must follow sequential steps. A child with sequential difficulties is a prime candidate for having problems in mathematics learning.

The second pre-skill is spatial orientation and space organisation: a student's ability to see parts-to-whole and whole-to-parts relationships. Every object in the environment has two positions: one is the absolute position of that object and the other is its relative position. For example, on a number line 5 comes always after 4 and before 6. That means it has an absolute position on the number line after 4 and before 6 - whether the number line is long, short, narrow or broad. But number 5 also has a relative position. Take the following numbers: 2,345; 3,456; 4,567. In all these numbers, 5 has a relative position: it changes with the number. The child must recognise the relative position of that number to know the value of that number in that particular combination.

Children who are good in spatial orientation/space organisation are better at identifying the absolute and relative positions of objects. Children poor in this skill focus only on the absolute position of objects; they don't pay attention to relative positions. As a result, they don't see the differing values because of relative positions.

As an example, look at the concept of the hypotenuse in a right-angle triangle. We define the hypotenuse as the side opposite to the 90 degree angle. That means the hypotenuse is dependent on the position of the 90 degree angle, ie we are talking about a relative position. After using this definition, the child was asked to identify the hypotenuse in figure 2. Forty per cent of 12 to 14-year-old children still identified the line indicated as the hypotenuse. Why? Because they paid attention to the absolute position of the hypotenuse.

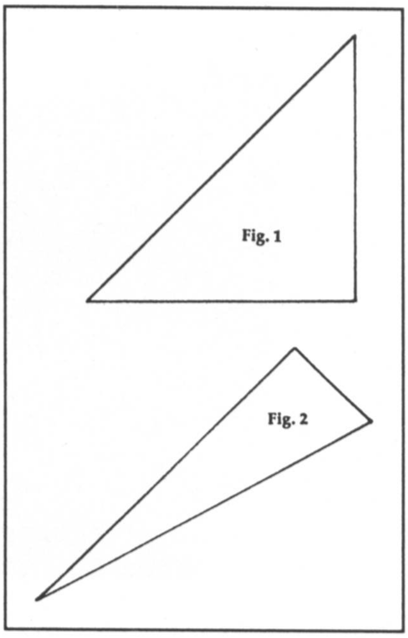


Fig. 1

Fig. 2

That means they said the slanted side was the hypotenuse in the previous case so the slanted side in the corresponding position is going to be the hypotenuse in the second situation. This is an example of lack of spatial orientation/space organisation and therefore difficulty in conceptualising a mathematical idea.

Let me take another example. Those of you who teach children 6, 7, 8 years of age may introduce the idea of place value in the following manner. One day we tell them that numbers increase to the right: 1, 2, 3, 4, 5 etc. A few days later we tell them place values increase to the left: ones, tens, hundred and so on. It is quite confusing. So what does the child do? He or she says this is my right hand so the numbers are increasing to the right, this is my left hand so the place values are increasing to the left.

Now, if the child has intact left-right orientation ability, problem-solving using places values presents no problem. But, if he or she doesn't have left-right orientation mastered, then the place value concept is not learnt. As a teacher, if I keep on teaching the concept of place value without paying attention to whether the child has mastered left-right or not, my teaching will be short lived.

Today the child may be able to answer my questions but five days later he may not be able to. Maybe he has a short-term memory problem. Maybe he has a long-term memory problem. It is neither of those. The problem lies in that child's ability to recognise left from right and right from left, which is a sub-skill of spatial orientation/space organisation. This skill directly correlates with mathematics achievement, especially with concepts of place value, fractions, integers, geometry, trigonometry and all the concepts after that.

The third pre-skill is the child's ability to discern emerging patterns in incoming information. I was in a classroom of 6 to 7-year-olds and I asked them a question. I asked them what is 8 plus 7 and invariably almost all of them said 9, 10, 11,12, 13, 14, 15. A few seconds later, I asked what is 7 plus 8 and they said 8, 9, 10, 11, 12, 13, 14, 15. For these children, 8 plus 7 and 7 plus 8 were two distinct, isolated problems. They were lacking pattern recognition.

I was in a classroom of 11-year-olds and I asked them what is 9 x 10? They were indignant that I asked such a simple question. They said 90, of course! Then I asked them what is 13 x 10? About three children out of 27 took out a piece of paper, wrote down 13 x 10, 0 x 3, 0 x 1, 1 x 3, 1 x 1 and then added it and gave me the answer as 130. So I said what is 59 x 10 and three more children took out a piece of paper and went through the same process. After about 12-15 problems, about 60 per cent of the class realised that we really don't have to go through this procedure. If we take a number and multiply it by 10, then the result turns out to be the number given with a 0 next to it.

This discovery on the part of the 60

per cent of the class is the ability to recognise patterns in incoming information. A few minutes later, I asked what is 153 x 100? Those who identified the patterns earlier were able to tell me to just add two zeros this time. Those who did not identify the pattern wrote out the problem in full.

Children who have good pattern recognition skills have a lower work load on their memory network. For the child who did not recognise the pattern in those multiplication problems, they are all separate, distinct problems whereas the child who identified that pattern for him or her there is a class of problems.

The fourth pre-skill is visualisation - a child's ability to hold data in the mind's eye and manipulate it. In mathematics, we call on the working memory and the short-term memory a great deal. We work on a problem and then we digress from the main problem and on the side we do a series of smaller problems. In the western world we place a great deal of emphasis on written mathematics very early on. Nothing will please a parent more than if, when a child is born, he comes complete with a pencil and paper and he writes things right away as soon as you ask him a question. We have an overemphasis on the written aspects of mathematics. As a result the child writes even the simplest of problems.

When he writes this that problem remains on the written level, on the visual level, and many times it is not transferred from short-term to long-term memory. If the amount of mental arithmetic is increased, visualisation abilities are improved and so is the child's ability to deal with data and manipulate it in the mind's eye.

The fifth pre-skill is estimation: to know what to expect in an answer, whether it makes sense. In real life, we estimate more than 95% of the time and actually calculate less than 5%. In classrooms, we calculate more than 95% of the time. Sometimes we wonder why children are not able to transfer this known knowledge, the mastery of actual calculations, to problem-solving. The answer is that that are poor in estimation. A lot of research shows that there is a high correlation between estimation skills and problem-solving abilities.

The sixth and seventh pre-skills are deductive thinking and inductive thinking. Deductive thinking means the ability to go from the general to the specific. Inductive thinking is just the opposite - going from specific cases to derive the general case. In mathematics learning, we use both of these. To be a good problem-solver, to be a good mathematician, we must have both. ”

Professor Sharma is Director of the Centre for Teaching/Learning of Mathematics in Massachusetts and Editor of Focus on Learning Problems in Mathematics.

Feature taken from 'Special Children' Magazine

•HSG STUDY DAY•

The next Hydrocephalus Support Group study day is on 15 September at our new offices in Peterborough.

Programme includes:

☐ Talk by a leading neurosurgeon.
☐ Choice of group sessions
☐ Free information pack
☐ Bookstall
☐ Toys display

* * *

❖ Creche available
❖ Easy access for wheelchairs

Contact Trish at ASBAH
House, 42 Park Road,
Peterborough PE1 2UQ.
Tel: 0733 555988

...BE THERE

•HSG STUDY DAY•

How hydrocephalus develops from a Dandy-Walker cyst

THE Dandy Walker Syndrome is frequently associated with hydrocephalus but what is it?; why does it develop?; how is it diagnosed?; what treatments are available? We asked paediatric neurosurgeon, Miss Carys Bannister, to answer these questions.

THE Dandy-Walker cyst is a fluid-filled sac lying in the back of the brain which is usually associated with hydrocephalus. To understand how the cyst is formed it is necessary to know a little about the anatomy of the brain and its related structures and how the brain develops.

Lying within the substance of the fully developed brain there are a series of four inter-linked chambers, or ventricles, which are filled with a clear liquid called the cerebro-spinal fluid or CSF for short. The CSF flows out of the fourth ventricle, which lies in the back of the brain, into fluid spaces surrounding the brain, from where it is absorbed into large veins lying just beneath the skull.

During the early stages of development of the human baby, the ventricles do not communicate with the fluid spaces outside the brain until the roof of the fourth ventricle breaks down in three places. This event takes place during the first few weeks of pregnancy. A Dandy-Walker cyst occurs when the roof of the fourth ventricle fails to perforate - the cavity of the fourth ventricle becomes distended with trapped CSF and balloons out to form the cyst. The associated part of the brain, known as the cerebellum, often develops incompletely so that the hemispheres and the midline part of the cerebellum or vermis are smaller than normal.

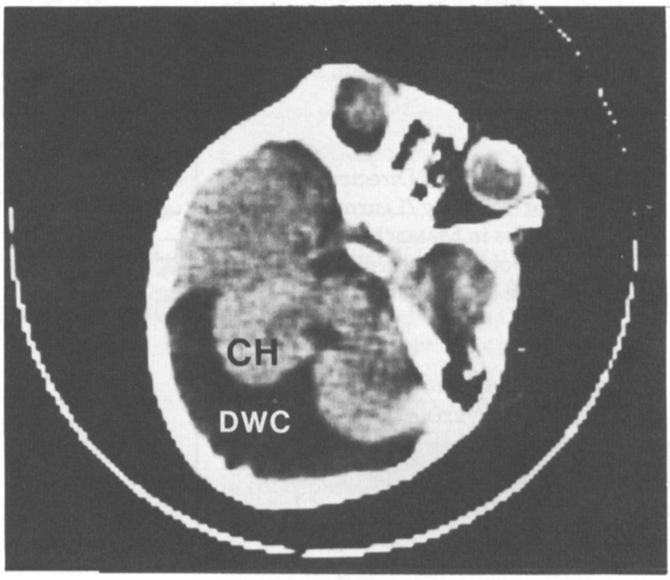


Figure 1 - A CT brain scan of a baby with a Dandy-Walker cyst (DWC). The small, under-developed cerebellar hemispheres (CH) are clearly seen.

The function of the cerebellum is concerned with the maintenance of the balance of the body. Even though it is poorly developed in patients with Dandy-Walker cysts, it is unusual to find that they are particularly unsteady; presumably because the small amount of cerebellar tissue present is able to function adequately for their needs.

When a Dandy-Walker cyst occurs, not only is the CSF trapped in the fourth ventricle, CSF is also damned up in the rest of the ventricular system. Unfortunately, the choroid plexuses are able to go on producing CSF even though the pressure within the ventricular system begins to rise. This raised pressure causes the whole of the ventricular system to become distended and leads to the development of hydrocephalus.

The diagnosis of a Dandy-Walker cyst can be made before the baby is born. Because of its frequent association with hydrocephalus, ultrasound scans carried out from the 20th week of pregnancy often show an abnormality. The presence of hydrocephalus is usually detected first. As the developing baby gets bigger, it may also be possible to see the cyst on the ultrasound scan.

As with all forms of hydrocephalus, the rate at which the hydrocephalus progresses varies considerably. Some babies develop gross hydrocephalus rapidly before birth and may have heads which are much larger than normal. Whilst, in others, the hydrocephalus develops much more slowly and the size of their heads may be within the normal range at the time of birth and only begin to increase at an abnormal rate several weeks later.

Dandy Walker cysts are relatively uncommon compared to the Arnold-Chiari malformation, which is the cause of hydrocephalus in children with spina bifida, or aqueduct stenosis which gives rise to hydrocephalus by narrowing the passage that links the third and fourth ventricles together. The risk of subsequent children in the family also having a Dandy-Walker cyst is relatively small and is estimated to be only about one to two percent.

Dandy-Walker cysts may be accompanied by maldevelopment of other parts of the brain or other organs of the body. An encephalocele or a hernia of a portion of the brain outside the skull - usually at the back of the head - may be present, or faulty development of blood vessels of the skin of the scalp and face may cause a skin blemish.

As has already been stated, at birth a baby with a Dandy-Walker cyst may appear to be perfectly all right, the head size can be within the normal range and there may be no signs of raised pressure until weeks, months or even years have passed. On the other hand, at birth the baby may already have a head size larger than normal and signs of raised pressure may be present. In these cases the soft spot is large and tense, the veins on the scalp and forehead may be engorged, a squint may be present and the baby often looks persistently downward. These signs are present in all babies with hydrocephalus, whatever its cause.

To make the diagnosis of a Dandy-Walker cyst it is often necessary to carry out further investigations, particularly if the diagnosis was not made before birth by means of ultrasound scans. Ultrasound scans can also be done after birth and will confirm the presence of hydrocephalus but they are not always able to clearly demonstrate the cyst

A CT brain scan, which uses X-rays, produces a much more detailed picture of the whole of the brain and allows the ventricles and the Dandy-Walker cyst to be seen (Fig 1). It also images any associated abnormalities that are present (Fig 2). These days yet another scan, which uses magnets to produce a picture, can also be used to image the brain but in this country it is only available in a few places.

Patients with Dandy-Walker cysts need treatment if the dammed-up CSF within the ventricles is causing raised pressure. The pressure is reduced by inserting a shunt which drains the CSF from the ventricles into the abdominal cavity from where it is absorbed into the blood stream. This is the same operation which is carried out for hydrocephalus due to other causes.

It might be thought that, in the case of the Dandy-Walker cyst, the roof of the fourth ventricle could be opened to allow the CSF to escape out of the ventricles into the fluid spaces around the brain. Unfortunately the spaces do not seem to function normally in these patients because they have not had any fluid in them from the early stages of development.

A total of 160 children with hydrocephalus due to a variety of causes were reviewed in our Department of Paediatric Neurosurgery to assess their mental and physical development. Only eight of the children had Dandy-Walker cysts. All eight had reached school age at the time of assessment. Six of these were attending mainstream schools, one a school for the educationally subnormal and one a training centre for the severely mentally retarded.This meant that the IQ of 70 per cent of the children was within the normal range.

From this small series, it can be seen that Dandy-Walker cysts cause a range of disabilities which vary from being minimal to very severe. As so often happens, with conditions affecting babies, when they are first seen there is no way of telling with certainty how they will develop, although there are a few indicators of what the outcome is likely to be.The babies who do best are generally those who have no other abnormality, and whose head sizes are within the normal range at birth.

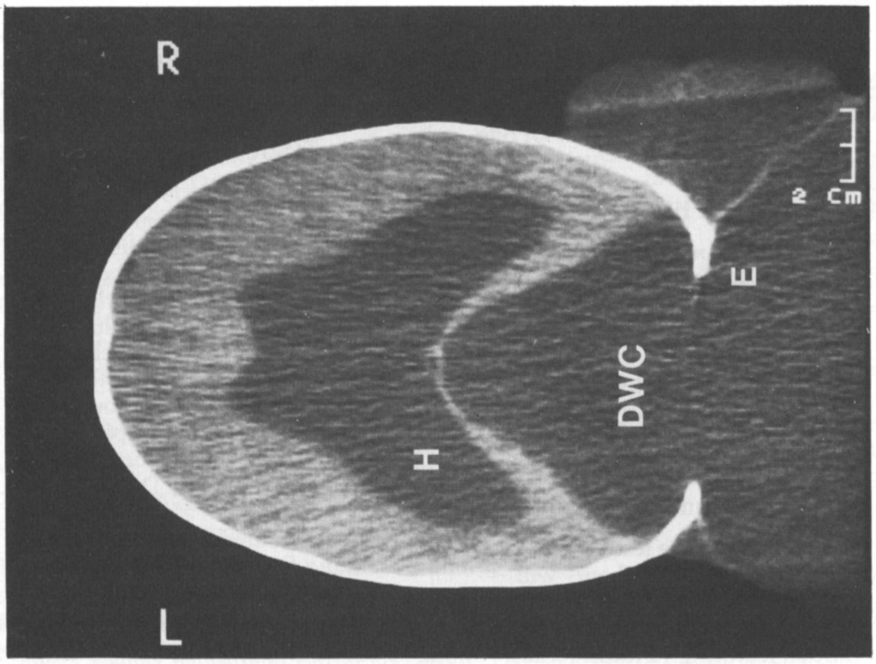


Figure 2 - A CT brain scan of a baby with a Dandy-Walker cyst (DWC) opening into a large encephalocele (E) herniating through a defect in the back of the skull. The dilated lateral ventricles of the associated hydrocephalus (H) can also be seen.

New catheter

A new self-catheterisation system has been developed at Birmingham Children's Hospital. The BISCATH system - Birmingham Intermittent Self-Catheterisation - was designed with the particular need to avoid urinary infection while being easily handled by young children.

Renal consultant Dr Mark Taylor and clinical nurse specialist in urodynamics, Sister Cindy Thomas, developed the BISCATH system with Peter Broadbent, of Malvern Medical Developments. Though initially intended to be used by young children and adolescents with neuropathic bladders, they say extended trials have shown that the system can benefit femalesof all ages.

BISCATH is made of highly polished stainless steel, with minimises trauma to the soft tissues. The double-eye formation has been used to speed total emptying of the bladder, while the eye design also minimises trauma.

The design of the handle allows positive handling and sure introduction, with the added benefit of the acceptance of a male luer fitting, enabling drug introduction to the bladder if necessary.

Being made of metal, it can be easily sterilised and lasts a long time. It is designed so that after use it may be rinsed in water, returned to its case and baked in a domestic oven to sterilise.

Sister Thomas said: "Reports say that infection rates are lower, something we're obviously pleased about. But also the catheter has been well received by patients: its rigidity makes it easier to introduce and they like the way it's contained, easy to transport and not embarrassing because it looks just like a pen".

A symbol of the future

Look out for the new 'Tourism for All' accessible symbol when on your holidays this summer. To qualify for the new symbol, accommodation must fulfil certain requirements:

*A public entrance to the building must be accessible to disabled people from a setting-down or car parking point.

*If there's a car park, a space should be reserved for a disabled guest on request.

*Access must be possible for disabled people to public areas, like restaurants.

*A minimum of one guest bedroom should have bathroom and wc facilities suitable for wheelchair users either en suite or on the same level.

The hotel will only be awarded this status after inspection so disabled travellers should have confidence in the symbol.

But the 'Tourism for All' campaign promoted by the Holiday Care Service and the English Tourist Board is about more than having access. It is also concerned with promoting training and awareness amongst hotel staff so that any traveller, whatever their particular needs, gets excellent service.

A working party recommended that businesses in tourism should produce a written statement of their commitment to the campaign - aimed at allowing disabled people to enjoy their holidays like ordinary travellers, and as independently as possible. Let's hope hotels take up the challenge of welcoming all their visitors.

If you find the promise doesn't match the performance, write to 'Link'.

TRAVEL INSURANCE

The Holiday Care Service Travel Policy 1990 is an insurance scheme for people with special needs. It includes unlimited medical cover and emergency medical assistance and optional cover for specialist equipment such as wheelchairs.

For more information, or an application form, write to: *Holiday Care Service, 2 Old Bank Chambers, Station Road, Horley, Surrey RH6 9HW.*

DIAL-A-RIDE IMPROVEMENTS

The dial-a-ride service for disabled passengers is improving in various parts of the country.

In Devon the service is spreading with Okehampton now added to existing services and Dawlish and Tiverton due to join the scheme this month. Further details from Phil Slater, Devon County Council, on 0392 273242.

And London Transport hopes its plans for regional organisation of its Dial-A-Ride facilities will improve the service.

Everything in the garden

If you haven't done so already there's still time to visit the fourth National Garden Festival which, this year, is being held at Gateshead, until 21 October. The festival is open daily from 10.00am to 8.00pm throughout August and from 10.00am to 6.00pm during September and October. Discounted day tickets are available for disabled visitors at a cost of £4.00 - book in advance or just ask for one at the gate.

But I don't like gardening...

Even if you're not a gardening enthusiast it hardly matters, there are so many other attractions that you'll still have a full day out. Non-gardeners can visit craft exhibitions, the Dr Who Dome, Health Theme Park, Flying Saucer, or Journey to the Centre of Electricity - these are just a few of the many displays.

Not so common gardens

The gardens on the festival site - there are up to 100 of them - will inspire and surprise you. Amongst the more unusual is the Radio Garden featuring 12 radio aerials picking up stations from around the world. The outdoor sculptures which feature large in this festival may also cause some raised eyebrows - can you work out the artistic meaning of three ladies in their underwear holding a horse statue, upside down, above their heads? - this is the first one you'll see if you enter the festival by the Riverside gate.

Special Interest

Over 90% of the site is wheelchair accessible and the organisers claim their staff are trained in disability awareness. And if you've been to similar events before and wished you could get round one of the luxury show homes in your wheelchair then you'll be glad to know that this time you can. There's a whole house dedicated to disabled people's living needs at site 22 in the Norwood section of the festival. The house has been planned with a disabled occupier in mind and features include a fitted kitchen with lots of useful gadgets, a specially equipped bathroom and a vertical chairlift.

For further information, contact Visitor Information, NGF90, Queensway North, Team Valley, Gateshead NE11 0NG.. Tel: (091) 460 5804

Raring to go: a team of surveyors from a top London-based firm of estate agents went on to conquer the heights on the North Yorkshire Moor in order to raise money for ASBAH.

Led by Chris Boulton, the surveyors from Hillier Parker May & Rowden tramped over Whernside, Engleborough and Pennyghent - climbing to over 7,000 feet - before handing over a cheque for over £500.

They covered 23 miles of rough terrain, in ideal walking weather, with the fastest person finishing in seven hours and the slowest coming in three hours later. This was the second year running they have done the Three Peaks Walk for us. Well done!

Chunnel Access

Better access to the UK end of the channel tunnel has been secured after a public enquiry heard the original proposals were "unsafe, inaccessible and impracticable" for disabled travellers.

Several suggestions from the Greater London Association for Disabled People (GLAD) have now been incorporated in the new access plans including:

*lifts as alternatives to escalators at all entrances

*improved ramps

*textured strips to mark the edges of platforms.

Historic Sites

James Pardoe, a lecturer in historic conservation at Dorset Institute, is conducting research into facilities for people with disabilities at English Heritage sites. Anyone who can help with reports on access to sites and monuments can contact Mr Pardoe at Dorset Institute, Dept. of Tourism, Wallisdown, Poole, Dorset BH12 5BB.

DIARY DATES

15 September: Hydrocephalus Support Group study day, ASBAH House, 42 Park Road, Peterborough, 9.45am. £4 parents, £10 professionals. Speakers include Mr A Waters, consultant neurosurgeon. Details, Trish, 0733-555988.

22 September: 'Working with special needs children - classroom and individual management', Castle Priory College (Spastics Society), Wallingford, Oxon, £39. Tel: 0491-37551.

28 September: Preparing for medical appeal tribunals, update for advisers, 336 Brixton Road, London SW9. £50. Details from Disability Alliance, 071- 379 6142.

11 October: Attendance allowance - reviews and changes, not suitable for beginners, 336 Brixton Road, London. Disability Alliance.

22-27 October: ASBAH Mobility Week, for those over 16, Hereward College, Coventry. Details from Trish, 0733-555988.

25-26 October: Introduction to Disability Benefits, 336 Brixton Road, London. Disability Alliance.

22-24 October: 'Being assertive', Castle Priory College, £169. Limited accommodation for wheelchair users.

1 November: 'Why does a child need communication to develop?', Prof Colwyn Trevarthen (Dept of Psychology, Edinburgh University), Edward Lewis Theatre, Middlesex Medical School, 46 Cleveland Street, London W1, 7.30pm. £5. Cheque and sae to Secretary, Parent Infant Clinic, 116 Woodside Road, London N22 5HS.

The loss of a child

a mother's personal account of bereavement

Our first child, Gregory, was born on 22 November 1989 and died three days later having been born with spina bifida and hydrocephalus. He was on a life support machine throughout his short life and had two operations, one to insert a shunt and the other to cover the spina bifida on his back so that it should not become infected.

My pregnancy had been an easy and a happy one. There had been no signs that there were any problems and I had felt well throughout. After two scans and all the other routine tests I was confident that the baby was healthy. Nothing could have prepared me for what happened.

Gregory was delivered by emergency caesarean section in a small maternity unit in Cheshire and thereafter transferred to Booth Hall Children's hospital in Manchester, where he was operated upon and nursed until his death.

My husband and I were told by the neurosurgeon, on the morning of Gregory's death, that the part of the brain which controls breathing had either not developed fully or was damaged and that Gregory would never be able to breathe for himself. We asked that he be taken off the life support machine immediately and that he be allowed to die in peace with us.

Though shocked we appreciated everything that was happening but could not grasp the enormity of the situation. We had touched and talked to Gregory during his time on the life support machine and had been encouraged by staff to participate in his nursing and had washed and changed him. We had also taken photographs, not realising at the time just how important they were to be to us.

When we knew that he was going to die, mixed with the sense of shock and sorrow, was a feeling of anticipation, that at last we would be able to cuddle him without all the constrictions of the life support machinery which over the last few days had acted as a barrier between us.

There was an urgency about the situation, a compelling need to convey our feelings to him, to cram a lifetime of love and care into a few precious minutes. And so we kissed and cuddled Gregory until he died and took more photographs. We can only hope that Gregory's last moments were ones of comfort and love as, I feel sure, they had been during the nine months I had carried him.

> "There was a compelling need to convey our feelings to him, to cram a lifetime of love into a few precious minutes."

Previously, had I been called upon to imagine the situation in the hospital when he died, I might have thought it bizarre or morbid even. Now, to me the memories are precious. I recall looking out of the window as Gregory died and seeing that the sun was shining. Both our families, who had been supportive since Gregory's birth, came to the hospital to say goodbye to him, arriving before he died or very shortly afterwards.

Gregory died with a peaceful look on his face, a look captured forever. My husband, who works as a research scientist for a photographic company, developed the photographs we had taken which gave him a sense of doing something positive and meaningful after Gregory's death when we were so consumed with grief.

Now we cannot imagine how we would feel if we didn't have the photographs to remind us of how Gregory looked. My favourite is one taken after his death where his expression is one of the utmost peace and which shows just what a beautiful baby he was. The cruel blow which was smote by nature in his development is compensated for by his beauty and in the fact that he was, in a physical sense, so perfectly formed. The photographs capture all of this and now bring to mind not only the way he looked but how he felt to touch.

We couldn't have imagined that events would take the course that they did at the outset of my pregnancy and are still, in these early days of bereavement, grappling with the enormity of what has happened and grieving for our son. But there are things which sustain us; the photographs which even at the blackest of times bring back the good memories; the recollections of my pregnancy and the expectations and excitement of that time which, although dashed, can never be taken away from us; and, above all, the fact that we had such a beautiful son who will live forever in our hearts and minds.

Of course we would have wished it different and still talk of how things should have been but with time we are slowly coming to an acceptance of what has happened and draw comfort where we can. I do have one regret, that I didn't keep a lock of Gregory's hair.

I take comfort from a passage in one of Wordsworth's poems called Intimations of Immortality, which will always serve as a reminder of Gregory, as will a tree which friends gave us in his memory and which we planted in our garden as a lasting tribute to the son we loved so much.

Francesca Nield

Ian Laker's dream comes true

With the help of an ASBAH bursary, Ian Laker, formerly one of our disabled living advisers, went halfway round the world to compete in his favourite sport. He tells us what it was like.

"I am a 30-year-old basketball player, who has spina bifida. Through the help of ASBAH, I recently went to Australia to play wheelchair basketball. This was the realisation of two dreams - one career and the other personal.

The first phase of the journey was by Air India, a bad choice as we stopped at four different airports instead of the more direct routes which only stop at one. The journey is very hard with two 10-hour flights, and two shorter ones.

There were many problems: lack of drink, too little sleep, too much food, boredom and poor toilet facilities. On both journeys, there and back, the plane had no aisle chair and consequently I was bumming it to the toilet. Luckily, I was allowed to use the first class privy which was much closer.

MANHANDLED

At most major airports, plane travel is relatively easy with good staff awareness. The transit lounge in Bombay, however, left much to be desired. One thing a seasoned traveller must take into account is that, when in transit, you never get your own wheelchair and could end up in absolutely anything.

In Bombay, the staff were nice but they basically manhandled me both on and off the plane with very little regard for dignity.

We arrived in Sydney and the tiredness dropped from us like a curtain. A breathtaking view of a large, sprawling city with acres of room. Living in London, like I do, you get to appreciate space and the first thing I noticed was how few tower blocks there were. . . heaven!

We were met by Gerry Hewson, the Australian who had given us the idea to try Oz. Gerry played with my own basketball club, the LGS Jets, in the 1989/90 season where, with his help, our first team was third in the first division.

In Oz they drive on the same side of the road and speak nearly the same language. Their roads are much wider than ours and, for the most part, of good quality. They have a huge choice of automatic cars. The ratio of manual to automatic is almost the opposite to the UK.

The people themselves are open and friendly. Their lives are more orientated to the home than the pub or other 'going out' places. The homes all seem different and, unlike here, you would be hard put to find two the same.

The food was cheap, as was the petrol. Anything imported though, like clothing and cosmetics, comes very expensive.

Basketball was my main reason for going. In the UK, I play in the first division and have represented my country abroad on several occasions. The Australians are currently one place higher than us in the world rankings after the last Olympics and this was due, as much as anything, to luck of the draw in the pools.

MACHO

My personal estimation, now having played with them, is that on the whole they are tactically and skilfully on a lower rank than the UK. They are, however, far newer to the sport than we are and they learn extremely fast. I believe we will see them undermining the top six nations of the world. They possess a fearless, macho approach to the sport unequalled by most other countries. More knowledgeable countries spend too much time thinking and not enough time getting stuck in.

What really impressed me was that basketball (wheelchair and running) was so popular with the Australian public, much as it is with Americans. I wish it was so here as I find the traditional English sports of football and cricket boring, and disabled people just don't play them.

SURPRISE

The biggest surprise for me was that there was only one Aussie player with spina bifida in the seven teams which make up their national league. I was disappointed. In the UK, of the 400 players in our league, somewhere in the region of one-third have spina bifida, and they play at every level.

Australians talk about recruiting more, but have done little to encourage participation.

This is an obvious area for new players and I hope I was able to demonstrate that we have something to contribute and can play hard. I hope their national association takes it on board and develops spina bifida players at every level.

I hope to go back next year to do the full season and take my wife with me. I believe in living life to the full. We only get one shot at it, and must make the most of what we get. The body may not work conventionally but the brain does and so do my feelings.

By the way, I was top scorer in both matches I played in.

SWEET SORROW

ASBAH funded research by Eileen Delight and Janet Goodall which enabled a study to be made of 44 babies who were cared for without surgery after being born with severe spina bifida, and looked at how the quality of their lives - and those of their families - might be improved.

The result is 'Love and Loss: conversations with parents of babies with spina bifida managed without surgery, 1971-1981', published this month as a supplement to the journal, 'Developmental Medicine & Child Neurology' by Mac Keith Press. ASBAH has copies, available from 42 Park Road, Peterborough, at £5 (inc p&p).

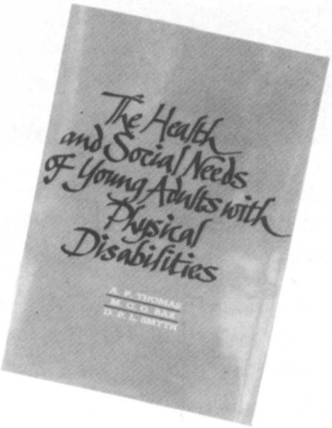
In one short decade there was a sea change in the way the medical community took parents into its confidence as families prepared for the child's dying.

In the early years of the survey, the baby was treated much as the hospital's own possession. Parents were kept at arm's length, and contact with the baby was often actively discouraged. It was not unusual for parents not even to have the comfort of a funeral.

Later on and today, parents quite often make the choice to take their newborn infant home, with medical and nursing support available when they call for it. The baby becomes part of the family for a precious few days or weeks, leaving a stream of happy memories to mingle with the more sombre.

It may take a Solomon to make the right choice, and clinicians do not get it right every time. But professionals, who have found the time to develop appropriate support systems, might be on a path to wisdom.

As Jeffrey Tate, president of ASBAH, writes in the foreword: "There are lessons here for professionals at every stage of the young life. I commend this booklet to all who want to see joy as well as sorrow become the currency of terminal care for the newborn infant." There are lessons, too, beyond spina bifida.



CALL FOR NEW ADULT DISABILITY SERVICE

A BLEAK picture of inadequacies in the delivery of services to young people after they leave school is painted in 'The Health and Social Needs of Young Adults with Physical Disabilities'.

This scholarly book addresses a topic which has received scant attention, and calls for the formation of an Adult Disability Service within each local health authority to spearhead genuine local attempts to remedy the deficiencies.

"The Adult Disability Service which we proposed would have both a planning and a clinical role, and would not be dissimilar in its aims and scope to the child development centres for children," write authors Andrew Thomas, Martin Bax and Diane Smyth of the Charing Cross and Westminster Medical School.

"It could be founded on, or expanded from, the present Community Mental Handicap Teams , but with the provision that it take into consideration all young adults with disabilities whether they be mentally, physically, sensorily or multiply impaired. We would expect this team to provide services for people with developmental disabilities from the time they leave the paediatric services through into old age."

The book, based on a study of a large sample of young adults living in two survey areas, is published by Mac Keith Press as its Clinic in Developmental Medicine No 106, and it costs £18.

The study found many youngsters with serious health needs not being met by the statutory services. Many leave schools with less than adequate skills to enable them to live independently. A life without work or stimulating daytime activity is commonplace. Benefits to which they are entitled remain unclaimed, and lack of social skills mean they are not developing worthwhile relationships.

All too often, as might be expected from any cursory contact with the subject, parents and carers are also suffering from a shortage of physical or emotional support.

The proposed new service would be a linchpin agency in the co-ordination of health, educational, social and voluntary services to a sector of society which simply seems to be thrown into limbo once its members have left the formal education system.

Co-author Martin Bax, who is senior research fellow in the community paediatric research unit at the Westminster Children's Hospital, is also the new chairman of ASBAH's medical advisory committee.

Having a baby

'The Baby Challenge' by Mukti Jain Campion is written in a straightforward manner that will appeal to both professionals and parents our parents-to-be. The book is divided into two sections. Part one deals with the process of having a baby - starting with a consideration of the factors involved in the decision to start a family and ending with the arrival and management of a new baby at home.

Although this book could be of value to any future parent it is aimed at women with a physical disability. Ms Campion clearly explains the various ante-natal tests, the three trimesters of pregnancy, and suggests clear criteria for choosing a hospital for the baby's delivery, but always with relevance to the possible needs of a disabled mother.

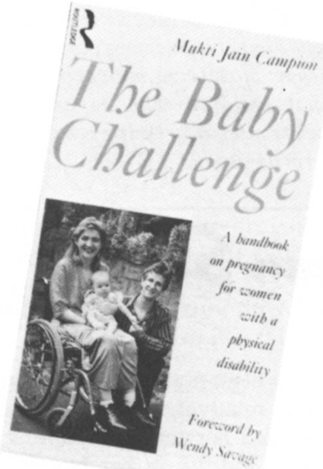
She notes, "It is important to recognise that parents with a disability have a spectrum of needs, just like other parents. A few will need support most of the time, some will need help occasionally, and others will manage perfectly well on their own". This underlying premise gives the book a refreshing tone which is positive yet realistic about those challenges a disabled mother may face at certain points in her child's development.

Mothers are usually the experts in managing their own disability and Ms Campion urges them to get the best out of support services by encouraging professionals to recognise this: "remember [to say] what you think your special needs are - they may not be the same as what an outsider perceives".

The needs of professionals are addressed at the end of part one - steps are suggested to improve the services they offer.

Part two takes a broad definition of disability: "Any physical condition which restricts a person from using their body as fully and as easily as an able bodied person" and the most common conditions that can cause physical disability, yet usually permit safe childbirth, are described. The most interesting feature in this section is the case histories of disabled women making 'The Baby Challenge' not only a useful book but a good read.

It is published by Routledge.



BOOK SHELF

EVERYTHING you ever needed to know about obtaining a wheelchair is contained in 'Choosing a Wheelchair', by Judith Male and Bert Massie, published by RADAR in paperback at £3 - a small outlay to set against a purchase which could cost hundreds of pounds.

Within its 592 pages, this voluminous tome contains price guides, specifications and comments about dozens of models on the market. There are also sections on finance, maintenance and advice on how to make sure the model suits your particular body.

⁂

'The World Wheelchair Traveller' has been published by the Automobile Association to help people with disabilities make the most of trips abroad. It covers travel by air, rail, road and sea and was inspired by a wheelchair-user who completed an eight-week camping trip across the USA. It is available from the AA or bookshops at £3.95.

⁂

'How to Get Equipment for Disability' is a reference book aimed at guiding readers through the jungle of equipment provision. It is aimed at those prescribing, advising or choosing equipment from the vast range available. If you can't see the wood from the trees of regulations and legislation, give this a try. Compiled by Michael Mandelstan and published on behalf of the Disabled Living Foundation, it costs £9.95.

TIME DAWNS FOR A RE-PRINT

IT'S not often that a review page mentions a book which is now probably out of print but, after having recently been loaned 'Red Sky in the Morning' by a colleague, we felt we had to put in a plea to the publisher to put it on the shop shelves once again.

Written by Elizabeth Laird and published in paperback by Piper Books last year, this is a children's book which tells the fictional story of Ben, who was born with hydrocephalus, through the unsentimental mouthpiece of his elder sister Anna.

I read it in one sitting on an insomniac, hot night this summer, and was moved to tears by the loss of Ben and Anna's later attachment to the little Down's Syndrome girl.

Elizabeth Laird is a gifted writer, who strikes shafts of illumination into a subject many of us find too painful to broach, and the book was highly commended for the 1989 Carnegie Medal and shortlisted for the Children's Book Award the same year.

The story is also a credible portrait of an adolescent girl, and her discovery through experience of the adult world.

If you ever do come across a copy, do treat yourself to a read. Better still, leave it around for the kids to borrow.

BOOK REVIEWS BY TONY BRITTON, GILL WINFIELD AND RACHEL STANWORTH

A mother visits Peto

WITH regard to your recent article 'Conductive Education', I was pleased that this long-awaited report has been finally released in Link.

As stated, it wasn't until 1985 that it became a focus for the media. A lot of water has gone under the bridge since then or should I say a lot of children have attended the Peto Institute since then.

Having read and re-read this report, I am somewhat a little disappointed. Not particularly because I feel the facts are wrong, but more from the point of view of what hasn't been said.

Trying to obtain continence in children with spina bifida is practised within the spina bifida group. Although a somewhat monotonous procedure, and one which I agree does take up a considerable amount of time, it could also be quite a useful training too.

In my opinion, it is probably a very basic way of dealing with the problem, while we in the West have far more advanced methods, ie catheterisation. But, nevertheless, it is a technique which could prove successful with some children.

Whilst incontinence is important, mobility was our main reason for going to the Peto Institute with our daughter. The conductors in the spina bifida group worked hard with her and she too put a lot of effort and determination into the time we had and, within a very short space of time, she had results.

She was never allowed to get used to any particular aids, sticks etc. They continued to present her with a challenge until she completely let go altogether and she now walks unaided. Nobody knows whether she would have achieved this in this country, or whether so quickly, but the conductors were so positive and encouraging.

Now, I'm not saying that every child will have this degree of success but there are several places in the spina bifida group at any one time for children from outside Hungary and, since 1985/6, British families have been grateful to accept whatever times have been offered to them. The waiting list continues to increase.

I haven't heard of anyone yet who has been disappointed with Peto. Where in your research are these families' comments? Surely we can't all be wrong?

My advice to any family considering making this trip is just go, and draw your own conclusions.

Jayne K Leiper, Wolverhampton,
West Midlands.

Editor's note: We are very pleased that Mrs Leiper's daughter was helped by her visit to Peto and we know that many families do enjoy a great boost to morale from going there. ASBAH, however, will remain worried until the medical evidence shows otherwise that the institute's potty training may result in kidney damage occurring in many cases of children with spina bifida and that children who do not have appropriate support for their legs may suffer long-term damage.

Train Strain

I READ with interest the item about easier rail travel in Link No 128.

The flights of stars at Doncaster, Leeds Central (a relatively modern station), Sheffield and York are intimidating to me with a toddler in her buggy, let alone an older person in a wheelchair, with no obvious alternative means of getting from one platform to another - or onto any platform at Doncaster.

"Readily accessible trains for handicapped people" sound wonderful, if one can get to the platform!

No doubt British Rail will say that staff and lifts are available - the goods lift! and, first, find your porter!

I enjoy reading Link and find articles about hydrocephalus particularly useful and informative. As the mother of an outwardly 'normal' three-year-old with hydrocephalus, I found the article about the 'hidden handicap' thought-provoking.

Elizabeth Vick, Rotherham.

Can you help?

I AM in the process of collecting a series of personal accounts by parents of children with spina bifida and hydrocephalus on how they coped with related problems and different stages in the children's lives.

The personal experiences I gather together will then be put into various sections such as ante-natal, birth, post-natal and infancy, school years, teenage and beyond.

It is hoped that this collection of experiences will be of interest and use to new parents, and perhaps provide greater information than we had when we found we were about to have a disabled child.

I hope that some of you will be able to find time to put some of your thoughts and feelings on paper for the benefit of others.

Jan Tippett, 30 Greenhill Avenue,
Sheffield S8 7TB.

New Home

WE WERE delighted to discover that so many of you were thinking of us in June as we moved from Upper Woburn Place to our modern, functional offices in Peterborough. Every day, the postman brought in more cards and messages of greeting until it became quite a problem wondering where to display them all.

So many of you wrote that it became impossible to reply to you all. I hope you will accept my warmest thanks by way of this letter.

If anybody would like to see us in our new headquarters, then please arrange a visit when you are next in Peterborough or passing through. Now we have settled in, we would be pleased to see you.

Moyna P Gilbertson, Executive Director, ASBAH, 42 Park Road, Peterborough PE1 2UQ.

The Editor welcomes readers' letters, but reserves the right to shorten them.

Write to Gill Winfield, Editor, Link magazine, ASBAH House, 42 Park Road, Peterborough PE1 2UQ.

ADVERTISING

FOR THE USE OF LOCAL ASSOCIATIONS AND OTHER READERS

Rates: £3 for 30 words max; £4.24 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 (October) should be submitted by Friday, 14 September. Please send them to: The Editor, ASBAH House, 42 Park Road, Peterborough PE1 2UQ.

HOLIDAY ACCOMMODATION

MAR Y SOL, LOS CRISTIANOS, TENERIFE

Wheelchair-accessible apartments and studioes, heated pools, restaurant, treatment centre, equipment hire. Video on request. Phone me for details of cheap flights and accommodation. Sue Abbott, 123 Coppermill Road, Wraysbury, Staines, Middx. TW19 5NX, tel 0753-685718.

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Six-berth chalet, sleep six, club and swimming pool on site. 10-minute walk to village for shops and banks etc. Details Mrs Bashford 071-735 5489, leave message on answerphone.

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Offers respite/care activity holidays throughout the year to disabled people over 16 years of age. A 24-hour facility is provided by skilled care staff and voluntary helpers. Accommodation is single, hotel-standard bedrooms. For details of what we have to offer, please contact Mike Webster on Inverness (0463) 234939.

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BATRICAR SUPER DE LUXE, red, 12-volts, never used. £1,500. Tel Wendy Andrews, 0443-410733 (anytime).

ORTHO-KINETIC large size 'Pony", two years old, in good condition. Used only in summer months. Complete with two batteries and charger. Cost £1,400 new. £950 ono. Tel 0206-272578.

ELECTRIC WHEELCHAIR. Model: Vessa Intermed, with safety belt and kerb climbers. Battery charger, cushion and pump included. Approx four years old. Good condition. £500 ono. Phone 081-943 1012.

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