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The magazine for people with spina bifida or hydrocephalus

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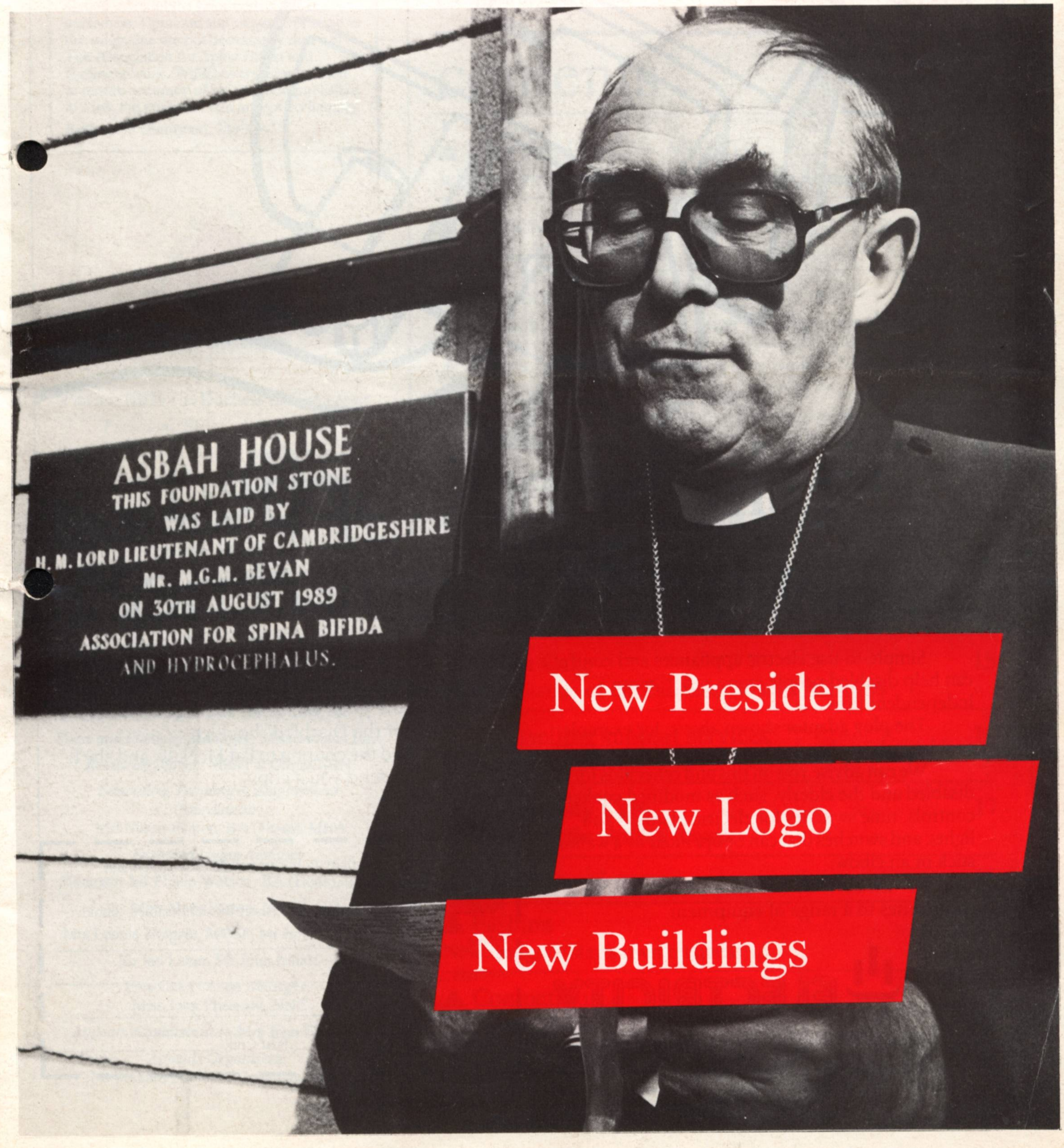
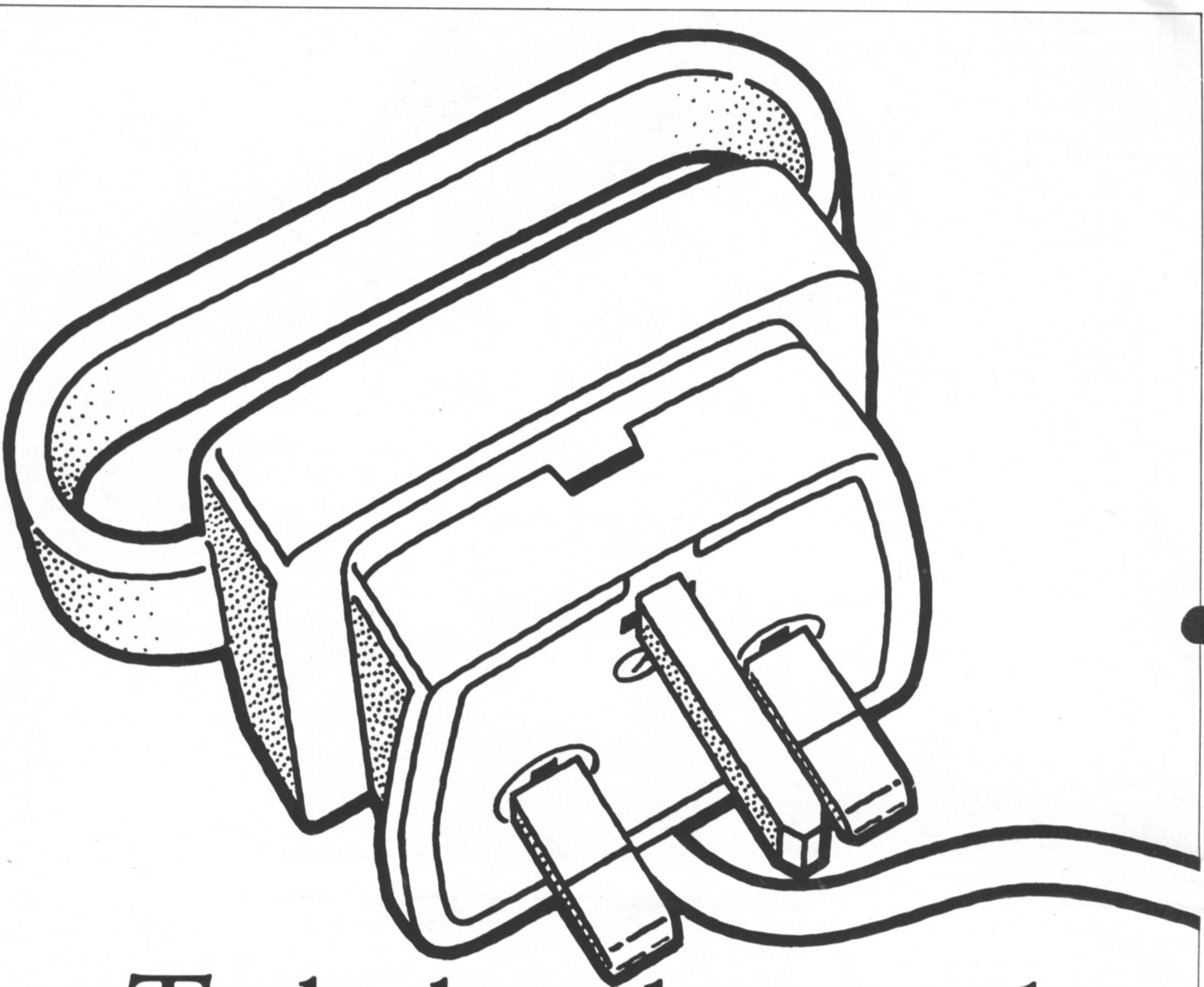


New President

New Logo

New Buildings



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OCTOBER-NOVEMBER 1989 ISSUE NUMBER 124

Cover Picture: The Foundation Stone of ASBAH receiving the blessing from The Bishop of Peterborough, The Right Reverend William Westwood. Photograph by Chris Morton.

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The magazine for people with spina bifida and hydrocephalus
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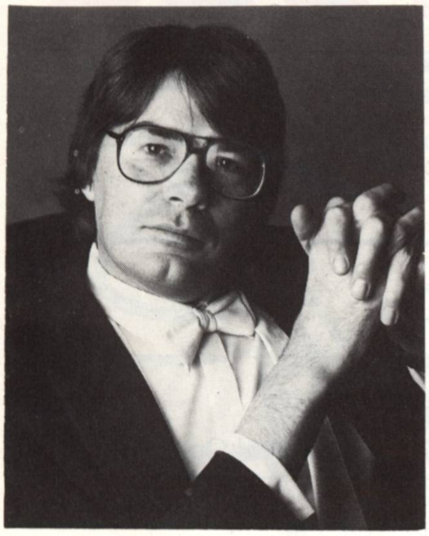
New President for ASBAH



Jeffrey Tate
Principal Conductor of The Royal Opera House

The Association for Spina Bifida and Hydrocephalus is proud to announce that Jeffrey Tate, Principal Conductor of the Royal Opera House has accepted an invitation to become their President. This appointment was announced at the Annual General Meeting of ASBAH on 7th October.

"This post means a lot to me personally as I have spina bifida" explains Jeffrey Tate. His successful career takes him around the world having become the first ever Resident Conductor of the English Chamber Orchestra and the first ever Principal Conductor of the Royal Opera House. "This does not leave much time to get involved with an organisation like ASBAH. I am sure that I will get asked to do fundraising activities, like a Charity concert. On the other hand I very much look forward to talking and listening to young people who have had similar experiences to myself.

"I am not a formal person. My authority begins and ends on the podium. As President of ASBAH I hope that I can give something back to people who supported me in my youth. The Association for Spina Bifida and Hydrocephalus fulfils a remarkable role and I am proud to be associated with them" Jeffrey Tate said.

He was a doctor first and then came later to music, virtually as an amateur. "My parents were terribly worried that I might not become a self-sufficient human-being and therefore pushed me into the medical profession. You have to come to terms with your problems in life, weigh up your strengths and persevere to succeed. I would hate to be viewed as a hero. I have had my own doubts and problems but I believe that I have come to terms with my disability and therefore look forward to the opportunity of sharing with others."

Jeffrey Tate's appointment as President comes at a time when Sir Hugh Rossi MP has finished his term of office. Sir Hugh Rossi has always been interested in the work of ASBAH. He was Minister for the Disabled during the International Year of the Disabled People when ASBAH won first place and an award for their Independence Training for young people.

New Image for ASBAH

A great deal of thought, time and effort has been spent over the last few months in raising the profile of the Association for Spina Bifida and Hydrocephalus. This work culminated in the launch of a new corporate logo at the Annual General Meeting of ASBAH On 7th October.

The change of colour was chosen to heighten awareness. It is hoped that the new logo will symbolize the two disabilities that ASBAH represents. The double band around the circle illustrates hydrocephalus and the column represents spina bifida. The hands appeal outstretched. In its entirety the logo should be seen as a winning post, with an ultimate goal for people with spina bifida and hydrocephalus to lead a fulfilled life.

ASSOCIATION FOR SPINA BIFIDA AND
HYDROCEPHALUS

Finding strength in adversity on a trip out of the spiral cage

*When **Al Davison** was born with spina bifida, the doctor noted that he was a "hopeless case". The doctor's report continued: "His parents are adamant, however, to proceed, no matter what, against my advice. So we must do what we can..."*

Now, 29 years and 21 operations later, Davison is a martial arts expert, a practising Buddhist and may be on the verge of a successful writing and drawing career, with a remarkable semi-autobiographical comic book, *The Spiral Cage*, due to be published next spring.

Born on Tyneside, he spent the first two years of his life in almost total isolation. His only experience of his mother was a rubber-gloved hand touching him through the bars of his cot, her strained, masked face hovering overhead.

The doctors said that even if he survived, he would never walk, but his mother was determined. During those early years she carried him everywhere. She lost more than three stone, and still her efforts seemed as hopeless as the doctors had warned.

The first breakthrough came after about four years. Al was playing with the other children while his mother talked, yet again, to the doctor. He pushed himself up to a standing position, using the wall as a support. "Mam, Mam!" he called. "In a minute pet", she said. "Won't be long". "But, look Mam". He took his first few faltering steps towards her. "Look, Mam! I can walk".

"I was so pleased with myself," he recalled last week. "But I couldn't understand why everyone was crying."

Davison lives in a small, two-roomed flat in one of the rougher parts of Newcastle. His flat is on the first floor, and he has to climb up and down the steep, winding stairs, painfully swinging one leg after the other. He is determined not to use crutches.

"I was so pleased with myself... but I couldn't understand why everyone was crying"

To start with, he went to a special school for disabled children. "That gave me a strange perspective on life", he says. "I thought that everyone was born disabled. All the children I knew had something wrong with them, so I thought that only adults could walk normally, and that that was something you learnt to do as you got older."

Although his book graphically portrays the grimness of his life, there is an underlying sense of joy and self-discovery running through it, with dry, northern humour. He was a happy child, with a habit of going into phone boxes to change into his Superman costume. The local police got used to being called to help when his wheelchair became stuck.

It was when he went to the local comprehensive school that he had his first brushes with cruelty and victimisation. "I suppose it was because I was different and they felt I was a threat", he says.

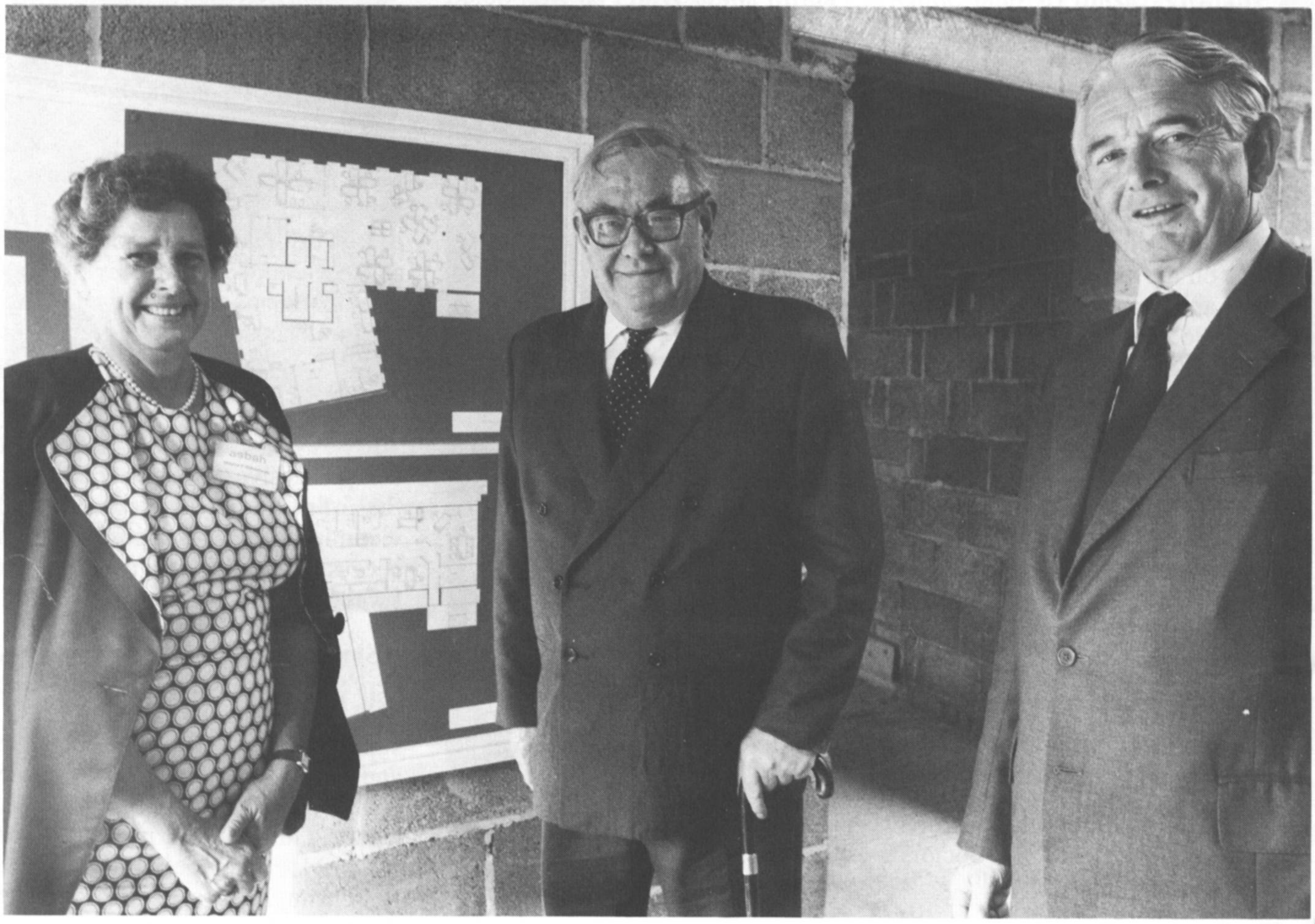
Since he was 18, apart from a not very successful term at art school, he has mainly lived on his own, supported by various disablement and training grants, as well as one from ASBAH, and gradually teaching himself to express his ideas in words and pictures. Through Buddhism, he says, he has cured the curvature of his spine, grown by more than two inches, and succeeded in dispensing with the wheelchair and other mobility aids.

All this he describes matter-of-factly. But what excites him is his belief that his attitude to life has undergone a slow transformation.

He now sees it as a journey, and any adversity as an obstacle to be overcome. He believes our lives are already mapped out for us before birth, and has used his book as a cathartic exercise, hoping that by reliving his life in graphic form, it will help him to find the key to the spiral cage of his own destiny.

By Gill Harley of The Sunday Times

ASBAH's new Headquarters in Peterborough



The Lord Lieutenant of Cambridge (Mr Bevan) *centre* accompanied by the Chairman of ASBAH, (Mr R R Mackenzie) and the Executive Director of ASBAH (Miss Moyna P Gilbertson)

The Foundation stone of the new headquarters of ASBAH was officially unveiled by The Lord Lieutenant of Cambridgeshire, Mr M G M Bevan on 30th August. The plaque had been generously donated by the builders Messrs F E Peacock and Son. The event was hosted by the Chairman of ASBAH, Mr Robin Mackenzie accompanied by Lady Jean Mackenzie. The stone was officially blessed by The Bishop of Peterborough, The Right Reverend William Westwood in the presence of Their Worships the Mayor and Mayoress of Peterborough, Councillor and Mrs Hedges. Also present was The High Sheriff of Cambridgeshire, Mr Odam and Mrs Odam, The Dean of Peterborough, The Very Reverend Randolph Wise and Dr Brian Mawhinney, MP.

***Right:* Mrs Bevan, wife of the Lord Lieutenant of Cambridge, receiving a bouquet from John Naude, Disabled Living Advisor, ASBAH**

Mrs Hedges, the Worshipful Mayoress of Peterborough, receiving a bouquet from Philip Watson, Disabled Living Advisor Manager, ASBAH

Mrs Odam, wife of the High Sheriff of Peterborough, receiving a bouquet from Mary Gilbert and her son, Ben, aged 4

Lady Jean Mackenzie, the Chairman's wife, receiving a bouquet from 5 year old Guiseppe Merola with the help of his mother

Following the ceremony ASBAH was officially welcomed to Peterborough at a Civic Reception given by The Lord Mayor. Peterborough, as the Lord Mayor stated in his speech, has become a national centre for charitable organisations. This sentiment was very much echoed by the warmth of the local community.

ASBAH hopes to move its headquarters to Peterborough early in 1990. The relocation is part of an overall commitment to providing better services to people with spina bifida and/or hydrocephalus. The brand new building which is being leased by ASBAH, is adapted to make it fully accessible to people with disabilities. Peterborough was chosen as a mid point in order to maintain good communication with Parliament and the media in London, whilst also being within easy reach of Five Oaks in West Yorkshire.

Photographs by Chris Morton.

Local Association News

London

The Lewisham Shopping Centre Public Awareness and Fundraising event in July organised by the Greenwich and District Branch was a great success and raised £2,766.26. Displays, song and dance with the involvement of children's bands and youth groups added to the spectacle along with balloons courtesy BOC.

Midland

Christopher Xifaroe, 15 years of age, and Richard Kilburn, 13 years of age, represented Great Britain in the World Wheelchair Games at Stoke Mandeville in July. Richard was the youngest member in the table-tennis team. Christopher won two gold medals in the swimming team. They both hope to be selected for future international events.

Life as a single father is not easy…

…neither is life after losing a child. Coping with both situations at once is very difficult, but possible.

In October 1985, my five-year-old son, Tristan, was admitted to hospital with hydrocephalus. At first, the diagnosis was vague. A form of brain tumour was suspected. However, all the CT scan showed was a lesion causing a narrowing at the end of the ventricles.

The death of a child is a very painful and totally bewildering experience for any parents, but I was alone. While Tristan was undergoing radiotherapy, I spent each day at the hospital with him. The other children in the ward had their mothers with them and for quite some time I felt the odd one out. Society is used to single mothers, not single fathers. I fell under scrutiny all the time. I worried constantly in case someone came to take the children from me.

During Tristan's treatment I travelled daily to the hospital (a 70-mile round trip) as I had two other sons of nine and seven at home. My loyalties were very much divided. Both boys knew their younger brother was unwell, but they were not aware he was going to die. The task of telling them had yet to come.

While Tristan was ill, working was very difficult. Fortunately, my employers were extremely supportive and understanding and I used to work at the weekends when Tristan was home. My social life, however, was non-existent, and my mind was constantly in a fog. Yet I felt as if the whole situation was somehow my fault, but I couldn't explain why I felt responsible.

When Tristan was first admitted to hospital with hydrocephalus, seven-year-old Vernon asked if Tristan could die, I answered yes. In fact, he was very concerned, and I found myself explaining what hydrocephalus was in terms that he could understand, and just what it was hoped a peritoneal shunt would achieve. As I recall, neither Gavin, my other son, nor Vernon asked any more questions after that initial explanation. Both visited Tristan in the Royal Preston Hospital and Christie's Hospital.

After the completion of radiotherapy, I felt that Tristan would not live until Easter. Call it a sixth sense, but I knew there was little hope.

"The other children in the ward had their mothers with them and for quite some time I felt the odd one out."

After a heart-searching Christmas, I decided to open 1986 in complete honesty. Gavin was nine years old and quite sensible for his age. I remember putting Tristan and Vernon to bed, as they shared a room, and allowed Gavin to stay up. Once I knew the others were asleep, I sat Gavin on my knee and began to talk about Tristan and his illness. Words just flowed out of my mouth, then the tears began to run down my cheeks, as I told Gavin that very soon Tristan would be going to stay with Jesus. I didn't need to say any more, we shared our tears together.

I remember asking Gavin not to say anything to Vernon and he didn't. I delayed telling Vernon until four days before Tristan died, by which time it was obvious that his death was imminent. I used a similar approach with Vernon as I had with Gavin. The language I used was more child-like, as Vernon was only seven years old, but again I told him that Tristan would soon be going to see Jesus. Vernon, like Gavin, responded with floods of tears. So did I. After a few minutes he wanted to go into the living room to see Tristan.

During Tristan's last three weeks of life, Gavin and Vernon went to stay with a friend of mine, and came to see Tristan every other day. Their last visit was on a Saturday evening. Tristan died the next morning.

I knew that during that day I would have to tell the children that Tristan had died. When I went to see them they asked, "Who is looking after Tristan, Dad," I replied simply, "Jesus". Silence was immediately followed by tears from all three of us. Our lives had finally been shattered.

I don't remember consciously deciding not to tell Tristan that he was dying. I did promise myself that I would not lie to him, but would answer questions as honestly as possible, in words that he could understand.

During a spell in Christie's Hospital, things Tristan said indicated he knew his fate. My father had died in 1968, and as a family we would visit his grave to place flowers on it. Tristan, like his brothers, referred to it as 'Grandad's grave', and he frequently asked if I would bury him near Grandad's grave when he died.

The help I received from medical and nursing staff during Tristan's illness was help that I requested. Perhaps because I am a nurse, I wanted to be the only one to look after him.

The day following Tristan's last CT scan, Bill (our GP and Tristan's godfather) and I realised that Tristan's life was nearing its end, and we decided that it was up to us to allow him to die with dignity. I decided that he would not develop pressure sores, conjunctivitis, thrush or any other problems associated with a terminally ill person. With the help of Bill, I succeeded.

I received visits from the nursing sister from the children's ward at Christie's Hospital, also their social worker. My own hospital kept me supplied with the necessary equipment to carry out my nursing of Tristan.

> **"I became very rational and non-emotional, but perhaps if I hadn't been a nurse I might not have survived this period"**

After almost three weeks of sleeping on the floor by the side of Tristan's bed, I reluctantly accepted help from a Macmillan nurse, who sat with him on alternate nights. The district nurses visited a few times but did not interfere with my routine. I also had two visits from the consultant paediatrician from the Royal Preston Hospital, who provided practical and, what appeared to be, unemotional advice.

My own parish vicar visited every day of the week. The hospital chaplains from my own hospital visited frequently. But what touched me most of all were the visits from the Roman Catholic priest whose church was next door to my house. Although I am not a Roman Catholic, the Father, who knew Tristan from when he played in the street, made frequent visits.

Being a nurse helped and still helps me. I found myself regarding Tristan as a patient when the situation began to hurt me. I discussed the progress of the tumour's growth with Bill, and pre-empted signs that would indicate the path of metastasis. But being a nurse deprived me of the feelings a parent should have for his dying son. I became very rational and non-emotional, but perhaps if I hadn't been a nurse I might not have survived this period.

During the last few days of Tristan's life, when only a miracle could have saved him, I began to become obsessed with his funeral arrangements. The poor child was barely alive, yet I had to make sure everything was just right for his funeral. I knew that I would not be able to encourage him through school or university, all I had left was his funeral. After his death I felt very guilty about these thoughts and plans.

So, Tristan's funeral was my final act for him. I am a piper in a local pipe band and, as Tristan loved the sound of the pipes, I asked one of my friends to pipe Tristan's coffin into church. The stirring sound brought tears to the eyes of the congregation.

The one aspect of his funeral which I was pleased to arrange was his final resting place, a plot adjacent to his grandad's grave.

In those months after Tristan's death I relived the previous five months both when awake and asleep. I couldn't bear to be at home. I would wander the streets alone aimlessly, just to get out of the house. I threw myself into any activity that would keep me out of the house where he died. I took a second job, joined a local drama group and began to study at night school. I felt alone. People sympathised with me, but I had no one to share my grief with, no one to help comfort the children at night.

Finally I moved house, only a few miles away, but I think that helped more than anything else. The children and I had a new beginning.

We have now experienced two anniversaries, two birthdays and two Christmases without Tristan. I have disposed of all Tristan's belongings, but in the bathroom his toothbrush remains. It is my last link with him. I'll probably never discard it. I was told that as the years passed I would forget the pain I experienced, but I'm still waiting.

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Bereavement Support Groups

- **CRUSE – Bereavement Care**, Cruse House, 126 Sheen Road, Richmond, Surrey TW9 1UR 01 940 4818. CRUSE helps in three ways: counselling, advice on practical issues and providing an opportunity for social contact. It also runs training courses for bereavement counsellors.
- **Still Birth and Neonatal Death Society**, 28 Portland Place, London W1 01 436 5881. SANDS offers friendship and support to parents who have experienced a still birth or neonatal death.
- **The Foundation for the Study of Infant Deaths** (Cot Death Research and Support), 15 Belgrave Square, London SW1X 9PS 01 235 1721. The Foundation gives support and information to parents bereaved by a sudden infant death.
- **Compassionate Friends**, 6 Denmark Street, Bristol, Avon BS1 5DQ 0272 2927798. An international organisation of bereaved parents, offering friendship and understanding to other bereaved parents.
- **Support after Termination for Abnormality,** 22-30 Soho Square, London W1V 6JB 01 439 6124.

Epilepsies: Spina Bifida and Hydrocephalus

*by **Ian McKinlay**, Paediatric Neurologist and Senior Lecturer in Community Child Health
Manchester University*

The brain is made up of about 4 million cylinders or brain cells known as modules. Each module contains 1000 to 3000 nerve cells, connected to about 500 modules on the same side and about 50 on the opposite side of the brain. Each nerve cell receives information from at least hundreds and often thousands of other nerve cells. It is the pattern and intensity of this information, carried as small electrical impulses along nerve fibres to the surface of the nerve cell, where the active fibre releases minute quantities of stimulating or inhibiting chemicals, which decide whether the cell should discharge or remain inactive. Such discharges can occur every thousandth of a second.

"All children with epilepsy should ensure that they avoid over-tiredness and take a good diet..."

Once a nerve cell has discharged (or depolarised) there is normally a recovery phase during which the cell is resting.

However in some psychiatric conditions and in epilepsy some nerve cells do not have a normal recovery phase. The nerve cells may discharge several times during what should be an inactive phase (known as paroxysmal depolarisation shift). When this happens within a group of nerve cells it interferes with the normal function of that part of the brain. If the activity spreads to other parts of the brain a more widespread disturbance of function occurs. For example an episode may start with discharge leading to a twitching thumb followed by hand, arm, leg and face. If it spreads to central parts of the brain this leads to unconsciousness. Such episodes commonly take the form of seizures (fits, convulsions, attacks, 'do's', turns). The symptoms and signs depend on the part of the brain in which the discharges occur. If seizures recur over a period of months or years the condition is usually described as epilepsy but if they occur within a few minutes, hours or days in the course of an acute illness this is not counted as epilepsy.

When seizures are provoked by high fever in infants and toddlers these are described as febrile convulsions, by convention, on the grounds that only 1:40 go on to have epilepsy after the age of 5.

Anybody could have a seizure under certain circumstances. For example a large dose of stimulant drug or an electric shock across the head (as is used in electro-convulsive therapy for some adults with depression) will produce one. In practice one child in 200 has one or other form of epilepsy. The risk of epilepsy is not equal for all children. Among the high risk groups are children with severe mental retardation or cerebral palsy where the risk is 1:3. Children with hydrocephalus have a 1:4 risk, increased to 1:3 if a shunt is inserted. Meningitis and ventriculitis increase the risk. About five per cent of children who have had serious head injuries go on to have epilepsy. Two per cent of children with Down's Syndrome have epilepsy. All of these conditions involve structural brain abnormalities. The risk reduces with age after puberty so only 1:10 adults with cerebral palsy and 1:30 adults with hydrocephalus have epilepsy. Why one person with hydrocephalus has epilepsy and another doesn't is not clear.

Ian McKinlay

"An episode can start with discharge leading to a twitching thumb followed by hand, arm, leg and face."

Not all blackouts and 'funny turns' are caused by epilepsy. Other causes include syncope (fainting), vertigo, breath-holding, nightmares and night terrors, and psychological events, including overbreathing with anxiety. Some epilepsies are the result of a reflex in special circumstances such as flicker or pattern sensitivity in the 5-15 year age range. One of the best ways of helping doctors to decide if episodes are the result of epilepsies is to record an accurate description of what happened and the circumstances in which they occurred.

The main test for epilepsy is the electro-encephalograph (EEG). The brain's electrical activity can be recorded from silver electrodes placed on the scalp in pads soaked in a salt solution (electrodes). The signals are weak and have to be amplified using quite expensive equipment. This is usually available in special centres with EEG laboratories and a recording will be made over 20 minutes or so with the patient sitting in a chair. Only 80 per cent of children with epilepsies will show abnormalities during the period of standard recording but the yield is improved if the patients take deep breaths for two or three minutes and if a flickering lamp or checked screen is used for part of the recording.

"If seizures are brief or infrequent and the child is under constant supervision at home and school it may not be necessary to give any treatment."

Another technique for bringing out abnormalities is to record during sleep. The child may be given a sedative before the recording or may have been deprived of sleep for part of the previous night. Sometimes several recordings are required before an abnormality is found.

New technology has allowed miniaturisation of the amplifier which can, like the electrodes, be glued to the scalp and connected to a battery driven tape recorder worn on a belt while the child moves about normally. This can be worn in the paediatric ward, at home or even at school (ambulatory monitoring). When the child has an 'attack', the nurse, teacher, or the parent can press an even marker button on the tape recorder. When the tape is run on a play-back machine it stops when 'events' occurred, allowing the reporter to study the brain-wave pattern in detail.

If seizures are brief or infrequent and the child is under constant supervision at home and school it may not be necessary to give any treatment. Also if seizures have ceased for a period of 2 years or more it may be justified to stop treatment. Otherwise medication is considered. The anticonvulsant drugs in most common use are carbamazepine (Tegretol) and sodium valproate (Epilim). For most children these cause few side effects though skin rashes, nightmares, changes in eating habits and alteration of hair texture can occur. Phenytoin (Epanutin) is a powerful anticonvulsant but can cause hairiness, swelling of the gums, coarsening of the facial features and, in higher doses, blurring of vision and unsteadiness. The other drugs used tend to have more sedative side effects or can cause hyperactivity. These include nitrazepam (Mogadon) clonazepam (Rivotril) phenobarbitone and primidone (Mysoline). They are all effective anticonvulsants in some children.

All children with epilepsy should ensure that they avoid over-tiredness and take a good diet (especially the vitamins folic acid and vitamin D as anticonvulsants can reduce their absorption or accelerate their breakdown in the body). Occasionally a special high fat (ketogenic) diet is used with a low carbohydrate intake as this can reduce seizures. Another treatment is to use high doses of Vitamin B6-pyridoxine. Very occasionally infants with severe seizures (infantile spasms) are given steroids (e.g. ACTH). Rectal diazepam (Stesolid) can be given as a 'mini-enema' to stop a prolonged seizure.

"Explanations for epilepsies and their treatments are important for parents and children if full co-operation is to be achieved."

It is better to use a single drug to its fullest capacity than to use mixtures of drugs if side-effects and drug-interactions are to be avoided. Some anticonvulsants speed up the rate of breakdown of others in the body, making them less effective. Others slow down the breakdown of second drugs increasing the risk of side effects. Anticonvulsants also interact with antibiotics, contraceptives and other drugs so specialist advice is required.

Explanations of epilepsies and their treatments are important for parents and children if full co-operation is to be achieved. It is too easy to discuss the problem with parents without engaging the child's interest. All too many adolescents with epilepsies have quite inadequate understanding of the problem or purpose of their treatment. The British Epilepsy Association provide helpful literature (New Wokingham Road, Wokingham, Berkshire, RG11 3AY).

Further Reading

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Five Oaks opening

From right to left: **Chairman of Five Oaks Management Committee (Miss Daphne Steel), Chairman of Ilkley Parish Council and husband (Cllr Ann Hawksworth and Mr Hawksworth), Chairman of ASBAH and wife (Mr Robin and Lady Jean Mackenzie), Deputy Lord Mayor of Bradford and Deputy Lady Mayoress (Cllr and Mrs Deryk Conquest)**
In the foreground: **The Countess of Swinton, Baroness Masham of Ilton**

Stephen Cooper entertaining The Countess of Swinton, Baroness Marsham of Ilton and the Deputy Lord Mayor of Bradford and Lady Mayoress in his Wharfedale flat

The two new buildings at Five Oaks – Denton View and Wharfedale – were officially opened by The Countess of Swinton, Baroness Masham of Ilton on 18th September. This most exciting development has been achieved with the co-operation of Sanctuary Housing Association.

Five Oaks is a leader in the field of independence training. During a course at Five Oaks students progress through stages of independent living. They start in the main house with full care, moving on to Denton View with its four well-appointed bed-sits. Here they receive support and help from staff but are able to experience living alone whilst being given a chance to assess and develop their skills.

Wharfedale offers young adults an experience of greater independence in one of four flats.

⇐
The Countess of Swinton, Baroness Masham of Ilton in conversation with residents at Five Oaks

Below
Back row from right to left:
ASBAH's Representative to Sanctuary Spiral (Mr Stuart Wroe), Regional Chairman of Sanctuary Housing Association (Mr Bob Holt), Regional Director of Sanctuary Housing Association (Mr Stuart Whyte), Previous Chairman of Five Oaks (Mr Michael Booth).
Front row:
Miss Moyna Gilbertson and Miss Daphne Steel
⇓

The Countess of Swinton, Baroness Masham of Ilton sharing experiences with a resident of Denton View (Melanie Howard) in the presence of Disabled Living Advisor (Miss Mary Barton)

The tenancies are secure and Helen Charlton has been appointed as a Project Worker to offer support and advice.

Baroness Masham was highly, complimentary of what she called "a half-way house scheme". "I have three piles of letters from disabled people who have difficulty purchasing property. This project shows what can be achieved when a voluntary body and a Housing Association work together. We live in a competitive world and if disabled people are not given the facilities to progress they can so easily be left behind."

Mr Robin Mackenzie, Chairman of ASBAH, acknowledged with grateful thanks all those who have, and continue to, support Five Oaks.

Photographs by Philip Bambridge.

From right to left: **Manager of Five Oaks (Miss Joan Pheasant), Regional Director of Sanctuary Housing Association (Mr Stuart Whyte), Deputy Chairman of Sanctuary Housing Association (Mr Roy Head), Chief Executive of Sanctuary Housing Association (Mr Michael Annan)**

The Government's commitment to improve psychiatric services

*In September, speaking at the first annual Charter Nightingale Lecture at the headquarters of the Medical School in London, **Roger Freeman**, Parliamentary Secretary for Health, restated the Government's policy for helping those who are mentally ill or mentally handicapped – or both. This article concentrates on provisions for those with a mental handicap.*

Mr Freeman stated that, in the field of mental handicap, the concept of care in the community was now widely accepted following the general lines established in 1971. The Government wishes to see health and local authorities, who have a statutory responsibility, co-operating together to develop a comprehensive range of co-ordinated health and social services for mentally handicapped people and their families.

Within the context of this overall policy the Government fully accepts that specialised residential health provision will continue to be necessary for people with special medical or nursing needs. However the Government takes the view that this is best provided in small homely units rather than in large mental handicap hospitals. He went on to say, "this is a consequence, not the main purpose, of the movement to community care".

Mr Freeman pointed out that people with a mental handicap whose management and treatment require special attention because of additional mental illness, behaviour disturbance, or because they offend, tend to get left behind in the planning process. "This" he said "only constitutes a small proportion of mentally handicapped people, but the particular difficulties posed by this group are a major factor influencing service provision".

A study team from the Department looked at a cross-section of services around the country for this group in a report in May *Needs and Response* which described service models, and basic principles behind service planning and provision. The report was intended to stimulate thinking and discussion especially in areas where plans and services are lacking, and thus lead to the provision of better services for the group.

Mr Freeman explained that he could not conclude his lecture without paying tribute to the vital role played by informal carers. He stated that the Government has consistently recognised the vital role played by carers in the community and acknowledged the importance of ensuring that information and support are provided to meet their special needs. "This commitment" he said "is demonstrated in the involvement of Ministers directly in the interests of carers' organisations between, and also in close and mutual beneficial contact with, the major organisations and the Department of Health."

He went on to point out that a great deal has been achieved in raising the profile of those organisations, both in Government and more widely, and that no significant policy decisions are taken without consideration of the role, contributions and needs of carers.

Mr Freeman reminded his audience that the Government intends to publish a White Paper in the autumn which will set out proposals for the future organisation and management of community care, and invited comments either before or after the publication date.

Linda Avery

‘Only half a cake’

(Implementation of The Disabled Persons (Services, Consultation and Representation) Act 1986
by Linda Avery

On 11th July members of several voluntary organisations gathered in Downing Street to demonstrate that after three years still only half the Sections of the DPA 1986 have been implemented.

So far, of the eleven Sections contained in the Act, only Sections 4 a-c, 5, 6, 8, 9 and 10 have been implemented. Those still awaited are Sections 1, 2, 3, 7 and 11. As is usual in most legislative measures, it is often the case that the operation of one Section depends largely on the operation of another. Hence, whilst some Sections have indeed been implemented, their actual effectiveness is held up because other Sections have still to be implemented.

- **Section 1** relates to the appointment of various representatives of disabled people.
- **Section 2** covers the roles of the various representatives.
- **Section 3** requires local authorities to allow a disabled person (or their representative) to make representations as to his or her needs, before the local authority itself makes an assessment of the person’s needs.
- **Section 4** confirms the duty of the local authority to assess a person’s needs for any of the services listed in Section 2 of the 1970 Act (CSDPA).
- **Section 5** deals with disabled people leaving special education.
- **Section 6** requires a local education authority to keep under review the expected leaving dates of disabled children identified under Section 5, both while they are in school and in further education.
- **Section 7** deals with the need for hospital managers to notify various bodies when a person who has been treated for a mental illness or handicap and the expected discharge date of that person.
- **Section 8** places a duty on local authorities to take into account the abilities of a person’s carer when assessing a disabled person’s need for any of the social services.
- **Section 9** requires social services departments to inform disabled people receiving any services from them of relevant services provided by the local authority or any other authority or organisation of which the particulars are in the authority’s possession.
- **Section 10** provides for the co-option to committees of persons representing the interests of disabled people.
- **Section 11** requires the Secretary of State to lay an annual report before Parliament on: the development of community services for mentally ill and handicapped people; the number of people receiving in-patient treatment for mental illness or mental handicap analysed by age and length of stay; and any other information he considers appropriate.

In 1987 the Government claimed that many of the most important measures of the Act, i.e. those Sections so far not implemented could not be implemented until extra resources were found. However, the Act’s sponsors felt that the Government’s estimate of £100,000,000 to implement the Act was exaggerated.

There are two forms of cost – that of directly implementing the Act and the estimated increase in demand for services already provided under other related legislation. As to the first, these costs are primarily to set up procedures for assessments and the training of staff. But these are only initial as opposed to annual costs. The extra costs because of increased demand are only based on estimates. Demand will take a number of years to increase. Any extra demand that does occur for services is simply to meet needs which already exist and results from services that people with disabilities are already entitled to be provided with in a more effective way.

The demonstrators tried to make their point in July by cutting a cake in half in front of 10 Downing Street and handing in one half. Their attempt to gain attention was met merely by a liveried doorman whose comment was “half a cake is better than none”. The demonstrators did not agree, and will continue to demand the whole cake.

New Counsellors and Workshops

The appointment of two senior counsellors to ASBAH's Fieldwork team has paved the way for a series of workshops. Here, in the second of two articles, we explore how important it is for teenagers to have an opportunity to look at their own personal development with respect to relationships.

Kath Pickin

A relationship as far as Kath Pickin is concerned is something we create with everyone with whom we come in contact – parents, siblings, teachers, and people of the opposite sex. Kath Pickin, an ASBAH counsellor, is also a trained Marriage Guidance Counsellor. She takes a lot of her own experience from watching her teenage children. "They learn so much from their peer group." Kath is convinced that young people with spina bifida and/or hydrocephalus are not always aware what a relationship really means. "They may get their role models by watching television. In a soap opera, people meet a few times and in the next episode they appear married. Due to lack of mobility it is not that easy for a disabled person to go out for a drink at the pub, they miss the courtship stage of a relationship."

Kath is also aware that as most disabled people have to rely on others for help with personal tasks, they do not necessarily realise that they have a right to privacy in a relationship. In fact, quite the reverse. A lot of disabled people do not see the need to be alone. A relationship almost becomes public.

Kath is also concerned that teenagers develop false images of what a sexual relationship really means. "One young man informed me that sex was like rape. His lack of knowledge meant that his relationship with a young woman terminated. I am sure that this was due to fear. Sex education in most special schools is non-existent. Teachers are embarrassed and just cannot cope with questions. It is easy for a novice to imagine that because someone has no sensation from the waist downwards they will not gain any pleasure from a sexual relationship."

"Relationships in any home are complex and those in a household where there is a disabled person are no different."

Emotions as far as Kath is concerned are complex. Jealousy towards a brother or sister who can leave the house and socialize more freely with friends is common. "It is naturally easier for a sibling to accept their disabled brother or sister once they have grown up and have developed interests and friendships outside the home. It is quite common for an adult sibling to take on a maternal parental role. Relationships in any home are complex and those in a household where there is a disabled person are no different" concluded Kath.

Debbie Simms is a confident 22 year old. She recently attended Hebden Green School in Winsford, Cheshire, in order to give her views to a group of older pupils and their parents on 'What every parent should know'.

Debbie Simms

Parent/teenage relationships can be strained at the best of times. Debbie found that most of the disabled students present found it difficult to have a really good argument with their family. "How can you possibly storm out of a room and slam the door behind you when you're unsteady on your feet or confined to a wheelchair? It can also be difficult to stay angry with parents or family when in the middle of it all you need assistance to go to the toilet?" she explained.

"Although shouting and arguing is, perhaps, not the best way to work out problems, why should the disabled teenager be expected to ignore their own feelings and 'keep the peace', or the parent for that matter? Everyone has the right to their own feelings, whatever they may be. Parents can also find it difficult to express their feelings – particularly anger. I know of parents who feel so sorry for their child that they find it impossible to discipline them."

Debbie is very philosophical. "It is important for parents and teenagers to work together as a team. You have to talk things through. How else can you possibly know how each other feels? It is not good enough to have an idea, or think you know, you need to spell it out to each other. It may not be easy but it is the only way. It is surprising how many parents have absolutely no idea how their disabled teenager feels, or what they want from life. Although it is easier to work together, if you have not got the support you need you can still fight for the kind of life you want. If you fight hard enough, you can do just about anything.

"Leaving the secure environment of a Special School can be daunting if you are not prepared for the real world – and for many young people that is exactly the kind of shock they face. I feel that it is the responsibility of the parents and the school to prepare the young person for life as an adult. It is important to be strong and determined in whatever you do, whether you are the parent or the disabled person. The struggle to succeed may not be easy – but the rewards are well worth it", Debbie concludes whilst reclining in a comfortable chair. "Although I need a wheelchair, I want everyone to remember me just as another ordinary person who is getting on with her life".

WORKSHOPS FOR PARENTS

On the 19th October at the Gateshead Metro Centre, ASBAH will be holding a day for parents to explore their own hopes and fears as their offspring step into adulthood. For further information contact Kath Pickin at Five Oaks, Ben Rhydding Drive, Ilkley, West Yorkshire LS29 8BD. Telephone (0943) 603013. All welcome.

Community Care

The long road to Care in the Community is still running. It started in 1971 with a White Paper *Better Services for Mentally Handicapped People*. Then, four years later, came *Better Services for the Mentally Ill*. For the next ten years the subject was debated, culminating in Sir Roy Griffiths' report *Community Care: Agenda for Action*. This deals not only with the above groups, but also with care for all people with disability and the dependent elderly.

The Government has, so far, agreed to the main thrust of the report which is that local councils should take responsibility for care in the community. However no additional funding is to be forthcoming – it is rumoured that, though some funding will be transferred from the Social Security budget, any additional costs may be met from the community charge.

From 1991 local authorities will have to meet the full care costs of those in council homes, but will not have to meet the hostel costs of those who rely on independent care.

People who now require residential care will, in future, be more likely to opt for domiciliary care within their own homes. It is likely that voluntary organisations will be under pressure to take on more responsibility for caring for physically and mentally disabled people, but will need the funding to do so.

Financially, social services departments will be penalised if they 'provide' rather than 'enable'. This means that people currently caring for the elderly and other dependent people, such as social workers, occupational therapists etc, may well set up their own practices and bid for local authority – or voluntary organisation – contracts. Already many local authorities are influencing how to contract out services.

However, the long debate is not over yet. At the time of going to press it is understood that a White Paper is to be published early in November, and there is to be a House of Commons debate on the issue on 17th October. There will be little time for consultation however, since legislative plans are already being drafted to be laid before Parliament in November.

STOP PRESS

CHRISTMAS CARDS

The annual Christmas season is once again upon us. ASBAH have produced a series of seven Christmas cards, one for every taste from traditional to humorous. To receive a free catalogue contact ASBAH, 22 Upper Woburn Place, London WC1H OEP

NAIDEX

The Major Exhibition of Equipment and Services for the Disabled and Elderly is taking place at Alexandra Palace in London between the 11th and 13th October. Visit ASBAH's stand where Disabled Living Advisors will be on hand to answer your questions.

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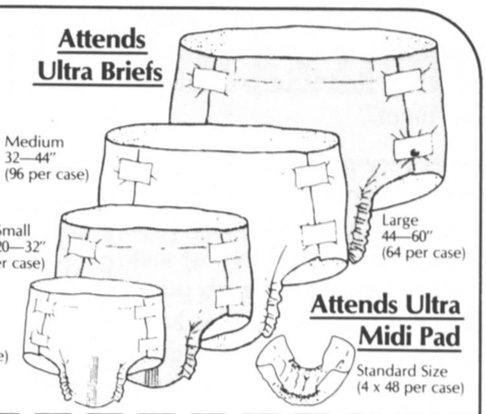

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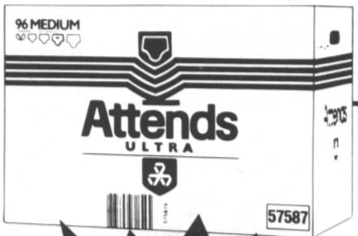

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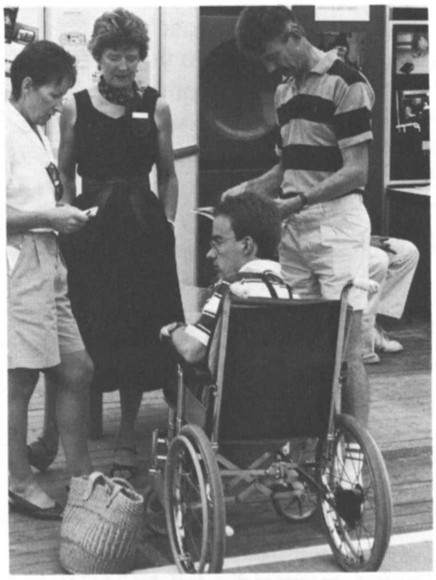
News Round-up

Mobility Road Show

Driving courses to come

HRH Princess Alexandra officially opened the Mobility Show in June at Crowthorne in Berkshire. This was the fourth and largest show staged in the extensive grounds of the Transport and Road Research Laboratories. ASBAH had a stand on this occasion which drew visitors old and new. It was estimated that 20,000 people visited the show. The theme of ASBAH's stand was transport, with the Driving Courses at Five Oaks as the focal point.

Organised by Banstead Mobility Centre is a one-day driving assessment course for young people who wish to explore the possibility of becoming a car driver despite their disability. A team of experts are on hand to provide a comprehensive assessment and draw up a recommended course of action for each individual. ASBAH offers a one-week driving course which is open to disabled people who already hold a provisional licence. It covers all aspects of driving including wheelchair loading, car maintenance and road safety as well as driving tuition. Motorbility and finance is also included.



Leonie Holgate, Disabled Living Advisor, ASBAH, with John Howell and his parents. John now drives and has his own car for getting to and from work

The next Driving Course at Five Oaks, Ilkley, West Yorkshire takes place between the 5th and 11th November and costs £302. For further details contact:

Lindsay Mitchell-Barnes, ASBAH,
22 Upper Woburn Place, London
WC1H OEP.

Creating medicine

The exhibition Creating Medicine was opened in the Senate House of the University of Cambridge by Professor Lord Adrian MD FRS on Thursday 7th September. This was preceded by most impressive presentations by Dr Max Perutzom CH FRS entitled 'Determining the Structure of Living Matters: What use to Medicine'. Dr Herman Waldmann spoke on 'Designer Antibodies: New Vistas in Therapy' and Professor Sir Roy Calne FRS concluded with 'Transplantation Now, and its Prospects'.

The presentations jointly emphasised the importance of basic sciences and research and how – sometimes after many years – they lead to revolutionary changes in clinical medicine.

Both Professor Keith Peters, Regius Professor of Physics at Cambridge, and Lord Adrian emphasised the importance of the cooperation between medical research charities, industry and the Medical Research Council with the University and the NHS.

ASBAH was represented on this occasion by the Executive Director, Miss Moyna P Gilbertson.

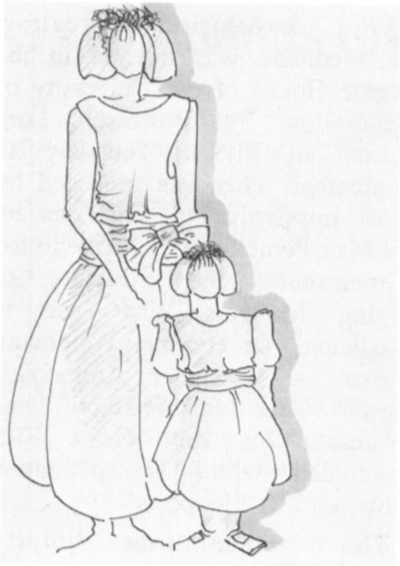
Charities to advertise on television

The IBA has lifted the 34 year old ban which stopped charities advertising on television. The ban, in force since the beginning of commercial television, was lifted after the Government recommended that charities should be able to solicit donations and promote their activities on air.

In an IBA survey 1,000 charities voted two-to-one in favour of broadcast advertising. This is already common practice in the United States. Charities wishing to advertise will have to prove their status. Their advertisements must avoid comparisons with other charities. The Charities Aid Foundation has welcomed this move. It is naturally fair to say that by heightening awareness of voluntary bodies, all charitable organisations will benefit. However, smaller charities will only be able to afford to advertise with the help of corporate sponsorship. It will be probably the more emotive images or disaster funds which will pull at the heart strings. This is clearly seen by the way children are portrayed each year during *Children in Need* or the Telethon.

Once branded like any other commercial product, one can only hope that the media will not refrain from offering the thousands of hours each year of free editorial time currently open to charities.

Fashion success for Karen



Karen Desborough is 22 years of age. Having taken a B-Tec Fashion Course after 'A' levels, she was disappointed when she could not find employment. However, determination and a love of fashion and design made Karen decide to start her own business. With help from the Government and the placement of advertisements in shop windows, Karen has been kept busy. "Word of mouth seems to work best" she insists whilst making a wedding dress in her bedroom, which has now become the headquarters of 'Pastiche Dress Designing'.

As well as alterations and making up people's designs, Karen also offers fashion advice. "Just because someone is disabled it does not mean that they cannot or should not wear fashionable clothes" she explains. Having spina bifida herself, Karen believes that the advice she is able to give comes from personal knowledge and experience. "I am not sure why some disabled people wear such unflattering clothing. Perhaps it is because restricted mobility means that they are reliant on parents or older carers shopping for them. I guess it is just not that easy to pop out to the shops with a friend."

One of Karen's main aims is to go out to visit special schools, or clubs, where she can talk to young people. "I even take some clothes with me so that people can see what they look like wearing a different image. Sometimes, by just having elasticated trousers, they can become much easier to get on and off. It is by making slight alterations that clothes can take on a new meaning".

Karen finds it most challenging when people present her with a design and she has to follow it. "It is all part of turning people's fantasies into wearable creations". Karen has also been known to make costumes for her local drama group, "anything from a mermaid's tail to a clown's outfit" she laughs.

With the help of the Small Firm Service, through which she is allowed three free consultations a year to help with accountancy and marketing, Karen is confident that her new business venture will succeed. "One of the hardest tasks is to become known. I try and keep prices competitive and am always willing to visit groups of people for the price of petrol", she concludes.

Your letters

Dear Sir,

We recently went to Bridlington for a week with our 3 children (aged 6, 4, and 21 months). The youngest has hydrocephalus and cerebral palsy. We decided to have a day at Butlins in Skegness which turned out to be a disaster.

After paying £14 to go in we took the children to the fairground section, I went to one of the children's rides and said to the attendant "would it be possible for me to go on a ride with my son as he is disabled?" I felt that I had to make this approach as there was a sign which said 'children only'. The reply was "no handicapped children, adults are not allowed on rides, apart for the dodgem cars". This was due to the fact that a disabled child broke his leg on an adults ride last week. I was very upset about this as my child was being singled out and discriminated against. How do you tell a child that he or she cannot go on a ride because they are disabled?

What annoyed me more was that there were no signs at the main gates, in the fairground or in the holiday brochure, stating that disabled people are not allowed on rides.

Surely parents should be allowed to decide if a ride is suitable. If an able-bodied child fell off a ride, would the Health and Safety ruling then change to 'No able-bodied children on rides'?

Could the ruling be changed if families campaigned together by signing a petition? It could state that all parents should be allowed to take disabled children on rides as long as they are accompanied and the rides are safe.

I would be interested to know other people's views.

Susan Bradford

Dear Sir,

I am looking for a pen-pal in the Liverpool area. I am 18 years of age and have spina bifida. My hobbies are football and my favourite teams are Celtic and Liverpool. I also enjoy fencing and archery. I would like to correspond with someone between the ages of 18 and 23.

Tracey Ayrshire

COMPETITION

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If you would like to enter our competition, simply follow the entry rules and complete the form below.

1) Write 250 words telling your funniest or most moving experience.

2) Send entry form and story to *Link* by the closing date, 7th November 1989.

3) The editor's decision is final and no correspondence can be entered into.

4) The cruise must be taken before 31st December 1989.

5) The competition is not open to members of staff of ASBAH or their relatives.

6) You must agree to the rules of the competition by signing below. (Winner will be notified in the week of 14th November 1989)

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Address ....

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....

Daytime telephone no ....

I agree to abide by the rules above and that my story may be published in *Link*.

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(Signature)

SEND THIS COUPON WITH YOUR ENTRY

Marathon efforts are well rewarded

Corporal Philip Sandford, a member of the Royal Signals stationed in Berlin, managed to raise £1152.78 for The Association for Spina Bifida and Hydrocephalus. This was achieved when he participated in the London Marathon. Through the pledges of friends and family his original estimated total of £400 was far surpassed.

28 years old Philip, originally from Thetford, chose ASBAH because he and his wife Carole lost an infant daughter to hydrocephalus, while a colleague's daughter has been born with spina bifida. He therefore wanted to help others in the same situation.

***Right:* Three times better than expected – Corporal Philip Sandford presents a cheque to the Commanding Officer of the 13 Signal Regiment, Lt Col J H Roberts**

Advertising

FOR THE USE OF LOCAL ASSOCIATIONS AND OTHER READERS

Rates: £3 for 30 words max; £4.25 for 30-45 words; £5.50 for 45-60 words.
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Adverts for the next LINK (November/December) should be in by 27th October. Send to: The Editor, LINK; ASBAH, 22 Upper Woburn Place, London WC1.

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