

Link

The magazine for people with
Spina Bifida and/or Hydrocephalus



April/May 1994

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Comment

TALK about stupidity, but the government scheme to make employers pay up to half the costs of providing support services looked like a monumental folly! Even fewer disabled people would have found jobs if that one had got through! Thankfully, the Employment Secretary has now shelved the idea and not included it in his new Access to Work programme, announced at the end of February.

After a hectic round of lobbying by the disability organisations, the Minister has produced an improved scheme, booting the individually-targetted employers' contribution out of play. . . for the moment. But this is one ball which could bounce back with a vengeance as the Department has promised to review the

situation after a year. We will remain on our guard.

THE ENTIRE disability movement is waiting to see what happens next to the Civil Rights Bill in Parliament. The Bill's sponsor, Roger Berry MP, says it will make a mockery of the Parliamentary process if the principles of the Bill, set in the second reading, were undermined in committee. Supporters want discrimination against disabled people outlawed in education, employment, housing, transport, public buildings and public services, and for there to be means of legal redress. To water down the Bill by, for instance, just focussing on employment - when disabled people cannot get to work on the buses or even leave their

own homes - would be a travesty.

The success of the second reading stage, after so many failures, took seasoned campaigners by surprise and temporarily stunned many a cynic. But, upon reflection, they are not running away with the idea that support from 231 MPs on a quiet Friday afternoon in March will guarantee a speedy passage to the same sort of rights that disabled people enjoy in the USA, Canada, New Zealand and Australia. The mother country, renowned for being set in her ways, might yet deny independence to her own citizens.

FINALLY, away from politics and thanks to the colleague who so kindly lent me such a clean pair of heels for the photograph which illustrates our feature on reflexology. I shared their splendour for a few moments but am sworn not to reveal the identity of their owner. Me, gossip about a colleague? Never.

Tony Britton

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Cover: Watching out for pilot whales off the coast of Tenerife (see pages 16 and 17).

Minister talks of millions too shy to ask

Derby ASBAH sets seal on a national week

ONE of the last great taboo subjects came under the microscope at a Derby and District ASBAH conference last month.

And, in a revealing admission from a government health minister, the conference heard that over three million adults and half a million children in Britain today suffer from one form of incontinence or another.

"The interesting thing is that as many as 70% of these people could be treated successfully", parliamentary under-secretary of state John Bowis declared in a message to 'The Cost of Incontinence' conference at Nottingham City Hospital.

"Sadly, however, we know that fewer than one in six sufferers ever seek medical help. Most suffer in silence, mainly for reasons of embarrassment."



The message from the minister - relayed to the meeting by Sir David White, chairman of Nottingham Health Authority - came during National Continence Week, which was a coordinated attempt to try to break through the taboo and get help to all those who need it.

Mr Bowis said the Department of Health had taken a great interest in continence problems over the years. In July 1991, it had published an 'Agenda for Action on Continence Services' which listed the key features of an effective local service.

The role of continence advisers with management and teaching skills had been emphasised in the paper. Recommendations regarding the education of medical and nursing professionals had been taken on board, as had a cost-effectiveness study.

He said it was up to health authorities and NHS trusts to organise their services to suit local needs and circumstances. And, in December 1992, the NHS management executive had issued guidance to health authorities and local authorities about funding community health services for residents of residential care and nursing homes, spelling out clearly what was expected of them in the provision of continence advice and continence materials.

"Help is as far away as the nearest telephone", said Mr Bowis.

Fair wind for Christine's publicity coup?

THE omens were auspicious when National Continence Week was launched with £100,000 of government backing on Monday, 14 March.

Only time, and the amount of new business for continence advisers nationwide, will tell whether the week sailed with a fair wind or was becalmed in a sea of indifference.

"Reactions have been remarkably good. We still get some journalists saying 'Yuk... we wouldn't touch the subject with a bargepole,' said Christine Norton, director of The Continence Foundation.

"But, on the whole, opinions change when people realise the

huge size of the problem."

The Department of Health printed nearly two million leaflets and posters encouraging incontinent readers to overcome their embarrassment and seek help, giving a helpline number. They went into surgeries, health sites, Post Offices and many public toilets.

On the opening day, Christine held a press conference with John Bowis, the health minister concerned, and Yvonne Moores, the government's chief nursing officer. The message was that most people do not know help is at hand and, for many, there can be a cure or at least a distinct improvement in quality of life.

And, the following day, she joined agony aunt Claire Rayner and another health minister, Baroness Cumberledge, at an all-day conference called by The National Council of Women.

Then, always with an eye on the photo-opportunity, Christine was at Waterloo Station on Wednesday, handing out leaflets to rail passengers. Interviews with 30 BBC local radio stations were booked during the week, with numerous local activities arranged by local continence advisers.

ASBAH continence adviser Mary White played a part in the week when on the closing day she and Derby and District ASBAH held their conference.

THE government has withdrawn a plan to force employers to pay towards the cost of special equipment needed by disabled people in the workplace. This follows protests by a group of disability organisations, led by RNIB and including ASBAH.

Employment Secretary David Hunt, in announcing a better-funded 'Access to Work' scheme, told Parliament on 28 February that he had reacted to complaints that a mandatory contribution could deter businesses from taking on more disabled workers or keeping them.

"I am particularly persuaded by the arguments of members of the All Party Disabled Group that we should try the new scheme for a year without an employer contribution and then review the position.

"However, we will continue to expect an employer to contribute when the help will be of general benefit to the firm and not solely for the disabled employee."

'Access to Work' will start on 6 June. It will replace four schemes - Special Aids to Employment, Adaptations to Premises and Equipment, Fares to Work, and Personal Reader Service - which

Changes announced to Access to Work scheme

will be wound up within a year.

An advertising campaign costing £1.3million has already been launched to raise awareness of the disability symbol and Access to Work. The Department of Employment will pump an additional £3.5million into Access to Work on top of expenditure on schemes it replaces.

Through Access to Work, the government will pay for:

- communicators for people who are deaf or have a hearing impairment
- a part-time reader or assistance at work for someone who is blind
- support workers, if someone needs practical help, either at work or getting to work
- equipment and adaptation to existing equipment to suit individual needs
- alterations to premises or a working environment so that an

employee with a disability can work there

Unemployed, employed and self-employed disabled people are all eligible for Access to Work. Help of up to £21,000 will be available for individuals over five years.

People receiving help under the existing four scheme will be supporting on their present terms until 31 March 1995, when they will join Access to Work.

The Employment Service will administer the programme and will, in exceptional circumstances, be able to authorise payments above this limit where necessary and reasonable.

ASBAH executive director Andrew Russell, who criticised the original scheme when he spoke to the All Party Disablement Group at the end of last year, commented: "This amounts to a victory for common sense, and shows what can be achieved when disability groups put up a united front."

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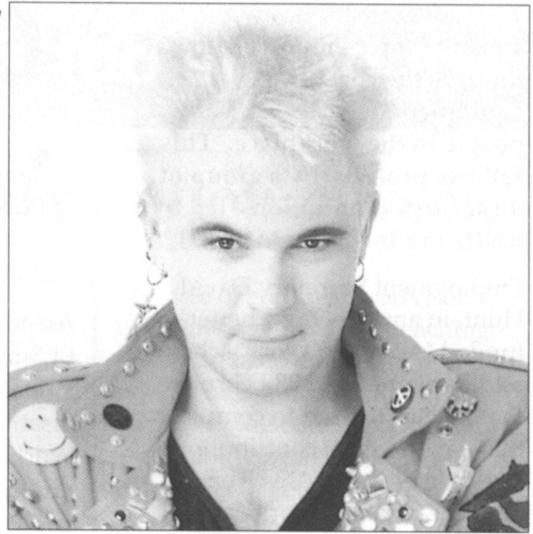
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HEAVY METAL STAR MIK AT OUR SPRING CONFERENCE

YOUNG people at the 'Your Voice in ASBAH' spring conference in Peterborough on Saturday 30 April will meet TV personality and heavy metal performer Mik Scarlet (pictured right). Mik, who began his TV career in true Hollywood style after being spotted by a TV producer singing in his band Freak UK, will be guest speaker.

After working on shows such as *Sex Talk*, *One in Four* and *The Holiday Programme* and acting cameos in *Brookside*, *The Bill* and *Two Point Four Children*, he was given his own show for Channel 4 called *Beat That*. This ground-breaking show for children proved a hit with both young and old and won an Emmy award in the USA. Since *Beat That*, wheelchair-user Mik has become a regular contributor to the BBC2 series *From The Edge*.



OUR RIGHTS

CIVIL rights for disabled people came a step closer in the House of Commons on Friday, 11 March, when Dr Roger Berry's Civil Rights (Disabled Persons) Bill was given its second reading by 231 votes to nil.

The reason for such an unusually high number of MPs in the chamber on a Friday was attributed to the mass lobby of Parliament two days previously - when an estimated 2,500 disabled people, badgering their MPs to support the Bill, packed Westminster Hall.

"We have got to keep up the pressure. The next battle is for the committee stage in the Commons and an indication of the government's support for the Bill", said Stephen Bradshaw, chair of Voluntary Organisations for Anti-Discrimination Legislation (VOADL).

Mr Bradshaw, who is also director of the Spinal Injuries Association, said: "The speed with which the Bill goes through Parliament depends on whether the government gives it time."

VOADL was meeting in the third week of March to discuss future action.

Airline bans disabled pilot!

AIRLINE officials banned a disabled tennis champion from flying on his own - even though he is a fully-qualified pilot, used to flying solo.

Wheelchair-user Ray Gainer, who has spina bifida, had booked tickets to fly to Thailand with Bangkok-based Eva Airlines.

The reigning French disabled open tennis champion was planning to take part in an overseas invitation tournament. But he was told he would need an escort because of safety regulations affecting passengers in wheelchairs.

"It was have cost Ray too much money for someone else to travel with, and supposedly look after

him, so he decided to shop around", Ray's wife Gill told the *Liverpool Daily Post* from their home in Crosby, Merseyside.

"Fortunately, British Airways did not make so much of a fuss, although it cost him £150 more than Eva were offering for a return flight".

In 1987, Ray and two friends landed a place in the record books when successfully touching down an aircraft 213 times in 18 hours at Liverpool.

At the end of last year, *LINK* reported how Ray and a friend travelled in their wheelchairs from Paris to Blackpool - 18 marathons in as many days!

Wounded soldier opens shop

A FORMER soldier, who was badly wounded in Northern Ireland, has set up Kent ASBAH's first charity shop in Watling Street, Gillingham - to raise funds for the local Association's proposed £420,000 residential training centre in the area.

Graham Ball (42) has had hydrocephalus since he was shot five times in Ulster. He lost a leg and is likely to lose the other.

Mr Ball, who lives in Rochester,

told his local paper: "I decided to get off my backside and do something. I went round with a collecting tin just before Christmas and managed to raise £1,500, which will go towards the planned centre."

The scheme - involving Sanctuary Housing Association - is expected to provide 10 individual bedsitting rooms with en-suite facilities and communal rooms, on level ground close to the centre of Gillingham and public transport.

WORLD FIRSTS FOR NEW SHUNT UNITS

ADDENBROOKE'S Hospital, Cambridge, has won its funding battle to set up the world's first hydrocephalus shunt registry and shunt evaluation unit.

Both units are poised to start extending the boundaries of medical knowledge. One of the aims over a period of years is to create such confidence in product bench-testing and performance that there will be a dramatic reduction in shunt failures.

The East Anglian Regional Audit Committee has picked up the baton and led the way with funding for the United Kingdom Shunt Registry. The Department of Health Medical Devices Directorate has also agreed to fund both the registry and the UK Shunt Evaluation Unit.

Both facilities will be based in the academic neurosurgical unit at Addenbrooke's under Professor John Pickard, who outlined his

embryonic plans in *LINK* two years ago. These have now come to fruition. At that stage, Professor Pickard forecast ways in which the manufacture of shunts and their behaviour in patients would be audited over a period of years.

As soon as developmental work has been completed, a record of every patient in the UK who has a shunt inserted will be kept in the shunt registry, and any further shunt operations will be noted.

A similar system has existed for artificial heart valves for some years, and has provided surgeons and researchers with helpful information.

The shunt registry is based on a very powerful computing system and is registered under the Data Protection Act. The form that will be completed at the end of each operation is currently being tested, and the registry should be established by early summer.

There are plans to extend the registry to countries abroad so that problems with a particular type of shunt will be identified much earlier than is possible now.

The shunt evaluation unit is already systematically examining the behaviour of all shunts being marketed in this country - both new valves and valves removed from patients because of problems.

Evaluation is being carried out by Dr Marek Czosnyka and Mrs Zophie Czosnyka. Their programme will take some years to complete but a report will be produced on each type of valve as the testing is completed. These reports will be made freely available through the Department of Health.

Both units are unique, and will give patients in the UK and their doctors the most up-to-date information about their particular shunt.

Help & Advice

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

London, Surrey, Kent, Sussex

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

Northern Ireland

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

Rest of England and Wales

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

WELCOME THE NEW FAMILIES!

BETTER medical technology, which in the past 35 years has vastly improved the life prospects of people with spina bifida and/or hydrocephalus, has also created significant numbers of disabled adults now raising their own families.

A total of 80 'second-generation' families with children are now known to the Association, ASBAH Council members heard in March.

The new figure was revealed by Joan Pheasant, manager of the Five Oaks Centre, after she had trawled for the information from our fieldworkers and disabled living advisers scattered round the country. Previously, the figure had been thought to be 40 families.

In turn, this had created greater demand for a new type of assessment - with local authorities asking for ASBAH's assistance in preparing reports on the success of individuals mothers in looking after their own babies.

"At Five Oaks, we've been getting more requests for help in this direction. We have had to assess three mothers in three weeks - two of whom had children taken into care, and the courts want reports", said Miss Pheasant. The centre also provides training and support for new mothers.

Maddie Blackburn, ASBAH's research fellow and a research health visitor at the Chelsea and Westminster Hospital, said her four projects for ASBAH had clearly delineated a raft of problems facing young people as they approached adulthood and independence.

Of 95 young people, for instance, who had agreed to take part in medical interviews as part of a study into the health and social needs of young people with spina

bifida and/or hydrocephalus:

- 86% were anxious about bladder incontinence
- 67% had bowel problems
- 42% carried out manual evacuation
- 32% used clean intermittent catheterisation
- 83% had mobility problems
- 79% used mobility aids
- 67% had skin problems
- 40% had sexual problems or anxieties

Of parents who looked after them, over half of 48 mothers who agreed to be questioned had developed health problems brought on by the effort of raising a disabled child. And a third of 17 fathers questioned said their physical health had also been affected.

In an hour-long talk about her work, as she nears the end of her three-year ASBAH fellowship in June, Ms Blackburn said she was pleased to leave a body of research which could be built upon, but an enormous amount of work remained to be tackled. She had produced a training package about continence and sexuality, available from ASBAH.

One exciting development had been her involvement in the opening in June last year of a purpose-built, adult clinic at the hospital led by consultant physician Dr Richard Morgan. The clinic had vastly improved access to multi-disciplinary services for people with a wide range of disabilities, who lived within 100 miles of inner London.

Ms Blackburn will continue researching the needs of people with disabilities, and has been

awarded a Calouste Gulbenkian Foundation grant to produce a study into relationships and sexuality.

During the Council meeting, ASBAH chairman Patrick Daunt announced that the government's chief medical officer would be attending a high-level symposium in London on 5 May to discuss the addition of folic acid to the diet to help prevent spina bifida in pregnancy.

The symposium is being organised as a joint initiative between the Wolfson Institute for Preventive Medicine and ASBAH. It will be chaired by Professor Nicholas Wald, who led the Medical Research Council's vitamin study, and it is being organised by Moyna Gilbertson, former executive director of ASBAH.

Faith Seward MBE, a headteacher and member of North Yorkshire ASBAH, said she feared that - despite the imminent publication of a code of practice to accompany the new Education Act - not all the wrinkles would be ironed out of the system. There was still potential for abuse.

"A child's placement could be delayed by up to two years by an authority saying they are following the code of practice. It worries me tremendously", she said.

Other points from the Council meeting included:

- A new model constitution for local Associations will soon be available, after ASBAH received a letter of apology from the chief charity commissioner for delays in responding to ASBAH letters, said finance director Derek Knightbridge. The Charity Commission had held things up for a year, he added.

■ Computer Sense Ltd, ASBAH's new Apple Macintosh trading subsidiary in Hemel Hempstead, started trading profitably in February. This could feed through profits earlier than expected to ASBAH.

■ ASBAH in conjunction with the NSPCC has developed a new training package for its field staff, which offers guidelines on working professionally with children.

■ Two of ASBAH's leaflets - those describing spina bifida and hydrocephalus - are now available from the information office in Punjabi, Urdu and Bengali translations. Translation into Hindi is also planned. Another leaflet is being prepared to make general practitioners more aware of the warning signs of hydrocephalus shunt malfunctions.

■ Boots Chemists have agreed to stock Cantassium Folic Acid tablets, from which ASBAH derives a benefit of 10p for each packet sold. This was the latest development in ASBAH's commercial relationship with the Larkhall Natural Health Group, which has been in existence since the middle of last year, reported the finance director. We maintain our policy of not endorsing any product.



Five Oaks: the next stages

TWO top priorities for service development by ASBAH were approved at the Association's Council meeting last month.

Both were identified by executive director Andrew Russell, following the decision to close the Five Oaks Centre later this year. From now on, ASBAH will focus energy on setting up a mobile assessment and training unit, followed - when money is available - by the opening of a regional centre in the north of England.

Council members accepted without question the financial

imperatives which will force ASBAH to close Five Oaks on 6 August. But the underlying sense of loss was shown when members endorsed an emotional vote of thanks to the centre's staff, proposed by Mrs Jo Baxter, of Leeds and Bradford ASBAH (*see below*).

Mr Russell explained that falling occupancy rates and the prohibitive cost of upgrading the premises had both contributed to the decision to close Five Oaks.

In spite of the centre's high reputation and effectiveness, local

Continued on Page 10

“ As a local Association which has made very heavy use of Five Oaks, we would like to record on behalf of all families our grateful thanks for the work undertaken by Joan Pheasant and all her staff over the years.

The staff have proved themselves to be dedicated employees of ASBAH, with seven of them having over 10 years service. Joan, herself, has been with Five Oaks 17 years; it is not just her job, it is her life.

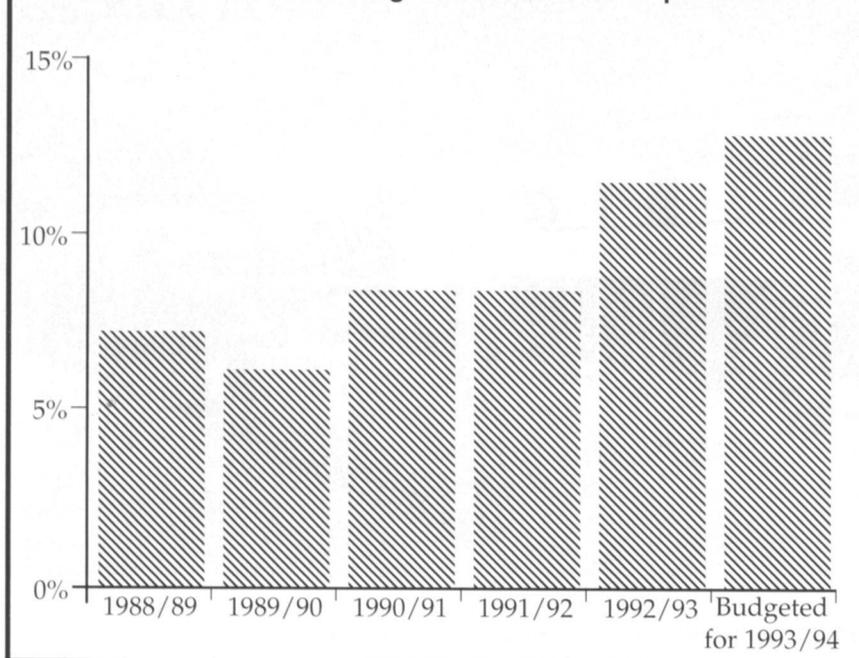
Our families have received a great deal of support, experience, help and loving care from the staff and cannot thank them enough for their service, which will be greatly missed.

As parents, Geoff and I have found the training, understanding and friendship of great benefit and Martin felt that Five Oaks was his second home.

It gives me great pleasure to propose a vote of thanks to Joan Pheasant and all the staff, past and present, at Five Oaks. ”

This vote of thanks to Five Oaks was accepted after being moved at the Council meeting by Mrs Jo Baxter (Leeds and Bradford ASBAH), and seconded by Mr Terry Foley (Cambridgeshire ASBAH). A suggestion from the floor that that appreciation should also be extended to the Five Oaks management committee was accepted.

Five Oaks as a Percentage of Total ASBAH Expenditure



From page 9

authorities have become reluctant to pay for residential training out of county, after funding was devolved to them under the community care arrangements.

ASBAH had been weighing up its choices for months. In the end, they boiled down to the fact that the Association now subsidises half the cost of every type of activity at the centre - be it long-term training, short courses, respite care or activity holidays.

This year, the Association expects to pay £145,000 out of its general charitable funds to cover the Five Oaks deficit. That will be 13% of ASBAH's total income, compared with six or seven per cent only six years ago.

"If we continued to carry this level of expenditure at Five Oaks, it would mean a virtual standstill in the provision of our other services. That would be an ineffective use of our limited resources", said Mr Russell.

ASBAH will sell the main house. In the present state of the market, we have been advised that best price could be obtained for residential use.

Mr Russell said discussions were

taking place with a view to Sanctuary Housing Association assuming responsibility for Denton View, while continuing to offer secure tenancies at Wharfedale. ASBAH was also discussing a possible partnership agreement with Bradford Metropolitan Council on providing services to both properties.

Following the closure, the first service priority will be to establish a new Service Team for Assessment, Rehabilitation and Training (START) under Joan

Pheasant, assisted by a therapist and with secretarial support.

The service - with its initial emphasis on the ability either to co-ordinate good quality assessments ourselves or work to social services as the lead agencies - will be widely marketed. The challenge will be to persuade local authorities that it will be in their interests to use us.

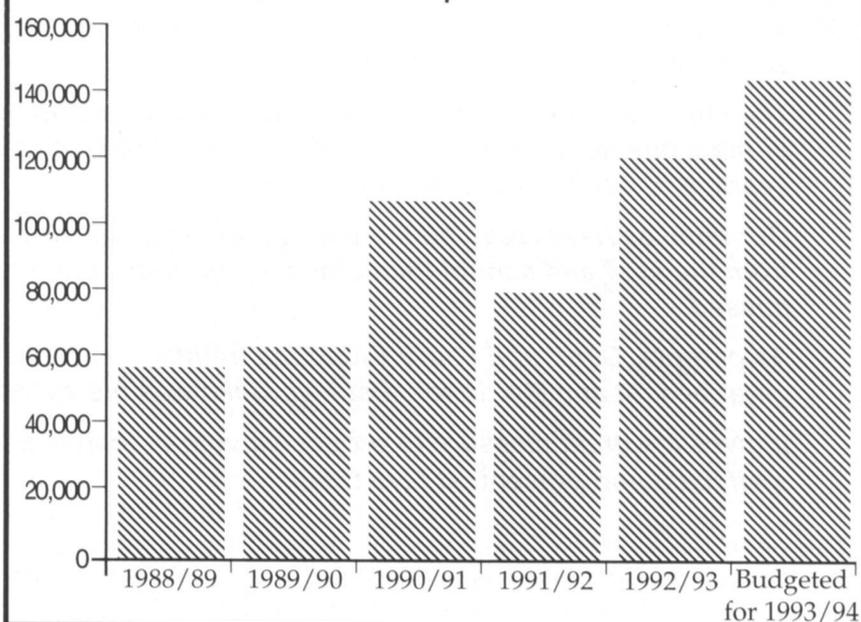
The watchwords will be flexibility and mobility, and START will bring in other expertise as required.

Mr Russell added that, following the introduction of START, ASBAH should then consider opening a regional centre for the north of England, with the additional appointment of a part-time disabled living adviser.

The existing proposal is for seven counties to be 'regionalised' - Northumberland, Durham, Tyne and Wear, North Yorkshire, West Yorkshire, South Yorkshire and Humberside. A consultation to ascertain the views of local Associations will be carried out nearer the time.

"In that whole area, we have just four fieldworkers. It is not well-staffed and we do recognise we need to improve our fieldwork cover there," added Mr Russell.

Differences between Expenditure and Income



FIVE OAKS COURSES

Activity courses and holiday weeks at Five Oaks are in full swing, as the centre makes the most of its final year. Staff have even had to slot in an extra course to cope with demand!

For an up-to-date picture of vacancies still available and costs, please telephone Sarah Peet on 0943-603013.

April 24 - 30:

Driving Course

May 28 - June 4:

Activity Holiday Week

June 5 - 11:

Day Tripper Week

June 18 - 25:

Wildlife Week

June 26 - July 2:

Fashion Course

July 8 - 10:

Fishing Weekend

July 16 - 23:

Outdoor and Recreational Pursuits

July 23 - 30:

Outdoor and Recreational Pursuits

July 30 - August 6:

Activity Holiday Week

Plans for a good START

PLANS for the development of START are described in some more detail in this year's ASBAH *Guide to Services*, to be published in April.

The guide states that the Association is determined to preserve the expertise built up so carefully at Five Oaks since the centre opened 18 years ago.

"Under the government's Community Care arrangements, services for people with disabilities depend crucially upon their assessment, which must be detailed and accurate if they are to benefit fully. Unfortunately, social services departments - the lead authorities - do not have the knowledge and experience in spina bifida and hydrocephalus to carry out these assessments properly. Hence the need for our START team.

"Although the closure of Five Oaks will be a sad point in ASBAH's life, it will release badly-needed funds for a great deal of productive work for our young service-users.

"The challenge for ASBAH will be to launch the START assessment team into a world of Health and Social Services that does not readily accept it needs it, at a time when public authorities are financially stretched."

The guide sets the scene for START to organise a variety of other activities, once its mobile assessment work is under way.

"The service will offer courses in wheelchair and mobility skills, in learning to drive, in building confidence - focussing on development of daily living skills and self-awareness. There will be practical sessions to enable service-users to cope with personal care, to move towards independence and to adapt successfully to change in their circumstances.

"START will be in a position to continue to collate assessments of needs and prepare reports required by local authorities under the Care in the Community arrangements. Much expertise has already been developed in the sensitive and highly specialised area of working with mothers and/or parents and their babies or older children, and this will continue as a significant part of our provision.

"This new plan offers a challenge to our team to explore new areas of service, to develop and reconstruct existing courses, and to enable our service-users to gain practical skills through experience while boosting awareness of their own abilities.

"The START team will be excellently placed to offer support and constructive advice to other professionals, who are less experienced at working with people with spina bifida and/or hydrocephalus."

Five Oaks: some background

FIVE OAKS was purchased by ASBAH in the mid-'seventies - using monies raised during by means of a special appeal, which lasted for several years. *LINK* mistakenly reported in our last issue that the centre was bequeathed to the Association, and we apologise for the error.

The main house, with its splendid views overlooking Wharfedale, was originally built and occupied as a private residence. ASBAH's patron, HRH The Duchess of Gloucester, opened the conversion on 26 October, 1976.

A modern activities centre and two purpose-built blocks of flats - Denton View and Wharfedale - were added in the late 'eighties.



A vital service on the cheap

COLIN Wheeler's fight to get his disabled daughter the incontinence supplies she needs began last year.

"Provision has always been patchy," said Mr Wheeler, who receives absorbent pads, plastics papers and waterproof squares to protect car seats and upholstery from South West Surrey District Health Authority.

"Last April, our supplies were cut drastically and eventually diminished to an inadequate dribble without any warning.

"At one point, there were no supplies for three months and no explanations. This meant there were no longer enough aids to keep our daughter clean or our furniture protected.

"I went berserk. The situation improved for a while, but we are having difficulties again. Supplies are being delivered late, the quantities have been cut and so has the quality."

Mary Connell (not her real name), from Yorkshire, has faced similar problems. Her district health authority (DHA) cut supplies of pads without explanation. "I was mad and kept on complaining until I got more."

Colin Rigby, from Oldham, was told last October that he would have to buy his own pads until he was assessed. "I bought four weeks of stock, which cost me £40. I wouldn't mind, but I wasn't refunded."

Baroness Masham, a member of the House of Lords, and a wheelchair user herself, is chair of the Continence Services Advisory Group, a group of charities whose members often have continence

The UK's first National Continence Week in March encouraged people to ask for help. But what about those who have already asked - and been denied? Tim Russell investigates.

problems. She said the difficulties experienced by Colin Wheeler, Mary Connell and Colin Rigby are not unique.

"Continence services are patchy in many areas. It's very frustrating when you're not given the pads you need. Unfortunately, some people are too embarrassed to make a fuss."

The UK's first National Continence Week, which took place in March, aimed to put that right, by breaking down taboos and increasing public awareness. It was funded by the Department of Health (DoH). A million posters, leaflets and stickers were distributed.

There are three million people who are incontinent, of which about 200,000 people get equipment. The campaign should increase that figure significantly.

Age Concern, the Spinal Injuries Association (SIA), the Association for Spina Bifida and Hydrocephalus (ASBAH) and the Continence Foundation claim DHAs are already underfunded.

"Continence Week is bound to generate lots of enquiries", said SIA parliamentary officer Fidelity Simpson. "So DHAs will need more money to cope with the extra demand on services."

The charities also want the DoH to issue guidelines on minimum standards of service to stop unfair variations across the UK.

"The quality and quantity of aids you get depends on the priorities and budgets of the DHA where you live," said Fidelity Simpson. "Some are great, others offer rubbish and limit supplies so that you run out and have to buy your own."

These variations occur because DHAs do not have to supply continence aids free, she said. "It is up to them what criteria they set and how much money they allocate. Some offer 300 different products, while others limit the choice to three. If there were minimum service standards, the situation would be a lot better."

The charities are backed by the Liberal Democrats' health spokesperson, Liz Lynne, who last month tabled an early day motion in the Commons calling for minimum service standards.

"Continence aids are an easy target for DHAs looking to save money," she said. "They often set unrealistically small budgets, and then ask people to buy aids when the cash runs out."

Labour MP Jeff Rooker believes "there are some huge variations in service and it is up to the DoH to iron them out."

His survey of 165 DHAs in 1991 found that many do not advertise their services and one in three do not provide continence aids to people in residential homes.

"This is grossly unfair," he said.

"People in residential care should be treated the same as people in the community."

The Leonard Cheshire Foundation's development officer Jo Stevenson agreed. "We're unhappy that several of our homes have been told to buy pads. It should be the DHA's responsibility, not ours."

Some of the UK's 350 continence advisers - specialists who deal exclusively with incontinence - feel that DHA policies have put them at a disadvantage."

Helen White, Newcastle incontinence adviser and development officer of the continence charity InconTact, said: "We often feel like piggy-in-the-middle. You want people to have the best, and may know of just the right thing for them, but lack of resources means you have to go for something cheaper."

ASBAH's national continence adviser Mary White said: "Many

people need stainless steel catheters and high bowel washout kits, but they aren't available on the NHS and people are spending £100 on them."

A manufacturer, who did not want to be named, said: "Some aids are not being bought by DHAs because of their cost. It is hard on service users."

A spokesperson for the National Association of Health Authorities and Trusts, said: "It is up to DHAs to provide a quality service, but lack of resources means they cannot always provide the service they want to."

Some DHAs are trying. Sheffield, for example, uses pop-in clinics at supermarkets.

A spokesperson for South West Surrey DHA said: "We aim to provide the best service. In the case of Mr Wheeler, many of the problems occurred because his daughter has not been assessed. We're trying to put that right."

But Mr Wheeler thinks the system is fundamentally flawed. "I'm sure there is a good service buried somewhere within the structure. But I can't understand why it needs so many people to provide it or why it's so complicated. There must be a better way of running things."

"The system is too fragmented," said Mary White. "We need to get experts, manufacturers, DHAs and service-users together and ask them what needs to be done."

Perhaps Continence Week will focus a few minds.

Meanwhile, a DoH spokesperson said: "There are no plans to issue more guidance to DHAs at present, but some extra money may be given."

■ *This article first appeared in the March issue of Disability Now. Sample copies can be obtained by telephoning the DN subscription department on 071-383 4575.*

Scenes from the Derby ASBAH conference

Pictured are some participants during a break at Derby ASBAH's conference on 'The Cost of Incontinence' on 19 March (see page 4). The event, with several highly praised presentations, closed National Continence Week, and included a message from John Bowis, minister for NHS care in the community.



ASBAH's Continence Advice Service

TO THOSE of us working in the field on incontinence, it is obvious that poor continence management has a catastrophic effect upon the quality of life of the individual. Among those worst affected are people with spina bifida and/or hydrocephalus.

Those fortunate enough to discover a successful method of independent continence management - no matter how late in life - know how radically the quality of their lives can change.

Incontinence is:

- Unhealthy
- Anti-social
- Expensive
- Unhealthy

We are keen to point out the necessity for early assessment and on-going monitoring throughout life. The need for health care does not stop at 18 - adults need care, too, if a good standard of health is to be maintained.

■ Anti-Social

Incontinence is a devastating social drawback. It may effect self-awareness, self-confidence, sexuality and relationships. It also undermines the potential for independence and so we strive to instigate a form of management which will make independent living a reality for those who aspire to it.

■ Expensive

The cost of incontinence in personal terms cannot be measured but, in terms of financial cost, it is measurable.



Mary White
ASBAH Continence Adviser

Most of the cost is carried by the Health Authority - treatment of urinary tract infections, continence equipment and investigations. But there is also a heavy cost to be borne by the family. This amount includes the cost of extra soap and towels for bathing and showering, deodorants, detergents, tumble-drying, replacement bed linen and clothes rotted by urine. This is quite a financial burden for the family to carry.

In March, we took part in National Continence Week. This was a government initiative designed to raise the level of awareness of the need for better provision of services for the millions of people who suffer from incontinence.

Many events were organised, including a multi-disciplinary conference on "The Cost of Incontinence" organised at Nottingham City Hospital by Derby and District ASBAH.

We like to think that this initiative, and our support for it, will result in greater understanding of the effects of incontinence on the individual.

GREAT

I AM 29 years old and have spina bifida with complete urinary incontinence.

I have been under the same urologist for 16 years but have become very despondent with him, having been on his "urgent" waiting list for surgery for the last five years.

My health deteriorated, resulting in chronic infection problems and kidney pain. My GP and continence nurse were very supportive and put me on permanent antibiotics to counter the infection and gave regular blood tests to check kidney function.

In July 1992, my GP requested an out-patient appointment. It was made for three months later in October. When I went, I was angry; by departure, I was livid.

There was no apology for the five-year wait. The urologist explained it was due to "pressure on beds". He was not unduly worried about the kidneys or the infection, even though by this stage I was urinating blood, was violently sick, had lost two stone in weight and gone from being pale to grey in colour.

I received an appointment for urodynamics in December 1992. The results showed the maximum capacity of my bladder was 50mls (previously it had been 150mls) and that I had two diverticulum pockets the size of 10p pieces over each urethra - the sources of my infection. I was told I should be put on permanent antibiotics, something my GP had done six months previously.

I was also told an IVP was needed urgently. In January 1993, I phoned the hospital about the IVP,

EXPECTATIONS... III



only to be informed that it had not been requested but they would "chase it up for me". The IVP arrived in February.

A concerned friend contacted Elizabeth Lawlor, an ASBAH fieldworker, outlining the situation. Elizabeth immediately made an appointment to see me. My mother, who was also present, confirmed what had occurred and Elizabeth said she was "horrified". I said I did not want to waste her time as I didn't think anything could be done but she reassured us it was not a waste of her time and, while she couldn't make any promises, she would with my permission contact Mary White, an ASBAH continence adviser.

On 28 January last year, the pain in my kidneys was excruciating and it spread to my groin. I took some more painkillers and went to bed: next morning, both kidneys ached but the pain had gone. I had passed a kidney stone.

Mary visited me in February, equally appalled at my situation. With permission, she contacted my GP and consultant. Mary spoke to the consultant several times and phoned me the following Friday to confirm an appointment with the consultant the following Wednesday. Elizabeth kindly accompanied me at my request, putting off another appointment.

At another appointment in May, the consultant admitted for the first time in 16 years that I was not going to be continent without some form of urinary diversion. He reiterated that I had a very serious and complicated illness - something he had been telling me for years. He said he would refer me to Professor Mundy at Guy's

Hospital, London. He suggested I was going to be expensive to treat but that was his problem, and that I would probably need several operations. I didn't mind, provided they preserved my kidneys. I didn't care about the incontinence as I'd had it for 28 years! Mary had requested the referral in February; he had apparently agreed but it took until May to do it.

I saw Professor Mundy in July, in company with Caroline Berkley, disabled living adviser from ASBAH's South East regional office. I emphasised that my priority was kidney function, not continence, and this was accepted.

For three days in October, I was an in-patient at Guy's having various tests. At last, a full investigation and some concrete results which were acted upon! It had taken 12 months to reach this stage.

The options I was given were urostomy, Mitroffanof or cystoplasty (having a piece of intestine removed and reconstructed to make a new bladder), with a second operation to implant an artificial urinary sphincter. I had two weeks to decide.

This was the most traumatic period of my life, but only I could decide. I chose the cystoplasty, the biggest operation, but could still have a urostomy or Mitroffanof if it failed. It was also more cosmetically acceptable to me.

I had my operation at Guy's on 15 December and was discharged on New Year's Eve. So far, bladder capacity is 300mls and increasing. I'm pain-free, infection-free and 95% continent. I also feel well for the first time in 18 months. It's wonderful.

I no longer take "swimming lessons" in bed each morning and now change the bedding just once a week. I use one small continence pad a day, instead of seven or eight double nappies. This has **never** happened before. I could not have had a better Christmas present or such an excellent start to 1994.

At out-patients on 11 February, the sphincter was put "on hold" by mutual agreement but will be reviewed in six months. If I have any of my old problems, I was told to go back sooner.

Although this is a personal story, I have tried to be accurate and unbiased.

It was be wrong to assume the cystoplasty results are the same for everyone. It was also be naive of me to assume the results will last for life but I intend to make the most of each day, as it comes. Should anything happen with the cystoplasty, I would return tomorrow for a repeat operation, with no hesitation.

It saddens me to have to recall that I couldn't get any action until ASBAH became involved. But then everything went at tornado speed.

...LITTLE HELP



Tenerife holiday

SUN block and sun hats in November, on an island paradise purpose-built for disabled people - that's what some of 'Reading Friends of ASBAH' enjoyed at the end of last year.

Seven young disabled people and five adult helpers took a week out from a dismal British winter to boost their energy levels at the Canary Islands' Mar Y Sol complex at Los Cristianos, Tenerife.



"I've been to Tenerife a couple of times before with the family. You could say I am a fan", said organiser Liz Clayton, who is ASBAH's Berkshire-based fieldworker.

"But this trip was a bit different. Besides relaxing in temperatures which reached up to 75F, we put in a lot of work on mobility training and lifeskills. By the end of the week, all the helpers were running a bit ragged!"

After a flight from Gatwick, Tenerife beckoned. And so did bus rides past miles of well-irrigated fields, a picnic above the clouds at the volcano, snow on the mountain tops, a boat trip to find pilot whales, and customs as Spanish as jousting - and burgers and chips.

The seven disabled young people, all in their twenties, got to know one another before the holiday by enjoying a day out at Blenheim Horse Trials. A contribution of £200, less than half the actual cost of £445, was asked from each - with trusts, charities and local fund raising making up the rest.

Enjoying the break were Tony Campbell from Bracknell, Sue Fueggle (Reading), Julia Rocker (Reading), Helen Bryant (Wokingham), and three people from Newbury - Angela Neale, Kim Staddon and Aubrey Creighton.

Besides Liz Clayton, the helpers were Reading Friends treasurer Pat

READING

Pictured: Kim Staddon and the group afloat (above), the Los Cristianos complex (below), on the volcano and at the Banana Garden (opposite) and the group dressed up for a night out (bottom right).

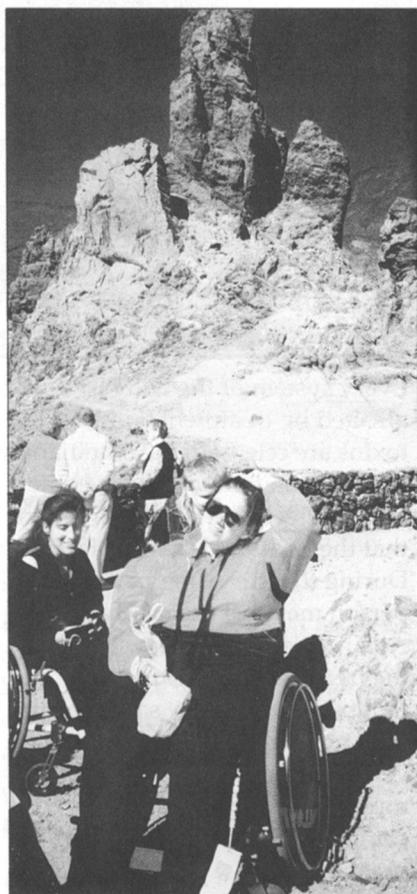
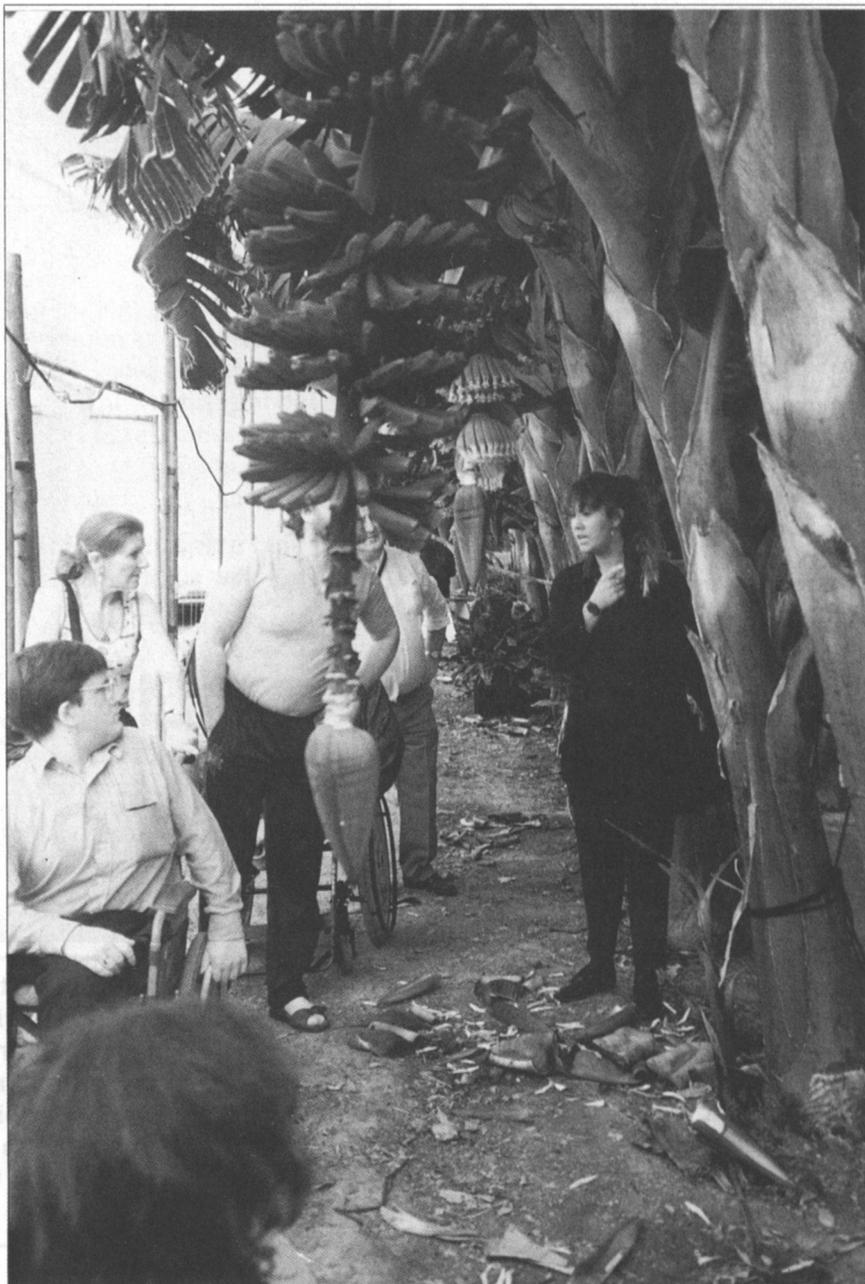


AHOY!

Owen, ASBAH fieldworker Margaret Stanton, Kay Owen and Owen McGee.

"Los Cristianos itself is very accessible. The two-bedded studio flats with loo and showers are not luxurious but very adequate. The lift system is complicated and the lifts small, which pose a problem when moving the group as a whole", said Liz.

"The main swimming pool is lovely; warm and accessible via the side or by hoist. And, because basically the complex is built for disabled people, the number of disabled people in the pool meant there was no embarrassment to anyone using it."



ASBAH FRIENDS GO BANANAS!

FOOT REFLEXOLOGY

Where does it come from?

Many cultures have recognised the unique sensitivity of the feet and have applied compression massage to this area to help alleviate physical and psychological problems.

Reflexology is thought to have ancient roots. Records indicate that it was practised thousands of years ago.

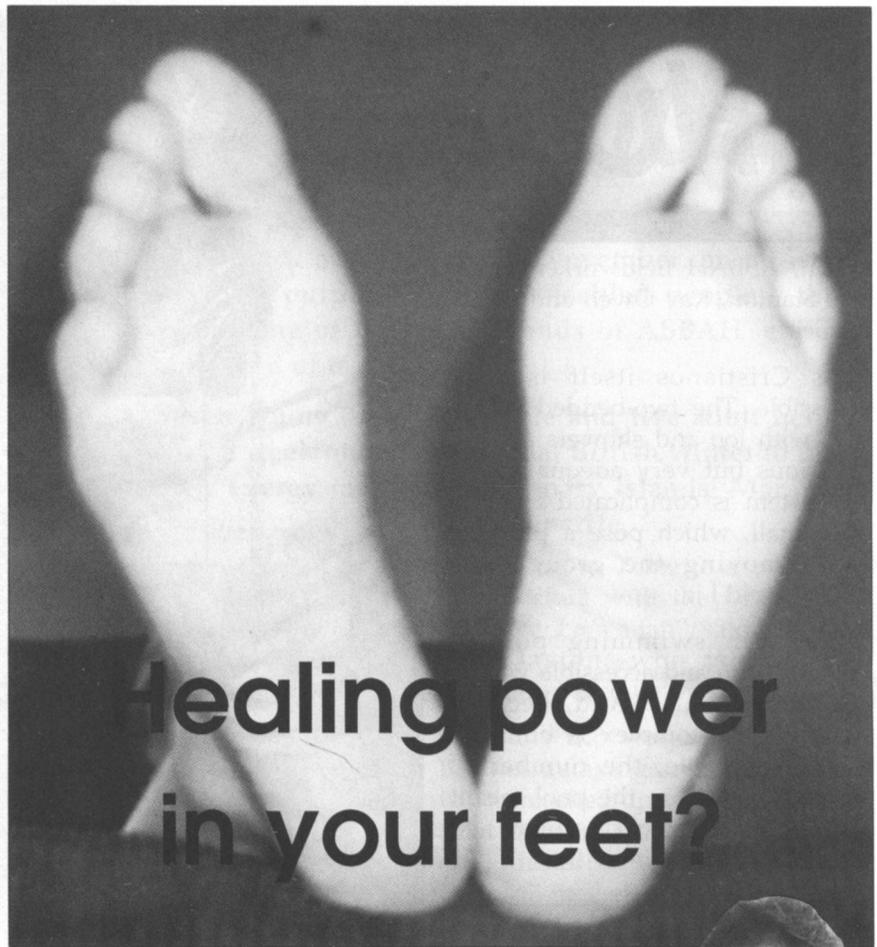
Early in the twentieth century, it was rediscovered by Dr William Fitzgerald, an ear, nose and throat specialist. He produced charts which showed the body divided into 10 zones, five to each side of a mid-line. Dr Fitzgerald proved experimentally that pressure applied on a point within a zone could produce an analgesic effect elsewhere, within the same zone.

This work was taken further by many others, the most prominent among them being Eunice Ingham, whose pioneering work on the mapping out of the feet is the basis for our knowledge today.

What is Foot Reflexology?

Reflexology is a form of compression massage, applied mainly to the feet, but which may also be applied to the hands and cranium. Reflexology is based upon the concept that the whole person is affected when one part of the body malfunctions, thus we treat each individual "holistically". We do not treat symptoms alone; we aim to correct the underlying causative factors. Reflexology is an entirely natural treatment, the aim of which is to normalise and harmonise the functions of the body at all levels - in other words to achieve homeostasis.

The body is designed to be self-healing, given the correct internal and external environment. When trauma, stress or disease impairs the self-regeneration and repair mechanisms, then intervention is



SUSAN JACKAMAN, a consultant reflexologist, contributes to our occasional series on alternative treatments with an introduction to foot reflexology. She suggests it may be beneficial for people with spina bifida and/or hydrocephalus, particularly when carried out in parallel with orthodox medicine - but warns that it might not be appropriate for all patients.



required to restore the correct environment for healing to take place. Here, the skills of a qualified reflexologist can be utilised to assist the body to repair itself.

Reflexologists work upon nerve fibre ends, of which there are more than 7,200 in the feet. The treatment stimulates reflex actions throughout the nervous system and this affects the free flow of the body's natural electrical impulses. Where disease, stress or trauma has affected the body, then a blockage may occur along one or more of these pathways. This reduces the flow of impulses and innate energy, thus causing the body part to weaken and eventually break down.

Every system of the body is affected by treatment and, as toxins are released, the elimination systems can temporarily become more active. This is a positive sign that the body is cleansing itself. During this cleansing period, a person may feel extremely tired. Again, this is a positive sign that the treatment is working. Reflexology is a very safe therapy with no adverse side effects and very few contra-indications but it must be administered by a competent, fully-qualified practitioner.

Does Reflexology work?

The answer is unequivocally, yes. Whilst the evidence is primarily

anecdotal, this should not detract from the fact that extremely good results have been obtained by thousands of practitioners, treating a wide variety of conditions. However, one should remember that every therapy - whether orthodox or complementary - has limitations, depending upon the extent that the body's own self-regenerative capacity has been affected,

Reflexology is a branch of complementary health care, thus the treatment is complementary to orthodox medical treatment. It does not replace it. When the two types of health care are used in balance together for the patient's well-being, then extremely good results can be achieved in many cases.

Can Reflexology aid bladder and bowel control?

Again, we have much anecdotal evidence that Reflexology is very successful as a means of improving bladder and bowel control. The treatment has been found to help both the aged and patients suffering from multiple sclerosis, Parkinson's Disease, cancer and partial paralysis to regain control of the sphincter muscles of bowel and bladder. This results in increased dignity and hence a better quality of life.

In some European hospitals, reflexology is utilised to prevent catheterising post-operatively. This works in preventing infection, which in turns speeds recovery and occasions less trauma in the patient.¹⁻²

Reflexology appears to act as a catalyst for healing, enabling the body to create the correct internal environment for self-regulation and improved function.

Who can benefit from Foot Reflexology?

Almost everyone, as there are very few contra-indications to the treatment. A qualified practitioner will be fully aware of patients who should not receive treatment or of

patients with conditions where caution must be exercised.

Ideally, Reflexology should be used as a preventative health treatment from infancy onwards; imbalance could then be detected at the earliest stage, when treatment can be most successful.

Reflexology promotes deep relaxation and therefore, where muscle tension is present, treatment will bring about a degree of relaxation, thus improving function of the area concerned.

Treatment of spina bifida and hydrocephalus with Reflexology

There is very little data on the treatment of spina bifida and/or hydrocephalus with Reflexology, but there is no apparent reason why Reflexology could not help these patients.

Generally, the younger a patient, the more receptive they are to treatment and a speedier response is often noted. Therefore, I would recommend treatment of patients with spina bifida and hydrocephalus from birth. This does not mean that older people will not benefit from treatment but it usually takes longer to bring about required changes.

Family members can also be involved in the course of

treatment. Relatives can be taught how to give relaxation treatments designed to provide continuity between sessions of professional therapy at the clinic.

It would be most enlightening for all concerned if patients with spina bifida and hydrocephalus combined a course of Reflexology treatment with regular monitoring by their orthodox medical practitioners to assess precisely what is taking place.

At present, Reflexology is under-researched and such a study would allow hard data to be produced on the effectiveness of the treatment.

Bridge House Clinic, where I practise, is a complementary health clinic located at Fairway House, 73 Village Road, Higher Bebington, Wirral, Merseyside L63 8PS. If enough interest was shown, we would be prepared to establish a Reflexology Centre for people with spina bifida and/or hydrocephalus.

References

¹ 'Reflex Zone Therapy: a textbook for therapists', Hanne Marquardt, page 94

² 'Nursing Times' special edition, autumn 1993, 'Complementary Therapies' - reflexology section, page 95.

FOOTNOTE: WHERE TO FIND THEM

READERS wanting to choose a reflexologist for a consultation can contact the British Reflexology Association for Information. The BRA publishes a nationwide register of members' names and addresses, which can be obtained on payment of £1.50, sent to:

British Reflexology Association, Monks Orchard, Whitbourne, Worcester WR6 5RB.

A leaflet about the work of the BRA will be sent out with every copy of the register.

The Institute for Complementary Medicine can pass on details of practitioners who are fully insured for professional and public liability and who comply with "a pretty fierce" code of practice. State what branch of complementary practice you are interested in, and send a large SAE:

Institute for Complementary Medicine, P O Box 194, London SE16 1Q2.

EVENTS

30 April

'Your Voice in ASBAH' conference, ASBAH House, Peterborough. Special guest: Mik Scarlet, presenter from BBC2's 'From the Edge' programme (see elsewhere in LINK), 11am-4pm. *Tony Britton, tel 0733-555988*

17 - 19 May

Midlands Naidex '94, NEC, Birmingham

21 May

Scoliosis Association UK, meeting to discuss treatment and genetics, Kent, 2-5pm. *Mrs Jacqueline Cooksey, 'Chalan', Button Drive, Lower Stoke, Rochester, Kent ME3 9SR*

11 June

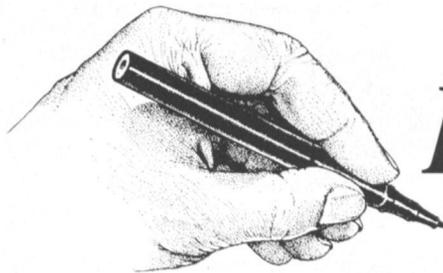
'Moving into adult life with spina bifida', conference organised by people with spina bifida for people with spina bifida, Portland Training College, Mansfield, Notts, 9am - 4.30pm. Special guest: John Bowis, Parliamentary Under-Secretary of State for Health, with representatives from Department of Health, Social Services Inspectorate, ASBAH and others. Topics include employment, mobility, sexuality, parenting, forming positive relationships. Fee £10 inc lunch and all refreshments. Please apply by 27 May. *Mary White, 56 Derby Road, Matlock Bath, Derbyshire, tel 0629-580297*

17/18 June

Mobility Roadshow, King's Hall complex, Belfast. *David Patterson, Disability Action, 2 Annadale Avenue, Belfast BT7 3UR. Tel: 0232-491011*

25 June

Scoliosis Association UK, meeting to discuss treatment and current research on scoliosis and lung function in severe curvature of the spine. Freeman Hospital, Newcastle-upon-Tyne, 10.30am - 4.30pm. *Mrs Gill Parsons, 5 Seltops Avenue, Darlington, Co Durham*



Letters

IN OUR last issue, we told the story of Gillian Machin, who lost an amazing 14 stones while on a Weight Watchers diet.

Now a reader writes with another personal success story - this time thanks to Weight Watchers on mail order!



I AM 28 years old and have spina bifida. I have used a wheelchair all my life. As the years went by, and with not getting much exercise, my weight steadily increased even though I ate very little and I had no sweets or cakes.

I seem to have been on a diet all my life, on all different diets. I have even been on one as low as 500 calories a day, and still nothing has worked.

When I was 27, I weighed 10 stone and - because I'm only four feet tall - I was very fat. I then met a cousin who I had not seen for quite some time. She had always been very fat but, suddenly, she only looked half her normal size. When I asked her about losing weight, she said she had started Weight Watchers and had lost four stone. She also told me that, if I wanted to join but had difficulty getting to the meetings, it was possible to join by mail. So my mother phoned Weight Watchers the next day and they checked with their medical panel and then rang back and said there was no reason why I shouldn't lose weight on their plan.

I sent £40 off for an eight-week course which consisted of set menus for each week. At the end

of the eight weeks, I began again on week 1 and just continued over again.

Each month I lost nearly 3lb. Now I am down to 7 st 9 lb. I have lost 2 st 5 lb in 14 months.

Now I have to stay stable as I have reached my target weight of eight stone so I also have a few pounds to play with! I also have never eaten as much in my life as I have on this diet. I feel and look a different person and I have received lots of praise from other people.

Name and address supplied

Editor's note: To find out more about Weight Watchers, telephone 0628-777077.



I thought my story might encourage anyone who has been refused a benefit to which they think they are entitled. I had a year's battle to try to get the new Disability Living Allowance.

I have right spastic hemiplegia, which means I have difficulty in walking. I am in a great deal of pain most of the time. In the past, I had no chance under the old Mobility Scheme of being awarded a benefit. I even wrote to the then Minister of State for Social Security telling him of my difficulties and pointing out how many people similar to me miss out on having any help with benefit. In his reply, he said he hoped that the new benefits would help people like me.

So, when I read about this new allowance, I thought it was to help

people like myself with hidden disability to get help. However - as I was to find out - things were not that easy.

As I CAN walk, the DSS argued that I was not entitled to the mobility component of this scheme.

I asked them to review their decision - pointing out that I thought it was to help people like myself with hidden disability to get some help. However, I was to find it was to be a long haul.

When I put in my claim for the allowance in August 1991, I thought that I would have no trouble in obtaining the allowance, due to my difficulties in walking and the pain I have. However, the DSS wrote informing me that as I could walk a small distance I was not entitled to any help.

So began the letters from me to DLA challenging their decisions, and twice they turned me down. I carried on and they then told me that they wanted me medically examined. "Good", I thought at least now I may be able to get the help I needed.

The doctor duly arrived, and I walked round for him and he examined my feet and asked me questions on how far I could walk. He was a very pleasant man but he

did not suggest I walked outside the house, which would have given him far more information on how I coped and an indication of the time it took. A few weeks later, I had a further letter from an adjudication officer refusing my application for DLA. By this time it was 5 January 1993 and I was getting despondent and on the verge of giving up my fight. It was only with the support of my family that I decided to carry on. I wrote saying I wished to go to the Disability Tribunal (independent from the DSS). While I was waiting for a date, I obtained a letter in strong support from my GP.

My initial hearing was to have been in London, but I wrote back advising that I preferred Peterborough. They wrote back, saying the venue had been changed as requested.

Several times during the months I waited I almost withdrew my claim because I was afraid of the idea of a tribunal: it sounded so formal and a bit like a court. During these months, I received several letters asking for replies to questions which I had already given, all of which added to the frustration, but each time Mary, ASBAH's assistant fieldwork manager, urged me to stay with it.

The day of the tribunal came. I was

so nervous, I did not know what to expect. Encouraged by my family and Mary, I did go to the tribunal. I wrote a few notes of special things I wanted to say, so that I would not forget them if I was nervous.

I need not have worried. The tribunal hearing was held in a sports club, and it was very relaxed. It consisted of only five people in all, including a representative from the DSS. I gave each one a copy of my notes. They asked how far I was able to walk, (*make a note of how long it takes to walk to a specific place and the distance it is. This and other examples will help you when the tribunal asks these questions*).

The DSS representative then asked me questions on how my disability affected me. After he had questioned me, they asked if I had anything more to add, and they gave me time to say all that I wanted to. We then left the room. When they called us all back they gave me their decision. I have now got Disability Living Allowance!

I hope my story will encourage those of you who are now in a similar position to carry on fighting.

*Marion Cole
Huntingdon, Cambs*



HAVING just read the article 'A Right to Life' on Sophia in the last LINK, I want to mention my parents' similar experience.

I was born in 1947 in January during the deep snow, a spina bifida baby. My parents were told that I would probably be severely physically and mentally disabled, and that it might be a good idea to let me die. My doctor had to persuade a reluctant consultant to operate.

On achieving school age, the education authority refused to let me go to school. They said disabled people could not be educated and only after a lot of argument was I allowed at the age of 10 to start school on a trial period of three months.

After leaving school, I worked at a printing firm making hand-made carrier bags and, in the evening, got my GCE certificates at technical college.

Eventually, I was taken on as a junior chemist at

A H Marks Chemical Company in Wyke Bradford. The firm paid for me to be educated to degree level. I now have a degree and work full-time as an analyst in the quality control laboratory.

I live alone and do all my own washing, cleaning and shopping. In years gone by, I have been a Brownie leader, a Guide assistant, a playgroup assistant and a Sunday school teacher.

I have not met Sophia and cannot judge how independent she is likely to become, but I do know her parents have the correct attitude. They will fight as hard as they can for her.

My parents were very strong. They saw me struggle, knowing it was the best for me and, thanks to them, I was given the gift of life. I am sure that one day Sophia will also be able to thank her parents.

*Christine Helliwell
Brighouse, West Yorkshire*

HOLIDAY ACCOMMODATION

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

ISLE OF WIGHT ASBAH

Fully equipped, wheelchair accessible 2 bedroom holiday chalet, sleeps 6 + cot. Clubhouse, indoor heated pool, shop, etc. Site overlooks sea. Own transport advisable. Details: Mrs P. Burnden, 36 Sherbourne Avenue, Binstead, Ryde, Isle of Wight PO33 3PX. Tel: (0983) 564604.

LOOE, CORNWALL

Fully equipped, wheelchair adapted, two bedroom, self catering bungalow. Sleeps six; site by sea with east access to beach, parking, shop, indoor pool and camp facilities. Well furnished and comfortable. Good situation for Plymouth, Dartmoor, Devon and Cornwall. For details: Mr P. Cash tel: (0425) 672055

NEW MILTON HAMPSHIRE

Fully equipped, wheelchair adapted, 2 bedroom, self catering bungalow. Sleeps six. Excellent all year site, indoor/outdoor pool and superb facilities all within 100 yards. Ideal for New Forest and Bournemouth areas. Well furnished and comfortable. For details contact Mr P. Cash tel: (0425) 672055

NEW FOREST

Fully equipped caravan designed for wheelchair access throughout, sleeps 5-6, club with indoor pool, shop etc, sited at Bashley Park New Milton. Contact Joan Searle tel: (0705) 376816

ROMNEY SANDS, KENT

Two-bedroom holiday chalet - sleeps six, fully-equipped, wheelchair-accessible, full club facilities, heated pool, etc. Across road from beach. For details, contact Diane Woodley, tel 0843-834909.



TENERIFE

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Support from life insurance

We draw a new life insurance scheme to your attention. If you are caring for someone with spina bifida or hydrocephalus, or if you have the conditions yourself, we recommend that you read about it. *In the first five years, 10% of every premium goes to ASBAH funds, a great help to our work.*

Think of a family with a young disabled child. The chances are that the mother spends most of her time looking after her child. Unlike other mothers, she probably does not go out to work. Her untimely death spells more than bereavement for the family. It puts an intolerable load on everyone: husband, siblings, relatives. Our message is simple. Carers need life insurance. Older sufferers can be in the same position. Without the people they love, they must pay for all the caring they need or lose their independence completely.

The value of carers

If we put a high value on caring, we should be prepared to protect it, as you will see, the cost need not be high. Generally, the carers will still be young and in good health. So a small premium buys a lot of cover. It needs to. If you have to buy care, it will cost a fortune. Buying the insurance costs pennies a day. We have chosen the simplest possible form of cover: term insurance. If your carer dies, the policy pays. It is not a savings plan. It is not an investment. There is no surrender value, there are no

A common bond

The members and supporters of ASBAH share together a common bond. Each one of them is committed to helping people with disabilities. It is often just as important to insure the breadwinner and perhaps grandparents who are helping with the extra money needed to support the family. They know that if the breadwinner dies, the carer is often forced to rely ultimately on the insecurity of State support. The breadwinner is an equally valuable member of the family.

BENEFITS FOR A PREMIUM OF £25 PER MONTH (that is less than 83p per day)

Insurance on a female helper, a non-smoker. The plan is available for people aged 18 to 59 inclusive. It can be renewed to age 70.

Age of carer now	Cover
35	£127,027
40	£110,156
45	£71,392
50	£43,721

you can afford. Do not overstretch yourself.

The amount of cover you get depends on the age of the person you insure, it does not depend on the age or health of the person with spina bifida or hydrocephalus. He does not have to answer any medical questions at all.

Financial difficulty

When our members lose their helper (whether spouse, relative or friend) they face immediate financial difficulties as well as bereavement. It is crucial that money becomes available quickly and that it is not immediately swallowed up by means-tested benefits. This is a difficult problem for most people to solve and not one which gets attention in the press.

How to join

Complete the coupon or telephone with your details. Sterling Life will send you a personalised quotation. No salesman will call.

Helpline 081-490 9202



complications. That makes it very much cheaper than the more familiar endowment policy. The cover runs for ten years and you are guaranteed the right to renew it up to age 70.

Affordable

It also means that we can offer plans most of our members and supporters can afford: premiums can be as low as £10 a month. Of course, we cannot guarantee the solution of all your problems for 33 pence a day, but the extra money would help. It might mean the continuity of the home, holidays for all the family. It also means that the breadwinner could continue to earn for all the family because he knows how to pay the domestic bills. Pick the premium

Please send us these details or telephone us with them. We will send you a range of premiums and full information.

Name		
Address		
Postcode		
Full name of carer		
Male <input type="checkbox"/>	Female <input type="checkbox"/>	Date of birth
Smoker? Yes <input type="checkbox"/>	No <input type="checkbox"/>	
Cover Required	£	
Or premium available	£	per month

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