

Link

Association for Spina Bifida and Hydrocephalus/ASBAH

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Association for Spina Bifida and Hydrocephalus (ASBAH)
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ASBAH Publications

**All available from National Office
Cheques payable to "ASBAH"**

Young People with Spina Bifida and/or Hydrocephalus — Learning and Development (1985) <i>Leonie Holgate</i>	£1.60
The Handwriting of Spina Bifida Children (1979) <i>Joan Cambridge, E.M. Anderson</i>	£1.60
Spina Bifida and You — A Guide for Young People (1985).....	£3.50
Sex for Young People with Spina Bifida or Cerebral Palsy (1984).....	£1.75
Children with Spina Bifida and/or Hydrocephalus at School.....	£2.50
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VISUAL AIDS
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Video — Training video on Hydrocephalus (May 1987). Contact Information dept. for details of hire or purchase.

MAGAZINES
LIFT — for members of young ASBAH (LIFT)..... Free
Causeway — for contributors to ASBAH's work..... Free

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ASBAH

22, Upper Woburn Place
London WC1H 0EP

The
ASSOCIATION
for
SPINA BIFIDA
and
HYDROCEPHALUS

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1989

issue number 122

Cover picture "Marathon Action" - by John Bundock.

Powering on in the London Marathon - Tony Sergent from Birmingham nears the finishing line.

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The International Federation for Hydrocephalus and Spina Bifida

1989 Conference Report

The generosity and co-operation from Local Associations who part-funded Fieldworkers to attend the Conference increased the number of ASBAH's representatives in Antwerp. The Belgian Association's hard work over many months ensured the great success of the Conference.

The international conference took place in Antwerp from the 5th to 9th April.

The social programme was also varied and included a well presented display of wheelchair formation dancing by a team from the Netherlands. The lectures which they devised were informative and each paper was followed by a lively discussion.

18 countries were represented this year - the highest ever and representatives came from as far away as Hungary. As well as the formal lectures, each country accepted an invitation to give a presentation of their own work in their own country which once again allowed knowledge and information to flow.

The scope of topics chosen for presentation included such complex issues as the medical treatment of new born children with a neural tube defect. The medical, legal and ethical aspects were explored leaving, as always, room for further debate.

A paper on accessibility to buildings and other public places was encouraging as it revealed that the EEC are taking positive steps to address the problem by producing working documents and guidelines.

An interesting concept on housing came from Mr Clement Matassen of the Technical University, Eindhoven, Holland, whose talk illustrated the possibility of flexible housing. The idea is to ensure that the original design takes into account the possibility that the occupier may become disabled. This would ensure that later adaptations can be made simply and relatively cheaply. Examples of features to be incorporated in the original design included wide door-ways, lowered windows, level door sills, stairs which later could take stair lifts if necessary, and lower door handles and locks.

Mrs Cornel from the European Registration of Congenital Anomalies and Twins emphasised the importance of recording information about birth defects. This data, which is computerised, enables research into the causes of such defects to evolve rapidly and efficiently. There are at this time 25 centres within Europe providing information to "Eurocat", two of which are in Ireland and three in England.



Miss Moyna Gilbertson, Executive Director of ASBAH with Fieldwork Manager Mrs Teresa Cole seated.

Dr. JJ Wijndaele, a Urologist from Belgium, spoke about recent evolutions in the field of Urology - 20 years ago the only treatment to aid continence was a urinary diversion. This has now progressed to such things as enlarging the bladder, self-catheterisation and the implantation of the artificial sphincter. Dr Wijndaele stressed the importance of thorough and regular investigations of the urinary system (Uro-dynamics).

Professor B Lumenter a Neurosurgeon from West Germany, gave a report on the findings after using the SOFI valve in the treatment of Hydrocephalus over the last two years. The SOFI valve differs in that the pressure at which the valve will work can be changed by using an external magnet. ASBAH still has reservations about the SOFI valve, however they were interested in this report as it represented the largest survey carried out so far. Further information is expected in due course from Professor Lumenter and his team.

A most relevant and important paper to be presented at the Conference was by Dr Schwarz a Neurosurgeon from University Clinic in Mainz, West Germany. His paper entitled "New Research and Findings in Cases of Spinal Deformities Caused by Spina Bifida" was very technical and therefore impossible to report on in this issue of LINK. However, it will be reported on in a future edition.

EDUCATION

A REPORT FROM HOLLAND

by Ineke Meijer and Hank Oosting

The idea of integrating children with disabilities into mainstream schools has not only taken root but has become acceptable practice. In the Netherlands, as in Britain, parents have the choice of integrating their children in mainstream schools or segregating them in special schools. Education in the Netherlands starts at the age of 2 and does not finish until the age of 20.

"Mytyschool" is the name given to a special school for children with motor-disorders. The curriculum can, if required, combine an educational programme with a rehabilitation programme. The school building is fully adapted for wheelchairs. The school population consists of children with different physical disabilities, including those with spina bifida.

Children with mental disabilities or those with both physical and mental disabilities are not educated in the 'Mytyschool' but are sent to other special schools; whilst children who are deaf or blind are also grouped together for educational purposes.

In 1987 The Working Group of Parents of Children with Spina Bifida (part of BOSK - Parents Association of Motor Handicapped Children), devised a questionnaire to gather together parental views on the educational provision they had chosen for their offspring.

There was a 50% response to the questionnaire. Of those who responded, 80 per cent had children whose disability was dominantly physical, whilst the other 20 percent were attending special school for children with a mental disability. It should be noted that it was felt that the questionnaire did not fully represent the picture of children with spina bifida in the Netherlands, as it is felt that more than 20 per cent do have a mental disability.

The questionnaires did, though, give a clear picture of both the advantages and disadvantages for physically disabled children when comparing the integrated and segregated systems on offer.

In the specially adapted 'Mytyschool' classes were felt to be smaller, individual teacher attention greater, whilst children were allowed to develop and achieve at their own pace. Children played a more participatory role in school activities and there was also more opportunity for help with personal care and hygiene. The 'Mytyschool' system is also equipped to offer a therapy programme alongside the normal educational syllabus.

The disadvantages of the 'Mytyschool' school system included insufficient emphasis on learning and performing well in class. The school provides such an overprotective environment that future integration in society becomes more difficult. It was also felt that the distance between the 'Mytyschool' and the home meant added strain.



illustration showing adapted stairway in mainstream school

It was interesting to note from the results of the questionnaire that the observations of parents whose physically disabled children were integrated in a 'regular' mainstream school were almost a mirror image of those from 'Mytyschools'. Children in mainstream schools felt isolated and were not always able to join in school activities. Integration did not leave room for educational interruptions due to hospitalisation.

The questionnaire showed that parents of disabled children are very much involved in the process of selecting the best schooling available to meet their child's needs. During the years of education, children had often changed from one system to the other, but this had only been done after a great deal of thought and consultation.

If a child is going to change from one system of education to another, this usually takes place between the ages of 6 and 12. The switch from a 'Mytyschool' to an integrated school is almost exclusively due to the higher demand on the child, concerning the academic content of the curriculum.

Children are also seen to move from a mainstream school into a 'Mytyschool'. The reasons for this move are varied. Intellectually, they may include the child's poor concentration and therefore the need for smaller classes, and special attention from teachers. Personal care due to incontinence problems is another factor, as well as the therapy programmes on offer at the 'Mytyschool'. For many disabled children playtime after school has to be cut in order to make space for physiotherapy sessions. If these can be included in the school day, the child can experience a greater social life.

The questionnaire has shown that, although modern thinking may veer towards integrated education, in reality the issue is far more complex, and each child should be assessed so that it can reach its full potential. In this way children can grow up to become active members of society.

MOBILITY ALLOWANCE

A special report by Linda Avery

The latest Social Security Bill which is currently being put through its paces in Parliament holds good news for anybody currently holding a Mobility Allowance award and who will reach their 75th birthday this year. To date, once a person reaches the age of 75, the allowance is withdrawn.

However, the new Bill contains provision for the upper age limit to be extended to the age of 80.

This represents an important step forward in the history of this particular benefit, and it is understood that this is intended only as an interim measure until the government has had time to fully study the Office of Population and Census Studies' review of the numbers and needs of people with disabilities. It is hoped that eventually all disability-related benefits will be revamped to reflect the findings of the OPCS report.

First, what is Mobility Allowance? It is a non-contributory, non-means-tested tax-free allowance, paid to those people who are unable, or virtually unable, to walk and who are likely to remain so for at least a year. The allowance is currently worth £24.40 from April. It is ignored for the purposes of other benefit assessments such as Income Support and Housing Benefit and the claimant need not be incapable of work to qualify.

There are however several qualifying conditions. First, the claimant must be resident in the United Kingdom, and have been so for 12 of the past 18 months. They must be able to make use of the allowance so, for example, people in a coma would not qualify. But this also means that people in residential homes or even in hospital can still qualify, providing they can use the allowance for mobility purposes. Second, there are certain age qualifications.

Mobility Allowance cannot be claimed before the age of 5, or beyond the claimants' 66th birthday. If the person has reached 65 they can still claim, providing it can be shown that they meet the medical conditions before reaching the age of 65.

The Mobility Allowance Unit will accept such claims providing they are received in the Department of Social Security before the date of the person's 66th birthday.

As already explained, unless the award is time-limited, in which case repeat claims are necessary, the claimant can continue to receive the allowance until his 75th birthday. The first people to lose the allowance would have been those who reached 75 on or after 29th November 1989. However, as mentioned this is now to be extended to the age of 80.

The medical conditions attached to qualifying for Mobility Allowance are particularly stringent and have been the subject of many campaigns by disability 'rights' groups to have the rules relaxed or extended.

Basically, the person must be unable to walk, virtually unable to walk, or the exertion required would, in itself, constitute a danger to the person's life, or would be likely to lead to a serious deterioration in health. "Unable to walk" means just that; the person literally cannot take one step. "Virtually unable to walk" means that the person's capacity to walk out of doors without severe discomfort is such that it is so limited that it renders one almost unable.

The medical assessors will take several factors into account when deciding this issue. These include the distance the person can walk, the speed, the length of time it takes to get from A to B and the way in which the process of actually walking is achieved.

It should be noted that the incapacity to walk must stem from a physical cause so that, for example, mental illness such as autism, agoraphobia and schizophrenia do not at present qualify.

However, it has been accepted that certain mental handicaps such as Downs Syndrome do originate from a physical cause and are therefore acceptable in Mobility Allowance assessments.

Note also that if an applicant can walk reasonably well with the aid of an artificial appliance, he will not qualify for the allowance.

It should be remembered that 'local' circumstances such as the lack of public transport or a hilly environment are not taken into consideration. In other words, the medical test relates purely to the person and not to his surroundings.



John Naude getting there, BR style

HOW TO CLAIM

Those who think they might qualify for the allowance should claim immediately as Mobility Allowance cannot normally be back-dated.

Claim forms are contained in leaflet NI211, available from local social security offices, and should be sent to the :-

Mobility Allowance Unit
Department of Social Security,
Norcross, Blackpool FY5 3TA.



Housing

The Right to Buy

In the first of two articles, Carolyn Smith - Accommodation Officer (ASBAH) - considers the implications for people with disabilities, of the new 'Right to Buy' provisions contained in the 1988 Housing Act. Her second article, to be published in the next issue of LINK, will consider the implications of the new Community Charge - or Poll Tax - which will be introduced in England and Wales in 1990.

Until recently, a local authority home which had been substantially adapted for a disabled person, was exempt from the 'right to buy' provisions enjoyed by most able-bodied tenants occupying non-adapted council property. Thus families which included a disabled member, and for whom adaptations had been carried out, were unable to enjoy all the benefits and discounts which are available under the scheme.

NEW HOUSING ACT

The new Housing Act has now extended the right to allow tenants of adapted homes to become eligible to buy their homes at a discount. The change only applies to tenants of 'one off' adapted properties. Homes which are classed as 'purpose built' or 'sheltered accommodation' will still remain exempt from the 'right to buy' provisions.

HOME OWNERSHIP

Many disabled people have welcomed the change as an opportunity to enter into home ownership - an option which the majority had been denied; and it is true to say that the new provisions remove some of the inequality and discrimination previously faced by disabled people in the housing market. Nevertheless, this must be balanced against the fear that the housing choice for people with disabilities could, over time, become even more restricted as a result of the changes.

DECLINE

The steady decline - and in some cases complete termination - of local authority house building has meant that there is substantially less opportunity for adaptations to be carried out in suitable properties. Obviously, the most suitable and desirable property for people with disabilities, as with elderly people, is ground floor accommodation and there can be no doubt that such suitable stocks are fast diminishing - a trend which can be exacerbated by the new 'right to buy' provisions. Since the demand for wheelchair and mobility housing does, and will continue to, outstrip even current supplies, disabled people will be forced to depend on private sector accommodation; in particular, that provided by housing associations.

PROVISIONS

Under the provisions of the Chronically Sick and Disabled Persons Act 1970, local authorities have a duty to investigate and meet the housing needs of people with disabilities. Whilst it is true to say that the housing associations do provide good quality housing for rent, they are under no similar legal obligations. Thus, disabled people may, in the future, lose their rights to appropriate housing; local authorities do not have the housing stocks available and housing associations continue to build and adapt on an ad hoc basis.

Where local authorities do continue to build, there may be a temptation to concentrate on the housing needs of the elderly, so that lettings can be classed as 'sheltered' or 'warden controlled' accommodation - both ineligible for 'right to buy' deals. Similarly, where young disabled people are concerned, local authorities could tend towards providing 'special schemes', 'disabled communities' and institutions, rather than adapt existing housing stock or provide integrated accessible housing.

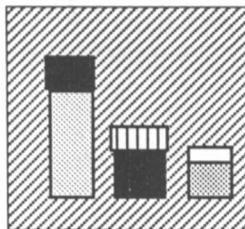
RESPONSE

Whilst the short term response is, understandably, delight at the 1988 Act's removal of barriers which have prevented disabled tenants from moving into owner occupation, the long term implications are ominous. Unless suitable housing provision increases dramatically, disabled people could find themselves facing even greater discrimination in the housing market than is currently the case.

Once again, architects of housing legislation have failed to recognise the real housing needs of disabled people. In doing so, they have also failed to find practical ways in which those needs could be met.

TO BE CONTINUED
IN THE NEXT EDITION OF

Link



PRESCRIPTIONS

CAN YOU AFFORD THEM?

The cost of being sick has risen again - in the form of yet another increase in the cost of prescriptions. A prescription now costs £2.80. This represents the fourteenth increase in charges since 1979 ie 7.7%.

Suppose then, that your GP prescribes two, or perhaps three, items for you? This could result in a bill of £35.60 or £38.40 respectively. No fun if you require a lot of medication fairly frequently. Indeed GPs themselves are increasingly conscious and concerned that rising costs actually deter patients from 'cashing' prescriptions. On the announcement of the increase, the British Medical Association warned that it could stop many people from coming forward for treatment. There are, however, several ways in which the cost of being sick can be reduced or, in some cases, eliminated altogether.

Exemptions

Children under the age of 16, or who are 16 or over but under 19 and still in full time education, as well as anyone over retirement age, are all automatically entitled to free prescriptions. So too is anyone who receives - or whose partner receives - either Income Support or Family Credit.

Charge 'Exemption' Certificates can be claimed on certain benefit grounds. For example, pregnant women and those who have had a baby during the past twelve months, are eligible, as

are War or Ministry of Defence Disablement pensioners, where the prescription is in connection with their accepted disability.

Exemption Certificates are also available to people who have a continuing physical disability which leaves them either housebound or unable to leave home without the help of another person. Note that temporary disabilities, even if they last several months, are not included.

There are also certain 'specified' conditions which qualify for Exemption Certificates. These conditions include epilepsy - where continuous anti-convulsive therapy is necessary - and permanent fistula (such as colostomy or laryngostomy) - which require continuous surgical dressing or an appliance. The medical qualifying conditions also include certain disorders for which specific substitutions therapy is necessary. These include Addisons Disease and various forms of diabetes. Note that diabetics are also entitled to free disposable syringes.

Those who do not fall within any of the above categories may still be able to get help with prescription charges, on grounds of low income - this applies even where the person(s) is not in receipt of Income Support or Family Credit.

Entitlement

'Low income' means that if the claimant - or the claimant and their partner - have savings of £6,000 or

less, and the weekly income is just above what would be applicable if Income Support were in payment. Form P11 gives precise details and a table which can be used by the individual to get some rough idea of their entitlement. Low income entitlement lasts for 6 months, after which a fresh claim must be submitted. If an exemption certificate is granted on grounds of low income, it will also act as an automatic passport to free NHS glasses, dentures and dental treatment.

Season Tickets

For those who are unable to qualify for free prescriptions, but who nevertheless have to have a number of prescriptions throughout the course of a year, it is worth considering buying a prepayment certificate or 'season' ticket. A four month prepayment certificate costs £14.50 so, if it is likely that more than six prescription items will be needed in a four month period, this will reap a saving. A yearly certificate costs £40.00. More than 15 prescription items over the year will, again, reap savings.

Finally, both GPs and chemists will usually advise patients if an item is likely to be cheaper purchased over the counter rather than on prescription, so it is always worth enquiring.

Linda Avery

1989 BUDGET CHANGES

ASSISTANCE FOR DRIVERS

More disabled people will be able to hire cars at a lower initial cost since April 1989, as cars leased to disabled people have been relieved of car tax.

During a visit to the Department of Transport's Mobility Advice and Vehicle Information Service (MAVIS) in Berkshire, Mr Nicholas Scott MP, Minister for the Disabled, predicted that up to 30,000 disabled people will benefit from this change which was announced in the Budget. It will mean an overall saving of about £400 on each car leased to a disabled person at a cost of about £10 million a year.

Motability, the charity established to help disabled people obtain cars on favourable terms, also welcomed the change. "The demand for Motability cars is ever increasing and without question this measure will help enhance mobility for people with disabilities, particularly those with very limited resources."

MAVIS was set up at the end of 1985 to provide advice and assessment on driving and car choice for disabled people and to give information on a wide range of transport and mobility problems.

Motability is a joint venture between Government and the private sector. Over 60,000 disabled people are currently obtaining vehicles by hire purchase or lease through the scheme. The Government has recently contributed £5 million to a special Motability 10th Anniversary Trust, which has been matched by a further £5 million from the clearing banks.

Cars leased to disabled people are already relieved of VAT. Since April 1st 1989, cars leased to disabled people are relieved of car tax provided:-

- * the car is leased for no less than three years;
- * the disabled person receives mobility allowance or war pensioners' mobility supplement; and
- * the lessor's business consists mainly of providing cars to such people.

If you need further details from either of the organisations mentioned above, write to :-

Motability
2nd Floor, Gate House
The High,
Harlow, Essex CM220 1HR

or

TRRL (MAVIS)
Crowthorne,
Berkshire RG11 6AU

VAT - ZERO RATED

RELIEF AT LAST

Amongst other announcements made in the Budget, VAT zero rate reliefs for charities - and certain other bodies - have been extended with effect from 1st April 1989.

Items covered include autoclaves and other sterilising equipment for use in medical research, diagnosis and treatment when purchased with charitable or donated funds and supplied to non-profit making eligible bodies.

The extension will also cover advertising published by a charity for educational or fund raising purposes in newspaper classified columns, programmes, annuals, leaflets, brochures, pamphlets and similar publications and on posters.

(Note that non-classified advertising in newspapers, periodicals and journals is already zero rated.)

FUND RAISING

The exemption for fund raising events covers goods and services supplied in connection with a one-off fund raising event such as a bazaar, ball or gala show. This applies where the supplies are made by one or more charities, providing the funds raised will be used for charitable purposes.

Certain other bodies, such as trade unions and professional and other associations, as well as non-profit making organisations of a political, religious, philanthropic, philosophical or patriotic nature, will also benefit from the extension, providing the event in question is held exclusively for that body's benefit.

The campaign for continued development of new VAT exemptions for charities in particular has been an annual pre-occupation of most charitable bodies at Budget time. These latest extensions are a further chipping away of the VAT block and are to be welcomed.

HRH THE DUCHESS OF YORK ACKNOWLEDGES RESEARCH

The Duchess of York recently met a young member of an Icelandic family who is helping British scientists in a unique medical research project.



The Duchess of York with Orn Omarsson

As President of the charity Action Research for the Crippled Child, The Duchess opened a new laboratory at Queen Charlotte's Hospital, London, which is conducting research into the genetic factors causing spina bifida.

She was introduced to 21 year-old Orn Omarsson, who has a rare form of spina bifida. He was flown over from the Icelandic capital of Reykjavik to meet her. Although he has been confined to a wheelchair since childhood, Orn - who is known to the research team as Ernie - plays table tennis and is also an accomplished pianist, singer and linguist.

In the year of his birth, seven other Icelandic children were born with the same condition. They have all since died. 'Ernie' has told doctors at Queen Charlotte's Hospital that he believes his survival was meant to contribute to their research.

Supported by grants including money from the Association for Spina Bifida and Hydrocephalus, Action Research for the Crippled Child and other charities, the research team is believed to be the only one in the world studying what is known as an X-linked spina bifida disorder.

Over 50 members of Mr Omarsson's family have given blood samples to help the British research. The scientists chose Iceland because it has a small population (approximately 200,000), keeps records of all its families and because its people tend to remain in the country - which makes it easier to trace a complete 'pedigree' or family tree. The Duchess saw how the researchers are using a sample of Ernie's own blood to seek the genetic origins of his disorder. She was also shown his family tree, tracing how he inherited the problem.

Thirty-third Scientific Meeting at St John's College, The University of Cambridge

The Society for Research into Hydrocephalus and Spina Bifida will be holding its thirty-third Scientific Meeting at St John's College, The University of Cambridge between the 12th and 15th July 1989. The Society for Research into Hydrocephalus and Spina Bifida was established in 1957 and has always recognised the wide variety of professionals concerned with spina bifida and hydrocephalus in its membership. Psychologists, educationalists, nurses and therapists, as well as physicians, surgeons and scientists make up more than 300 strong membership drawn from all over the world. Recently some parents have been elected to membership.

Miss Moyna P Gilbertson, Executive Director of ASBAH was appointed President of the Research Society last year and The Association for Spina Bifida and Hydrocephalus is pleased to be involved in hosting this international meeting. This is the first time that the post of President has been held by a 'non medical professional' and indicates recognition for The Association for Spina Bifida and Hydrocephalus.

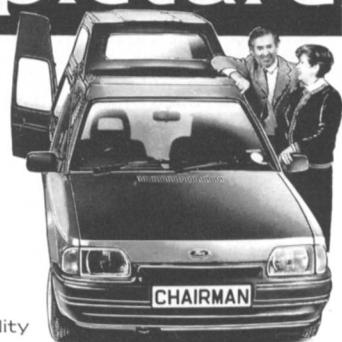
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ULCERATION OF THE LOWER BACK

by Douglas D McGeorge F.R.C.S.
Regional Paediatric Plastic Surgery Unit
Alder Hey Children's Hospital, Liverpool.

PRESSURE ULCERATION OF THE LOWER BACK

Pressure ulceration is a disastrous complication of immobilisation. It results from prolonged pressure, interfering with tissue perfusion, leading to tissue ischaemia and necrosis. Contamination with moisture, urine and faeces compounds the problem as does infection and malnutrition.

Most pressure ulcers are preventable. In the early stages they can be managed conservatively by strict skin care but once established treatment is usually difficult and prolonged. The morbidity and cost is enormous.

Much has been written on the prevention and care of pressure sores. Essentially this consists of relieving pressure and improving the environment for wound healing. Whilst small ulcers may be expected to heal, larger ones will require surgery with flap cover.

The principles are well established.

1. Removal of the ulcer with surrounding rim of normal tissue
2. Removal of the underlying bony prominence
3. Closure of the defect with a well vascularised flap.

Over recent years the number of flaps available has increased enormously with a better understanding of vascular anatomy. Whatever flap is used, reconstruction should allow primary repair under a minimum of tension. Suture lines should be sited away from the defect and where possible the donor site should close primarily. Ideally the techniques should allow the possibility of further reconstruction in the event of failure.

One area which has caused particular difficulty is the closure of defects over the lower back. Traditional surgical procedures are less than optimal and as a result many patients with defects over the lower spine spend many years, with repeated hospital admissions, living with the problem of chronic ulceration.

We have used five reverse latissimus dorsi flaps in four patients. One flap was used to cover a pressure sore over a kyphosis, three used to cover wound breakdown with exposure of metal work after spinal stabilisation and one to cover a persistent CSF leak following surgery and radiotherapy to a spina tumour.



Reverse latissimus dorsi flap

Currently, perhaps, the most versatile flap available is based on the latissimus dorsi muscle raised alone or with its overlying skin. The muscle is usually raised on its dominant superior vascular pedicle, the thoraco-dorsal vessels, but it also receives a secondary segmental blood supply based on perforating branches of the intercostal and lumbar arteries.

Apart from some minimal loss of skin grafts used to line raw edges on two flaps, wound healing was uneventful. Despite protracted pre-operative courses all patients remain healed between two and four years following surgery.

Reconstruction using the reverse latissimus dorsi flap has proved reliable and extremely useful in covering the lower back. Its blood supply enters away from the defects and therefore reconstruction is safe even when previous surgery has been performed. Because of this excellent blood supply, provided proper debridement is carried out, surgery can be performed without the need to remove implants.

Although many patients presenting with lower spinal defects are dependent upon good upper limb function, the deficit following surgery is slight. Only the lower part of the latissimus dorsi muscle is removed and this is rapidly compensated for by hypertrophy of the upper part.

The treatment of pressure ulceration involves a multidisciplinary approach. Although an outsider in the day-to-day care of these patients, the plastic surgeon has much to offer in the treatment of long term problems. Prevention is certainly better than cure, but reconstruction should allow these patients an improved quality of life.

'To a Different Drumbeat'

'To a different Drumbeat' is a new book, written by three women whose experience of parenting children with special needs spans from here to America. The book, published by Hawthorn Press, not only offers a wide knowledge gained through personal experience, but also tries to give practical advice.

37 years old Jenni Lauroul is one of the authors. She is the mother of three disabled children. With Parkinsons Disease and cleft palate in her own family tree, and spina bifida X-linked in her husband's genetic make-up, they see the birth of their children in spiritual terms. Jenni is adamant that she intuitively knew before her children were born that they were going to be disabled, although none of the scans proved conclusive.

Marie is now 7 years old and has Dandy-Walker Syndrome, which means a congenital malformation of the 4th ventricle of the brain. This blockage of cerebral fluid has left Marie with a form of hydrocephalus. As a baby Marie constantly stopped breathing and five or six times, Jenni and Jacques, her husband, found themselves having to give mouth to mouth resuscitation. "At that time no one knew about cot death. It was terrible having constantly to watch your child to make sure that she was alright", Jenni explained. Patrick is now 6 years of age. He has a cleft palate and a hearing loss. Daniel is only 4 years of age. His condition is medically undiagnosed, although it is apparent that his motor ability has been delayed, as he is just starting to walk.

"anger and guilt"

Jenni talks frankly about her own emotions of disappointment, feelings of anger and guilt. When Marie was born she had to look deep inside herself to fight off depression.

"It felt as if all choice had been taken away from our lives, we had been given a burden to bear, but that was not the case. We then realised that we could choose to 'cope - to survive'. We have learnt through our children, they have taken us down paths we would never have trodden," Jenni states proudly.

"Guilt is an emotion we can all equate with. However, it is difficult to verbalise one's disappointment at giving birth to a child who does not look normal, who is not going to keep up with the neighbour's offspring, or hold down a job in society. I also grieved about the loss of a relationship I had been looking forward to - the mother / daughter friendship we all dream about. Of being able to share a laugh as two adult women - that is not to say that we do not have a special relationship which will go on developing," Jenni points out.

"Why me ?"

Anger also had to be addressed "Why me ?" is a question which can evoke a great deal of reaction.

In fact Jenni, like many Americans, is adamant that there is a time and place for counselling.

counselling

"Seek help if you cannot contain your emotions. You can't expect friends to act as therapists. That is a sure way of losing them. If you want the friendship of others, you have to be prepared to offer something in return. Once

there is a disabled child in the family, it is all too easy to think that you are the centre of the world . It is alright to seek counselling, to offload onto someone else in order to take the pain away", she philosophises.

marriage

Marriage is another area the book explores. Jenni considers that she has been very fortunate that Jacques, a Frenchman by birth, is not a traditional husband and has been pleased to lend a hand in the home. However, they have had to work at their relationship. They married in France where she was a teacher at a Steiner school and he was the resident cook. Their colleagues were most supportive when Marie was born as were their respective families. Without the close family support both financially and morally, their story might have had a different ending. "We budgeted for baby-sitters and managed to get occasional weekend breaks. We regularly talked about our



The Lauroul family - (left to right) Jenni, Patrick, Daniel and husband Jacques with Marie

"If a man does not keep pace with his companions, perhaps it is because he hears a different drummer. Let him step to the music he hears, however measured or far away"

H D Thoreau.

marriage, analysed it and gave ourselves time together" she confesses.

practical advice

'To a Different Drumbeat' also offers practical advice. The kind of hints our grandparents might have passed on but modern times have helped us to forget. A warm bath before bed-time, warm feet and hands, lying on a sheep-skin rug are all sleep inducive. Make sure your child is comfortable, talk to the physiotherapist to find the best position for rest periods.

routines

Jenni is also quick to point out that parents should look at the routine they are offering a child in order to make sure that there are tranquil periods, as well as stimulating times in a day.

rhythm

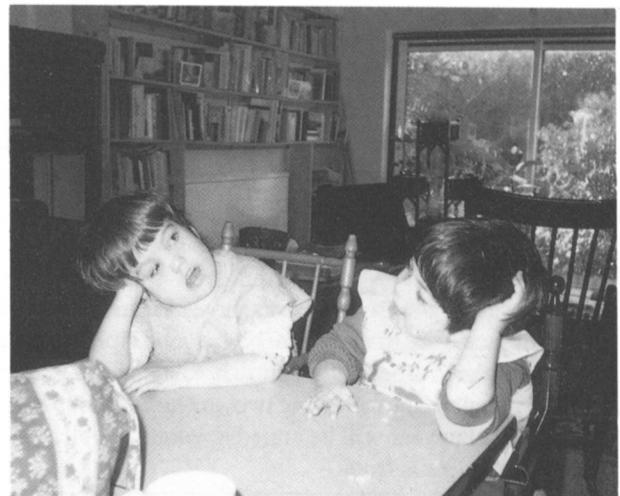
"It is too easy to blame behavioural problems on the child's disability instead of considering one's own standard of parenting," says Jenni. "A day should have a rhythm to it, singing and music are important. We should not expect children to fall asleep in front of the television, or with a loud poster hanging near their bed. Colour is important, so is atmosphere - perhaps my views are old fashioned," she laughs.

Jenni hopes that 'To a Different Drumbeat' will fill a gap in the market. There have been numerous books on bringing up children, whilst those on disability are usually written by professionals. Jenni sees herself as an advocate for women, and is sure that the book will raise a few eyebrows. At the same time it is hoped that it will give people courage.

hospital

Children in hospital is an area which needs to be approached with sensitivity.

"By all means be diplomatic with doctors or nurses, but remember that it is important for you to stay with your child and it is right for you to be your child's advocate. I could quote you hundreds of stories of doctors whose prognosis was worse than the outcome." she insists.



Marie and Daniel

intuition

Intuition is one of Jenni's favourite words and on several occasions it has allowed her to challenge the medical profession, when she has seen her children's condition deteriorate rapidly and she has known that treatment was required.

It is Jenni's strength and ability to persevere which has given her the courage to share her experience.

"I always take notes of my children's medical condition. I believe that I have a right to see their records and know as much as I can about their health. I have fought for social services and now receive home help. Do not rely on other people to help you - **help yourself.**"

help yourself

"If someone is not available when you telephone, phone them every day at the same time until you get through. Make sure that social workers make appointments. They expect us always to be at home, awaiting their visit. They do not realise that we also have appointments which have to be kept with doctors, physiotherapists and schools."

Some of Jennifer's ideas are radical, some indigestible, but many stimulate the mind, so that one is left balancing sadness with laughter, tiredness with achievement.

'To A Different Drumbeat' is available either from bookshops or direct from Hawthorn Press, Bankfield House, 13 Wallbridge, Stroud, Gloucestershire GL5 3JA price £7.95.

ASBAH APPOINTS COUNSELLORS

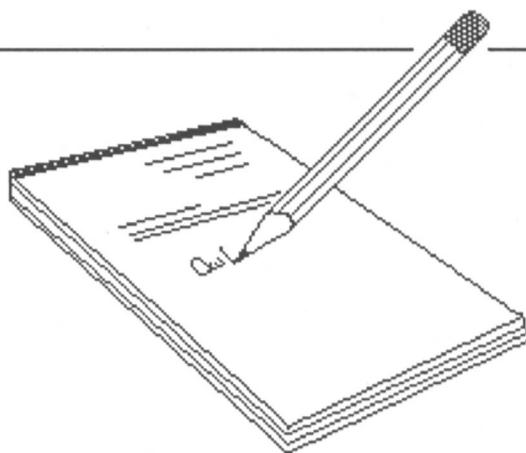
Due to the many requests received by ASBAH for counselling support, a team of part-time counsellors will be in post by the summer. The new appointments will be based in Shropshire, Yorkshire, Kent and Lincolnshire. They will work closely with ASBAH'S team of Fieldworkers in order to offer further support to families.

COUNSELLING AND DISCUSSION DAYS

A series of counselling workshops organised by ASBAH will shortly be underway. The first one is planned for July 1st at the Prospect Day Centre in Reading and is intended for parents. The following two, in Durham and Newcastle later in the year will be aimed at young people.

Further details from:-

Teresa Cole, Fieldwork Manager,
ASBAH, 22 Upper Woburn Place,
London WC1 OEP.



If you enjoy sports, live in Somerset, have a disability and feel isolated because there are no sporting events in your area I would like to hear from you. I am trying to get in contact with school-leavers and upwards who would be interested in joining together to form a sports and social club interested in competing at a regional level. Please write to me with your views. I myself have spina bifida use a wheelchair and have competed in swimming and field events at both regional and national level.

Phil Stevens
The Albemarle Assembly Rooms
Albemarle Road
Taunton, Somerset TA1 2HL

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I was delighted to hear of the successful treatment of a shunt infection using antibiotics alone without removal of the shunt, reported in a letter by Mrs Trustcott of Oxford in the last issue of Link.

However, as she says, this is unusual. The symptoms of infection can often be made to disappear with such treatment, but usually this is temporary and they return later. This is because the infection itself is still present inside the shunt, requiring its removal. However, a few organisms which cause shunt infections less commonly can be eradicated using antibiotics alone. Unfortunately, at the moment we do not have any tests to see if the organisms causing a particular infection fall into this uncommon group, but we are doing research into this area at the moment.

Dr R Bayston

Senior Lecturer in Bacteriology

Bacteriologist to Department of Paediatric Surgery
Hon Bacteriologist, National Hospital for Nervous Diseases.

With Reference to January/February 1989 Link -
re:- intermittent catheterisation.

I was put into intermittent catheterisation when I was 15 months old. I am now 15 years old and catheterise myself five times a day.

Catheterising has to fit in with my school day.

I decided that morning break, lunchtime and once I got home were best. The school opened up an unused toilet for me.

I found the plastic catheters were best. They have never hurt me, although I do have feeling. I do not wet between catheterising but I wear a pad when I go out because I feel safer.

I have learnt to keep to regular times and not get constipated, otherwise, that leads to infection.

Catheterisation has helped me in many other aspects which I could not have done if I had had the diversion. This include swimming and going on holiday on my own.

Rachel Murray
Birmingham

I would like to pay tribute to Sue Gearing, Editor of LINK. There are few journals which have grown continuously not only in size but also in quality. What an excellent balance Sue has kept, too. She has never lost sight of those cheering success stories - so often missed from the main news media whilst never ignoring the realities of the multiple problems facing those who have spina bifida and hydrocephalus or the ethical problems which may confront those helping to care for them. All this was set against a broad background of solid, useful information.

Sue will certainly carry with her the good wishes of the many friends she has made in her long association with ASBAH.

Dennis Bryant,
Vice President, ASBAH



LONDON

The Greenwich and District Local Association have been given the opportunity of staging a fund-raising and information giving event in the Lewisham Shopping Centre from 26th June to the 1st July. They are looking for volunteers to help on the stand. If you are in the vicinity and have a few hours to spare, please contact Douglas Endersby, Chairman of the Local Association on 01 690 0342.

SOMERSET

18 year old Tracey Bolter from Yeovil in Somerset has just been presented with the Jack Hall Cup in respect of her "meritorious services to the YMCA as a young person". The trophy was awarded in respect of Tracey's voluntary help, her commitment and determination to the YMCA. It is Tracey's Senior Youth Worker, Heather Weetch who has watched her progress over the last year with delight. "When Tracey first came to the YMCA

she was accompanied and remained in her wheelchair due to her spina bifida. Today, she walks to meet us." Tracey has progressed from helping in the coffee bar to running the reception desk single-handed. Making bookings, handling money, answering phone calls have all brought her into contact with the public. Tracey has also recently gained her Duke of Edinburgh Bronze Award. "Tracey has taught me that we all have strengths and weaknesses and can learn so much from each other with the right opportunity, support, space and time," Heather concluded.



cup - winner Tracey

SUSSEX

The Hastings Branch of SASBAH are very concerned that their specially adapted caravan near Rye, is not being used by people with disabilities as holiday accommodation. Their Chairman Mr Borthwick, telephone 0424 51145 would like some marketing advice from fellow members of other Associations.

THE NATIONAL HEALTH SERVICE —

“Working for Patients”

According to The Right Honourable Mrs Thatcher MP, the “most far reaching” reforms ever seen by the State hospital and medical services were unveiled in the new Government White Paper “Working for Patients” published on the 31st January 1989.

The proposals contained in the document represent the most sweeping reforms attempted in the 40 year history of the National Health Service. They offer “new opportunities and pose new challenges for everyone concerned with the running of the service” she says, and “all the proposals put the needs of the patient first.”

The bulk of the proposals are the result of a year long review of the NHS. This was ordered by the Prime Minister following the crisis of December 1987. The changes are planned to come into effect by 1991.

extend patient's choice

Although the Prime Minister is on record as stating that the NHS “at its best is without equal”, she is clearly determined to carry through reforms which look to the future. “We aim to extend patient's choice, to delegate responsibility to where the services are provided and to secure the best value for money.”

proposals

The main proposals are varied in their methods and aims. Waiting times for operations should be reduced. Currently, although a patient may need an operation quickly, they are not necessarily treated as emergencies. So, for example, a patient needing hip replacement surgery, or the removal of a cataract, may have to wait a year or more before surgery is carried out.

The actual length of waiting times varies widely around the country, and the Government claims that extra expenditure of over £60m during the past two years has had the result that half of all waiting list patients are now admitted within 5 weeks or less. It is anticipated that once the new reforms are in place waiting times will be cut for all those on waiting lists.

travel for treatment

General Practitioners will eventually be able to refer their patients to hospitals outside their own districts in cases where waiting times elsewhere are known to be shorter, so that although the patient may have to travel further afield for treatment, the waiting time will be reduced. There are currently two major obstacles to this. Firstly, there is a lack of information. The new system aims to ensure that both hospitals and GPs will have up-to-date information about local and other waiting times.

Secondly, GPs currently have little scope for referring patients to hospitals outside their own districts because the receiving hospital may not have been allocated funding for out-of-district patients. In future however, large GP practices will be allocated their own budgets so that they can buy a range of services either direct from the NHS or from private sources. Thus the GP will be able to purchase the service needed for his/her patient from an out-of-district hospital.

appointments systems

Once in hospital, the White Paper says that at present the service provided on admission is sometimes too impersonal and inflexible. “This” the Paper says “is not what either the Government or those working in the

health service want to see.” Waits of two or three hours at out-patient clinics are unacceptable. All hospitals will therefore be expected to have better appointments systems so that patients can be seen more quickly.

results of tests

Patients should also be given more rapid notifications of results of diagnostic tests.

Other recommendations include the need for more sensitive explanations to be given to the patient about where to go, who to see, what exactly is happening and what the proposed treatment will entail.

In addition, hospitals will also be expected to provide optional extras for which patients can pay, such as single rooms, personal telephones, TVs, and a wider choice of meals. Further, the White Paper argues that hospitals should provide quiet, pleasant waiting areas with suitable facilities not only for parents with children but also for counselling worried parents or relatives.

As already mentioned, some GP practices will be allocated with their own budgets. Initially this will apply to about 1,000 of the largest practices in the UK who between them cover about a quarter of all patients. The average budget will be £650,000 a year. This is intended to cover the cost of out-patient services and day treatments such as hip replacements, cataract removals and hospital diagnostic tests.

Since urgent treatment must always be available to patients in all circumstances, the GP will be allowed to overspend his budget by up to 5% if there are good clinical reasons for doing so. However, any overspending will be recouped from the following year's budget, and overspends in excess of 5% for two years running,

— WHITE PAPER MAIN PROPOSALS

“at its best is without equal”

may mean the practice forfeiting the right to hold its own budget.

In all cases of persistent overspending, responsibility will be given to the Family Practitioner Committees to carry out a full audit.

GPs pay structures have also come under scrutiny. At the moment, “capitation fees,” ie the amount of income linked to the number of patients a doctor has on his or her list, forms about half of a doctor’s income. This is to be increased to 60%, thus encouraging GPs to increase the number of, and retain existing, patients. Patients themselves will have more freedom to “shop around” for GP’s, so that if they are dissatisfied with the service received from one doctor they can transfer to another with relative ease. In this way, any GP who increases the numbers on his/her list, at the expense of satisfactory service, may find numbers dwindling as dissatisfied patients transfer elsewhere.

special fees

GPs will also receive special fees if they can demonstrate that the majority of their patients have received the benefit of preventative medicine such as cervical cancer screening or childhood vaccinations. GPs will be entitled to advertise the different services their practices offer, so that prospective patients will have some clear idea of what is available.

The White Paper also introduces the concept of “quality control” for hospital doctors - this follows an investigation conducted last year which revealed striking differences in surgical success rates around the country. The performances of some 75,000 doctors will be analysed for the quality and effectiveness of their treatment of patients.

medical audits

The medical audit will apply to every hospital consultant, junior doctor and general practitioner.

The audit scheme is described by the White Paper as “a systematic, critical analysis of the quality of medical care, including the procedures used for diagnosis and treatment, the use of resources, and the resulting outcome for the patient.” The proposed scheme will be “a means of ensuring, through peer review of medical practice, that the quality of medical work meets acceptable standards.”

The audit will not just help to improve clinical practices which are considered below standard, but will also highlight surgeons who are particularly good at performing certain operations, and is therefore likely to lead to the formation of more specialist units.

One of the most controversial proposals in the document is to encourage as many hospitals as possible to become self-governing whilst remaining within the NHS. Most of the 320 acute hospitals which have more than 250 beds will be eligible to “opt out” and become the new self-governing NHS Hospital Trusts. These hospitals will have to guarantee that essential services will be provided, but they will be free to earn their revenue by selling their services to GPs who have their own NHS budgets, private patients, private hospitals, employers and other NHS Hospital Trusts.

They will be free to employ their own staff, including consultants, and set their own rates of pay, at the local market rate. Junior doctors posts will however, still need approval from the Royal College for training purposes.

The White Paper argues that hospitals will be able to finance improved and expanded services because the money will flow to where the patients are going, thus “hospitals which prove more popular with GPs and patients will attract a larger share of NHS and other resources available for hospital services.”

Buying and selling of services will be carried out on a contract basis and any hospital which fails to meet the terms of a contract will risk losing patients and revenue. The Secretary of State will have powers to oversee the workings of the Trust and will be able to prevent any Trust, with anything near to a local monopoly of service provisions, from exploiting its position for example by charging unreasonably high prices for its services.

Other proposals will affect the management and structure of the NHS, as well as tightening control over the work of consultants.

insurance tax relief

Finally, the White Paper envisages greater private sector involvement and introduces tax relief on private health insurance premiums for those over 60. This will be sanctioned in next year’s Budget, and will apply even if the patient’s premium is paid by another member of the family.

For those who are concerned that medical services will be taken beyond their reach, take heart from the declaration that “The Government will keep all that is best in the NHS. The principles that have guided it for the last 40 years will continue to guide it into the 21st century. The NHS is, and will continue to be, open to all, regardless of income, and financed mainly out of general taxation.”

Linda Avery

Dream comes true

Josie Cichockyl is a vibrant 24 year old. This year her dream came true.
"I won the London Marathon in the women's wheelchair section"

"It took me 3 hours, 3 minutes and 55 seconds", she laughs. "I felt that I was doing it not only for my family - six sisters and three brothers - but for every disabled person."

Josie is convinced that the party atmosphere created through the London Marathon does a lot to improve relations between able-bodied and disabled people. "I train in the same way as any athlete does, so why not get the recognition for it ?" she asks.

Every day, Josie finds a minimum of three hours to undertake a 7 mile wheelchair push around her local park in Huddersfield. Sometimes, her emphasis is on speed, at other times on stamina, while weight training to keep herself as flexible as possible is important.

One of her greatest achievements was attendance at the International Paralympics in Seoul with the Great Britain Basketball Women's Team, of which Josie is Captain. "I really felt proud to be British at the opening ceremony. It was also an historic moment, as it was the first time that the Women's Basketball Team had been to the Olympics" she stated.

It is hard to imagine, when listening to Josie enthuse about the world of sport, that she hated PE classes at school and never took part in physical activity. "Because I have spina bifida and am in a wheelchair, the teachers tended to ignore me" she explains.

In fact, although Josie went to an integrated school, she felt quite cut off in the evenings and it was only when, at the age of 14, she ventured to a local sports club that doors opened, and isolation became a past complaint.

"In those days I used to swim or play table tennis. It was a way of keeping fit" she insists.

It was at an open day at a local club called SPEN, in Cleckheaton, Yorkshire, where she asked a young man whether she might just try out his racing wheelchair, that she was spotted by a coach.

A few weeks later Josie was to win the 100 metres at the National Athletic Championships.

Josie's philosophy is sound:

"If you have a natural ability to achieve at something in life, you should not waste it. Sport changed my life - it made me more confident, more independent. Too many disabled people take a back seat. It is up to people like myself, with spina bifida, to make sure that we mingle with able-bodied people. Nowadays people ask me to do things which I know I could never achieve, but it is because they forget that I am in a chair - they just see my personality which overcomes my disability."

At present Josie coaches a group of able-bodied juniors at a Youth Club. "I believe that I have a lot to offer them, even if I don't know all the foot positions" she smiles. "I am like their hero, I inspire them."

Josie is very keen to make disabled people aware that the world of sport is open to them. Her love of writing and enthusiasm for basketball have led to her becoming Sports Editor for Getting Around Magazine.

"I believe that I have a great deal of knowledge about sport and I would

like to motivate other young people. Get out there, enjoy it, have fun," she shouts.

"Through the National Sports Association young people can be put in contact with their local club. Most of them have racing chairs.

If you are like me you will not only join a disabled club but also one that caters for able-bodied people. If we don't go out there and join in, no-one is going to ask us" she concludes.

MINISTER FOR SPORT,
Mr Colin Moynahan MP, attended a sports conference on 26th April, which was aimed at sportsmen and women with disabilities. In the Minister's speech he pledged half a million pounds to a new fund to provide for sport for the disabled. There are to be grants for individuals, training, equipment, governing bodies, as well as for spectators who wish to watch sport. It is hoped that matching private sponsorship will be forthcoming.

SPORTING CHANCE

Three young men with spina bifida - Ian Laker, Jamie Gilham and Steve Brown - who have been using wheelchairs all their lives, both for getting around and for sport, have started their own business. They aim to provide good second-hand wheelchairs which they are prepared to service, supply and fit parts, as well as pick up and deliver around the Hounslow area in London.

GBL Services is at
100 Midsummer Avenue, Hounslow,
Middlesex TW4 5BB.

Mobility Week

The Association for Spina Bifida and Hydrocephalus is holding a Mobility Week between the 3rd and 8th July at Stoke Mandeville Olympic Village.

The emphasis of the week will be on mobility - hence the name - and will include wheeling, walking, driving and using public transport. There will also be other sessions providing information, advice and counselling. During the evenings there will be opportunities for participating in different sports. These will include swimming, table tennis, archery, shooting, bowls, snooker and basketball. Alternatively youngsters can simply watch television, chat to friends and compare notes.

No local education authority, disability organisation or similar body offers as varied or comprehensive a course. Whilst aiming to be a catalyst in the development of the 'whole' person it will target mobility as the main stimulus.

To participate fully in life, everyone must move, be it for health, work or social reasons. Mobility is the 'key' for everyone and it dictates how wide a circle you travel in. For the disabled, the inability to move, or inaccessibility to buildings, governs their lives. The ability to cope or manage various obstacles can be a major factor in an individual's development. Every form of mobility requires a person to learn certain skills.

Be the method of mobility feet, crutches, wheelchairs, cars or public transport, each has positive and negative aspects. These are determined by an individual's knowledge and understanding of the skills needed for each task. The confidence, motivation and approach taken to solve each and any problem can be termed 'skills for life'.

Most people learn by trial and error or from their peers and parents. The disabled may be denied this by over caring and a lack of social contact.

The week will not just aim at wheelchair mobility but will encapsulate other subjects such as incontinence management, fashion and self-awareness. It aims, by covering such a variety of topics, to be able to offer personal attention and to equip people with the experience and confidence to meet the challenges of daily living. Although the week will be hard work, it is hoped that it will be full of fun and excitement.

The cost of the week is £75 which will cover full board and lodging.

For further information contact John Naude or Ian Laker, Disabled Living Advisors at ASBAH's London office.

NEW INITIATIVES FOR PEOPLE WITH SIGHT AND HEARING PROBLEMS

"Access Around London for Disabled People", a leaflet produced by London Regional Transport's Unit for Disabled Passengers, is now available in a cassette tape version for the benefit of people with visual handicaps. And a special notepad has been introduced to help speech- or hearing-impaired enquirers at LRT's Travel Information Centres.

Produced in conjunction with the National Tape Magazine for the Blind, the "Access" tape describes wheelchair-accessible services such as the Docklands Light Railway, AIRBUS to Heathrow, the Carelink service linking London's main-line railway stations, and suburban Mobility Bus routes for local shopping and social trips. It lists other LRT facilities for people with mobility, sight, hearing and other disabilities, and refers the listener to other free publications and cassettes.

The new cassette tapes - and the original leaflet on which it is based - are available, free of charge, from the Unit for Disabled Passengers, London Regional Transport, 55 Broadway, London SW1H OBD.

The notepads are displayed at all the Travel Information Centres and are readily available for use.



A change for the better!

Next time you're travelling across London and need to get from one Main Line terminal to another, try Carelink. It's an hourly door-to-door bus service between stations with cheerful little red and yellow buses. They're wheelchair-accessible and they've got friendly, patient drivers.

Carelink is especially for people who find ordinary buses or the Underground difficult to manage (you might be carrying luggage, for example). And at Victoria and Euston, Carelink becomes an air link, meeting up with the frequent Airbus services to and from Heathrow. These buses, too, are now wheelchair-accessible.

For more information about these and other special facilities on London's buses, Underground and Docklands Light Railway, call London Transport's Unit for Disabled Passengers on 01-222 5600 Or write to the Unit at 55 Broadway, London SW1H OBD.



APPEAL REPORT

For two consecutive years Fiat Motor Sales in London have entered the Beaujolais Challenge.

This entailed recording the shortest mileage between Le Cusage de Beaujolais and Calais whilst collecting the first bottles of the famous young red wine. The event is organised by the British Automobile Racing Club in aid of ASBAH. A cheque for £6,700 was presented by Tony Blackburn on behalf of Fiat Motor Sales to Miss Moyna P Gilbertson, Executive Director of ASBAH together with Mrs Jennie Whiting their newly appointed Appeals Director.

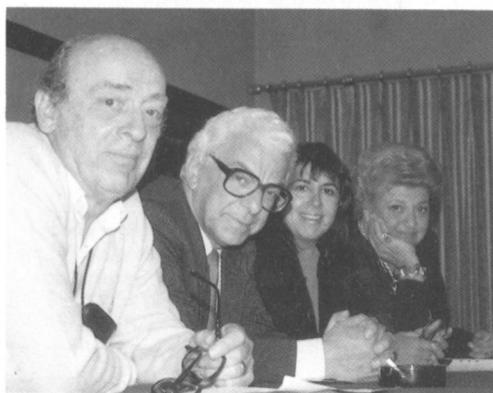


Tony Blackburn on behalf of Fiat Motor Sales presenting cheque for £6,700 to Miss Moyna P Gilbertson, Executive Director of ASBAH with Mrs Jennie Whiting centre.



Nancy Price wins competition and a trip in a hot air balloon.

*below
this year's panel of celebrity judges were John Junkin,
Barry Cryer, Jeni Barnett and Claire Rayner.*



HOT - AIR WEEKEND

The Competition to find the 1989 Conversationalist of the Year was held again at the Glaziers Hall in London on the 13th and 14th May. Some 3 dozen contestants were invited to converse intelligently on given subjects. Judges awarded points for humour, sticking to the chosen subject and clarity of discussion.

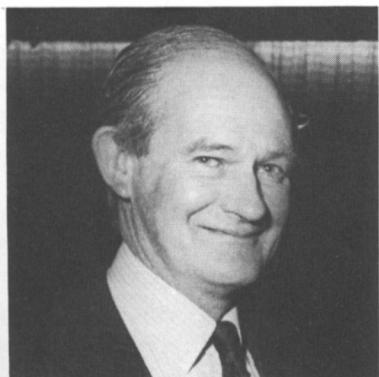
BBC RADIO

On Sunday 30th April ASBAH was the chosen charity for The Week's Good Cause. Sue MacGregor of BBC Radio 4's Today Programme made the appeal on behalf of the organisation

The SUN SWEAR BOX COMPETITION was launched on April 24th. The SUN are targeting £1,000,000 to be raised by Christmas to be devoted equally between five charities. ASBAH has been chosen, together with the NSPCC, Leukaemia Research, Action Research for the Crippled Child and Barnardos. People interested in trying to cure the **** habit of swearing, and those who just enter for the fun of it, are being invited to send for a Sun Swear Box for their pub, shop, home or office. There will be prizes, with a Ford Fiesta as the major prize for the individual raising the most money.



Appeals director Douglas Jack retires



Douglas Jack Appeals Director

After a career in commerce, Douglas spent a year as Appeals Director of an Enterprise Development Agency before joining ASBAH as Commercial, Industrial and Trusts Fundraiser in August 1983, and took us successfully into this previously unexplored territory. He became Appeals Director at the end of 1985 and when last year, the future plans for locating the central office were uncertain and his retirement was looming, he most generously agreed to defer the date for one year. Now the time has come to say goodbye to Douglas and it is a sad moment for all of us. Not only has he been a successful Appeals Director but he has been a marvellous colleague. He combines business acumen with wisdom and gentleness, he is always courteous and helpful. One of his original referees described him as a "thoroughly nice person" - all of us at ASBAH heartily endorse this view.

Douglas will be visiting his family in Australia in the near future. We all wish him a wonderful visit and many years of happy retirement with lots of contact with us.

Moyna P Gilbertson
Executive Director

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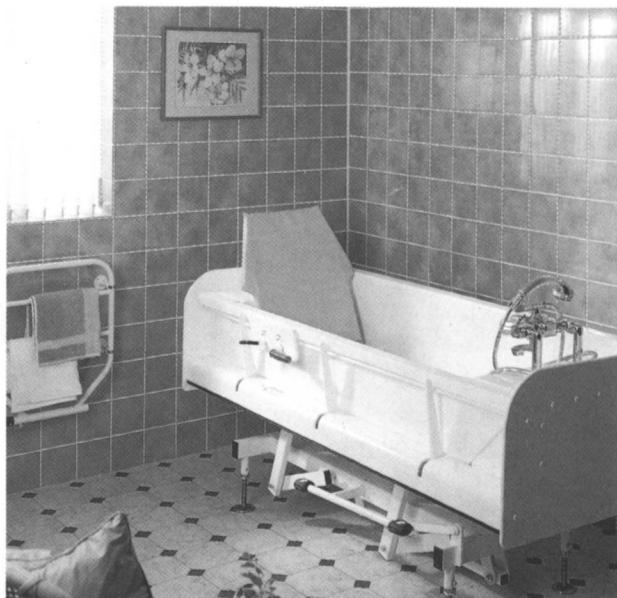
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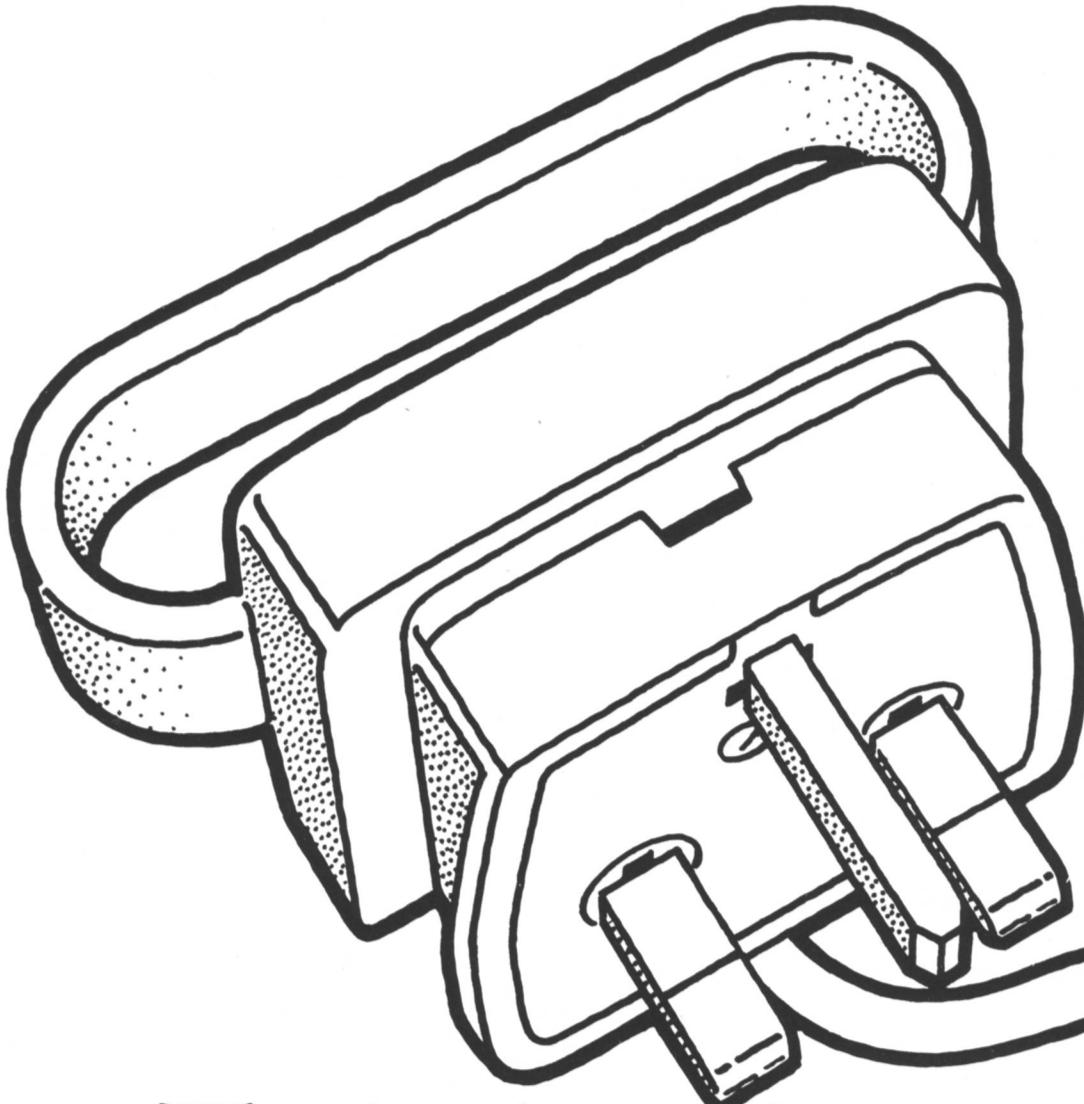
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