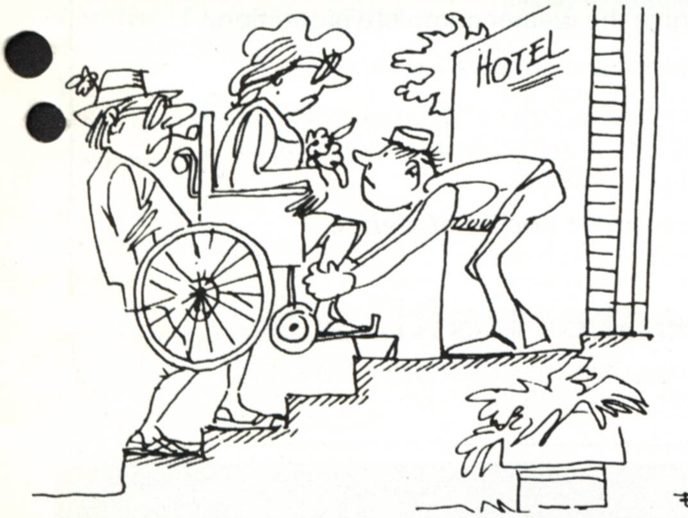
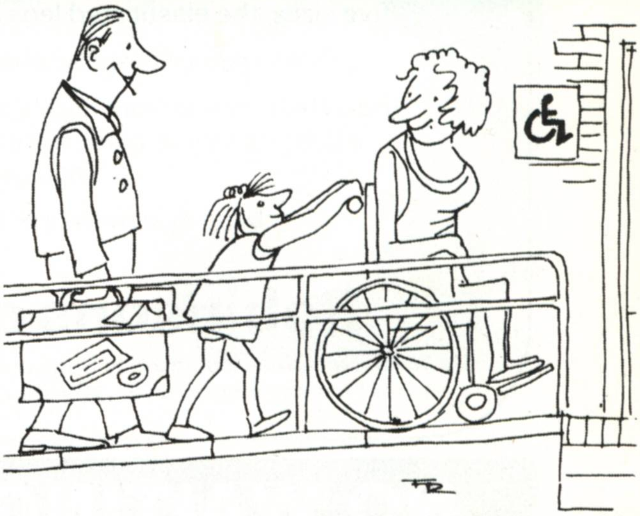
Link

Association for Spina Bifida and Hydrocephalus/ASBAH 10p Sept/Oct 78

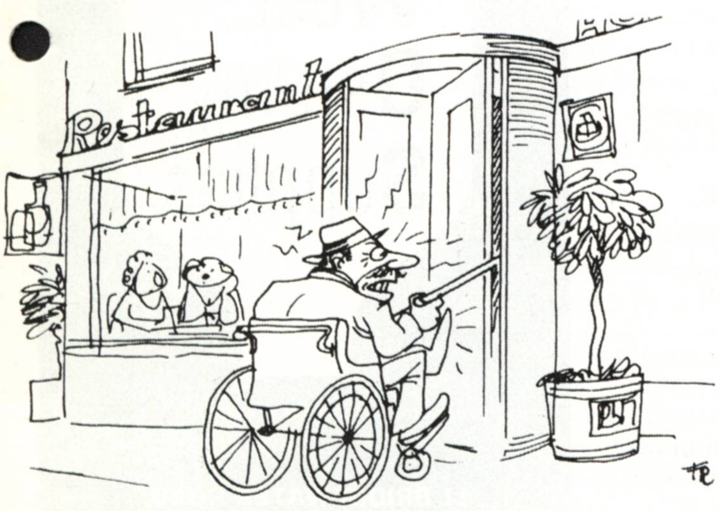
SOME INS AND OUTS OF ACCESS



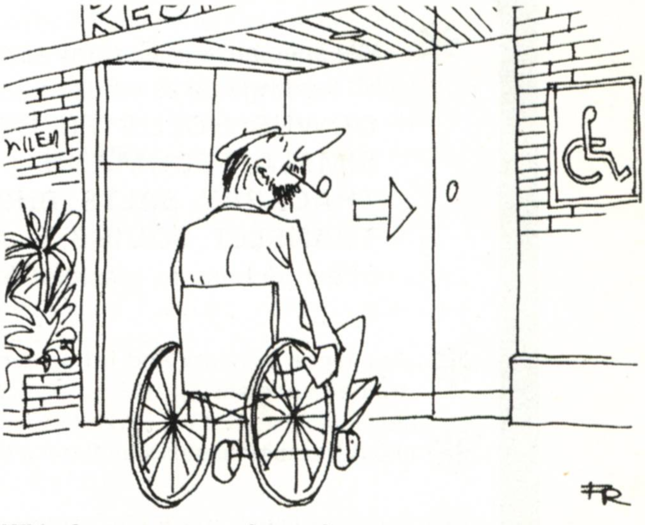
Even two or three steps at an hotel entrance can mean that a wheelchair will have to be lifted, involving help from others. It may also cause risk and discomfort as most people, however well intentioned, are unused to lifting someone in a wheelchair.



If the main entrance is inaccessible, it is often possible to form a ramp to a side entrance which should have an easy gradient, preferably at 1: 20. It will need to be clearly signposted and it will probably turn out to be very useful for trolleys and pushchairs as well.



Revolving doors are impassable for wheelchairs and the cause of great difficulty for anyone with impaired mobility.



Wide front entrance doors that are easy to operate not only help wheelchair users, but also assist people carrying bags and accompanying small children.

In this 20-page LINK—Leisure: Social Workers: One Child's Story: Use of catheters

LINK 58

Growing Concern?

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London WC1H 9HJ.
Registered Charity No. 249338
Tel: 01-388 1382/5

Patron:
HRH The Duchess of Gloucester

Chairman: Mr O J Colman

Hon Treasurer: Mr R M Nichols

ASBAH has an experienced staff ready to help with any problems relating to those with spina bifida and hydrocephalus.

Chief Executive Officer:
Miss M P Gilbertson, MCSP

Finance Officer:
Mr F G Armour, FCA

Appeals Secretary:
Miss Judy Kay

Liaison Officer:
Mr H D Macfarlane

Education, Training & Employment Officer: Mrs B Newman

Aids & Appliance Officer:
Miss J Vernon, BSc.

Information Officer:
Miss B Holland

LINK Editor:
Mrs S I Gearing

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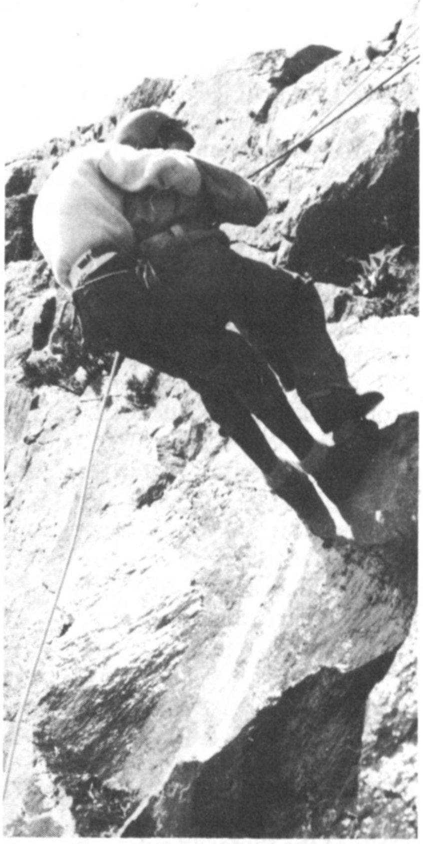
IN RECENT years there has been a marked increase in leisure time for most people and this is especially true for the handicapped. We are, as a nation, becoming aware that leisure time can be spent purposefully and often requires a specific educational programme to prepare one.



Churchtown student in action

Consequently we now see expansion in the number and variety of courses available, an increase in sports and club facilities and a wide-scale use of environmental recreation. Reservoirs are no longer merely to store water, they must also site a sports complex with sailing, angling and water-skiing and provide a nature reserve for the bird-watcher and naturalist. Picnic sites for the tourist and abundant car parks are also required.

But what of acceptance and access for the handicapped participant?

Many special schools already provide initial stimulation in a variety of leisure activities but there must then be opportunities for their continuation. The handicapped person will be better able to integrate with his fellow sailors, fishermen or bird-watchers if he has already gained some experience in a selection of events and afterwards received a training in the chosen field.

For three years Churchtown Farm Field Studies Centre has been instrumental in developing courses for physically and mentally handicapped children and adults. The range of leisure activities available includes sailing and canoeing, fishing and riding, photography and bird-watching, rock-climbing and camping, painting and pottery and many others.

Over a thousand visitors a year receive an education for leisure and the success is seen from their continued return to the centre. Many who feel initially unable to participate suddenly find a whole new world introduced to them and gain a confidence which can be carried forward into life.

DR M. J. COTTON, Churchtown Warden

Footnote—details of this centre may be obtained from The Warden, Churchtown Farm Field Studies Centre, Lanlivery, Bodmin, Cornwall.

LINK: The last date for material for Nov/Dec LINK is Oct 1. *Write to Mrs Susan Gearing, Editor, LINK, at ASBAH.*

The yearly subscription for LINK (UK) is £1.15, which includes postage. While every care is taken to ensure the accuracy of information published in LINK the publishers can accept no liability.

COVER STORY

FOUR amusing and perceptive cartoons about access. They are taken from a series by A. Frederiks Utrecht who produced them for the Netherland Society for Rehabilitation and their booklet *'Welcome In(n)'*. They have also been reproduced in a recent publication by the English Tourist Board *'Providing for Disabled Visitors'* which gives advice to hotels and restaurants on ways of improving access and facilities for the disabled.

Rate relief takes on a new look

NEW laws governing the payment of rate relief to the disabled were passed in July and will come into force on April 1 1979.

The new legislation—Rating (Disabled Persons) Act 1978 provides for relief to be given in the form of a deduction from the rate bill, rather than as a deduction from the rateable value as at present.

The Act specifies that in England and Wales standard amounts should be rebated from rate bills for certain facilities required for meeting the needs of a disabled person.

Standard deductions include, for the use of each room, a sum equal to the rates that would be chargeable on a rateable value of £30, on a bathroom £20, on a lavatory £10, on floorspace for the use of a wheelchair £30, on a garage £25 or as assessed, on a carport £15, and on land for parking a vehicle £5.

Deductions for heating appliances and other facilities will be subject to individual assessment by District Valuers. The Department of the Environment will be issuing advice about the administrative arrangements for the new scheme and the way in which relief should be applied for.

Where to find our social workers

ONE of the things I found a bit confusing when beginning work at ASBAH was where the social workers are and what locations they cover writes Rod Harper, ASBAH's Head of Social Work.

I thought that members might find it difficult to keep up with the changes too, so this then is where ASBAH social workers are now.

Portsmouth Area
Mr B. Davey,
33 Wych Lane,
Bridgemary,
GOSPORT.

North Hampshire, West Surrey & South Berkshire
Mrs P. Gammell and Mrs A. Brennan,
The Old Police Station,
Leapale Road,
GUILDFORD,
Surrey.

Staines & Hounslow
Mrs C. Caporn,
22 Sunna Gardens,
SUNBURY-ON-THAMES,
Middlesex.

West Sussex
Mrs H. Hinchley,
33 The Street,
Bolney,
HAYWARDS HEATH,
Sussex.

East Sussex
Mrs S. Wilkinson,
Church Settle,
WADHURST,
Sussex.

Birmingham & North Warwickshire
Mrs L. Bellshaw,
20 Walter Cobb Drive,
SUTTON COLDFIELD,
West Midlands.

South Warwickshire
Mrs S. Davies,
64 Rugby Road,
LEAMINGTON SPA,
Warwickshire.

St Helens
Mrs A. Lansley,
25 Buckingham Avenue,
LIVERPOOL 17.

Liverpool
Mrs F. Campbell & Mrs V. Branthwaite,
Tudor House,
Wood Lane,
Netherley,
LIVERPOOL L27 4YA.

Leeds & Bradford
Mrs R. Scott,
Cragg House,
Harden,
BINGLEY,
W. Yorkshire.

South Wales
Mrs S. Erasmus,
50 Heol-y-Bont,
Rhiwbina,
CARDIFF.

If you have any difficulty with which you feel a social worker could help don't hesitate to write to the local person. The Welfare Committee is very aware that there are large areas of the country where there is no ASBAH social worker at present, and would like eventually to have one in easy reach of all members. In the meantime I would be very willing to try and help albeit in a limited way.

Ed: Welcome to Mr Harper who has recently joined ASBAH at National Office. He was formerly Area Team Leader for Westminster Social Services.

NOW LIFT HAS ITS OWN OFFICER

OVER the past few months LIFT—the newly formed young ASBAH organisation—has been growing and getting underway—and now it has a full-time National Officer of its own, Miss Jan Tomlinson.

Jan, whose office is at National Office of ASBAH—has the job of planning LIFT's activities and co-ordinating its expansion.

At the moment she is very busy trying to form local LIFT groups, in areas where there are already a good number of LIFT members.

'It will be a slow process' says Jan 'so don't expect to see a group in your area tomorrow, but I hope that before too long we will have LIFT branches in different parts of the country.'

Jan has recently graduated from Loughborough Polytechnic where she was a very active President of the Students' Union. If the energy she showed there is anything to go by, LIFT will be really taking off in the future.

If you want to join LIFT—or if you are already a member and want to get in touch with Jan (maybe send her a news item or viewpoint for LIFT's Newsletter) write to her at: LIFT Office, ASBAH, Tavistock House North, Tavistock Square, London WD1H 9HJ.

New holiday centre

A NEW purpose-built holiday centre for the severely physically handicapped has opened this summer just outside Nottingham. Called 'Skylarks' it is run by the Winged Fellowship Trust and provides fortnightly holidays for 36 disabled people. More details from the Trust, 2nd Floor, 64/66 Oxford St, London W1N 9FF.

Very special appeal of Kate White

MRS Kate White, ASBAH's energetic and resourceful Appeals Organiser retires this month (September)—a very sad occasion for everyone at National Office and indeed for the Association as a whole.

Moyna Gilbertson, ASBAH's Chief Executive Officer, writes: "Kate White joined us seven years ago to run ASBAH's Appeals department; she quickly proved her sound business sense and professional skill at persuading people to do things they may not want to do—to the great benefit of ASBAH.

The demands made on an Appeals Organiser are onerous and diverse. Kate has accepted every challenge cheerfully, whether racing pigeons, inflating hundreds of balloons in the pouring rain or selling hundreds of Ball tickets. To have helped treble the income coming to the National Association has been an important contribution to ASBAH's needs; to have arrived when there was no fund for a Research Fellow nor an ASBAH Home, and to leave with Mr Bayston in post and Five Oaks in full operation should afford Kate White more concrete satisfaction.

Those of you who have seen the dedication and hard work—sometimes to the point of exhaustion—that Kate White commits to her task know the great debt of thanks we owe her for the personal contribution she has made to ASBAH. None of us who have worked with Kate will forget her humanity and capability; we very much hope Kate and her husband Ted will not disappear entirely from our lives just because she will no longer be running the Appeals office."

☐ ☐ ☐

THE new Appeals Organiser is Miss Judith Kay, who has joined ASBAH—indeed the staff were delighted that she was able to be at National Office for three months before Kate White retired, to ensure a smooth change-over.

Miss Kay was formerly fund-raiser for the Bournemouth Symphony Orchestra, and before that was with Action Research so she brings a wide experience of appeals work with her.

Warnock Report: ASBAH is asked to comment

ASBAH is one of 400 organisations in England and Wales who have been asked for their comments on the Report of the Warnock Committee on the education of handicapped children and young people.

The Government is anxious that this Report is given the fullest consideration before decisions are taken which will set the direction for future developments in special education for many years to come.

The Report covered the whole range of special educational provision, from the earliest years to adult life, including the health, social and careers services which support the work of the schools and colleges. The Report also dealt with the contribution of voluntary bodies, the critical importance of parents, the co-ordination of local services and many other aspects of the subject. It proposes a fundamentally new concept of special educational need, encompassing the whole range and variety of additional help, including that now described as remedial, by which children may be helped to overcome educational difficulties however they are caused.

It suggests that up to one in every five children will require some form of special educational provision in this wider sense during their school career.

Organisations are also asked to comment on the question of early legislation, and early provision for under-fives and young people over 16 who have special educational needs.

GOVERNMENT GIVES £½m LEAD

DURING this Access Year it is fitting that the Government has announced a new plan to spend £½ million on improving facilities for disabled people at Government offices in towns throughout Britain.

The Property Services Agency is to spend £500,000 in 1979/80 to adapt at least one public building in 56 towns to provide the facilities necessary to extend employment opportunities for disabled people.

Peter Large, Chairman of the Silver Jubilee Committee on Improving Access for Disabled People said: 'I hope other employers will emulate the Government's efforts. All too often disabled people are prevented from working merely because of lack of adequate facilities in offices, shops and factories.'

He said his Committee had been concerned to make more people aware of access problems, and said that the Committee members were pleased that the Government had listened to their case and acted with commendable speed.

Minis on offer

LONDON's Mini Centre always has a selection of guaranteed used Minis with various types of hand controls. These can be purchased on HP or as a part exchange deal. Alternatively it may be possible to arrange hiring facilities on a self-drive basis. Vehicles are delivered nationwide. Please contact Mr Reed of H.R.X. Garages, 125 Lower Richmond Rd, Putney, London SW15. Tel: 01-788 6036.

Stop Press

As from December 1, 1978 people receiving Mobility Allowance will be exempt from paying Vehicle Excise Duty (road tax), which is currently £50 pa.

● RADAR has updated its guide to the Mobility Allowance. Excellent value at 20p from Radar Publications, Dept 25, Mortimer St, London W1N 8AB.

Norwegian way to independence

LINK has reported on the Independence Weeks that LIFT (the young ASBAH group) has organised. Here is the news of similar endeavours in Norway, written by Dr John Lorber MD, FRCP on a recent visit to Oslo.

Before the meeting of the Society for Research into Hydrocephalus and Spina Bifida in Oslo, I had the opportunity to visit a purpose-built convalescent home not far from Oslo. It was out in the woods among the trees and lakes, in a place called Framby.

This visit was arranged through the courtesy of Mr and Mrs Sommerstad whose daughter of 14 has spina bifida and was in Sheffield recently for treatment.

The unit is beautifully built on similar lines to our best special schools for handicapped children. The purpose is to give independence and self-reliance to children and youngsters with all sorts of handicaps.

Orchestra

This summer 23 spina bifida youngsters were there, very freely looking after themselves, under supervision, and without visits from parents, so that they could really feel that they could do things for themselves.

They had their own kitchen, bedrooms and even an orchestra. They could swim in the lake but didn't while I was there—it was bitterly cold.

At other times, the parents are invited and are given talks and courses on all aspects of handicap relating to their own children. The unit is not only for spina bifida and hydrocephalus, but for other disabling conditions.

It is owned privately by an endowment fund. The children and parents do not have to pay anything for going there.

Paul gets his car

PAUL Cripps, 18, who has spina bifida, was one of the first ten young people to receive cars through Motability. With him after the 'hand over' ceremony is Moyna Gilbertso ASBAH's Chief Executive Officer, and Dr Adrian Stokes of Motability. Paul is an engraver in a workshop run by Hampshire County Council.

Hull stages its first sports day

CONTESTANTS came from far afield for Hull Association's first Sports Day for physically handicapped children at the Frederick Holmes School for the Physically Handicapped. Events ranged from an obstacle wheelchair race to a darts contest.

The sports day was set up as an alternative to the Humberside

Quiet word with the Princess

PAUL Maryon, of the Isle of Wight Association, presents HRH Princess Anne with a donation for the Save the Children Fund.

Paul, 12, has hydrocephalus and lives in Newport. He attends Watergate School, Newport, a special school for handicapped children.

Princess Anne recently visited Carisbrooke Castle with Lord Louis Mountbatten, Governor of the Isle of Wight to receive donations for the Fund from schools and Paul was selected to give her the Watergate School collection.

Photo: Southern Newspapers Ltd.

Disabled Sports. Hull Association Secretary, Mrs Gerritje Brown said it was unfair for the spina bifida children to have to compete against others less seriously disabled.

'The children used to come away really downcast, so we thought we would start our own. It is better for them to compete against each other.'

Gold, silver and bronze medals were presented to the winners and all contestants received certificates.

■■■

A HIGHLIGHT of the year for members of Hull and District Association was a trip to Holland. The party—12 handicapped children and 18 adults—travelled aboard a Dutch ship 'The Norstar' from Hull to Europoort in Holland.

'The Dutch crew were very helpful, and so were the customs in Europoort' commented Philip Brown one of the youngsters.

The first day's excursion included a visit to a birdpark, to Le Hague, and a miniature village at Madurodam. 'All parts were easily accessible for wheelchairs' said Philip.

After a visit to Rotterdam the party went to Amsterdam for a trip down the canals and around the harbour. A visit to Volendam, a beautiful little Dutch fishing village where the Dutch people wore traditional costumes, was greatly enjoyed. Indeed the whole four day holiday proved a success even if the weather was a little too hot at times.

Fashion success

NORTH Wales Association recently held a Laura Ashley Fashion Show which proved an enormous success, raising more than £300.

Tracey Roberts of Abererch, Pwllheli, had a wonderful surprise on her third birthday, a specially adapted hand-cranked Raleigh tricycle provided from funds raised in the area and donated to the North Wales Association for Spina Bifida and Hydrocephalus.
Photo: Peter Westley.

Stepping smartly towards £640

PETER and Dorothy Sargent of Ightham in Kent were so grateful to Sydenham Hospital for the treatment that was given to their spina bifida son, Tristam—now aged 2½ years—that they organised a sponsored walk to show their gratitude.

Friends and villagers from Ightham and staff of GPO Telephones, Sevenoaks, took part in the 10-mile walk and raised £640 which has been used by Sydenham Hospital to buy one oxygen analyser, four Chailey Chariots and a number of specially adapted tricycles for the physiotherapy department.

Mr Ellison Nash retires

AFTER many years as Consultant Surgeon at St Bartholomew's Hospital, London, Mr Dennis Ellison Nash retires in September. He is well known to many members of the Association, has often attended our Spring Conference and is a member of ASBAH's Medical and Finance Committees.

On Sunday July 30 some 30 or so of Mr Ellison Nash's older stoma patients accompanied by some parents, husbands, wives and children, and joined by Miss Moyna Gilbertson and other colleagues gathered at Mr Ellison Nash's home for an informal pre-retirement lunch. Mrs Nash had prepared a delicious meal and all the guests enjoyed the opportunity to exchange experiences.

Despite heavy rain the previous night and early morning the weather cleared in time for the guests to admire and enjoy the lovely garden. During lunch Mr Ellison Nash paid tribute to Miss Saunders of Barts Stoma Clinic from whom he said he had learned much about his speciality. Miss Saunders retires in December.

A letter of appreciation from the Minister for the Disabled, Mr Alfred Morris, was read by Dr Scott Stephenson, in which the Minister paid tribute to Mr Ellison Nash's efforts in improving the well-being of those with spina bifida and hydrocephalus.

It was a very happy occasion and demonstrated the great affection felt towards him.

ALAN and MARGARET TWYFORD
S. London Association

Industry lends a helping hand

MR R. T. J. Reast, Managing Director of Z. F. Gears (Gt Britain) Ltd presenting a cheque for £455 to Mr D. H. Plant (left) Chairman of Nottingham and District Association.

The money was raised at a Trade Fair—a further cheque for £155 was also sent to the Association—and is an excellent example of the support which can be given by industry.

Photo: Paul Bloomer, ARPS

. . . the Lord Chamberlain is commanded to invite Miss Faith Seward to a Garden Party at Buckingham Palace . . .

I THOUGHT LINK readers might be interested to read of my recent 'invitation to tea' with the Queen at Buckingham Palace.

I don't know when I was more excited—when I got the invitation or actually went to the Garden Party at Buckingham Palace. What a surprise to have a very impressive envelope arrive on my door mat with "Lord Chamberlain's Office" on the envelope. When I opened it I found the invitation "the Lord Chamberlain is commanded to invite Miss Faith Seward to a Garden Party at Buckingham Palace on July 20th." My sister was equally surprised when I phoned her and informed her that the Queen had "invited me to tea."

Having established that I could have the day off from my education authority I began to search for THE dress. I found it. It didn't fit anywhere, but with the help of an able needlewoman it became me. Hat and gloves followed and frantic phone calls to the hospital to beg for my new shoes to be ready. They were being made—in the process since April—and promises of delivery for the day followed. I hardly need say I went in my old shoes—the new ones weren't finished! Never mind I was sure the Queen wouldn't mind my shoes.

I made arrangements for parking my car at the station car park which is usually full mid-morning, had correspondence with Moyna Gilbertson and the London office regarding using their powder room, bought my train ticket and waited.

The day dawned—cold and rather dull. I was so merry that I couldn't stay at home until train time so I went to school and did some work. I left mid morning amid great excitement from staff and children.

Dress and hat and gloves safely in a bag I headed for the station in my Mini. The car park attendant made me feel so important saying that the space he had reserved for me was always kept for Lord Ingleby, Lady Masham and me.

Pat Silverthorne met me at the station and at Tavistock House I dressed in my finery. We hailed a cab and proudly displayed our Buckingham Palace badge. Pat was as excited as me and we had a great time going down the Mall with other cab drivers teasing ours that he needed a tie to get in. As we drove into the Palace gate there were so many people watching that I felt like giving a Royal wave!

The car door was opened and I bade farewell to Pat. I walked in and up the steps into the Palace—they're not really geared for the disabled. Through the hall and out onto the verandah, past guards and into the grounds—lots of beefeaters around and lots of people. Well I would stand until the Royal party came out but I had already located the chairs in case of 'toppling'.

A very sweet lady, the Mayor of Blandford adopted me. She too was alone. We were both adopted by the wife of the Lord Lieutenant of Cornwall who was sweet to both of us, telling us all the procedure. She goes every year!

The Queen, Prince Phillip, Prince Charles and the Queen Mother came down the steps into the garden and we both had a very good view. After that, alas, my 4′ 10″ began to show. I couldn't see anything. Everyone surged forward to the Royal party. I really think they would have trampled the Mayor and I underfoot, but we retired for tea—kindly brought for me by my new friend.

Then we went for a garden stroll and finished up near the Royal tea tent. My friend then asked some larger people to move so that I could see and we both finished up sitting really near the tent. All the important people eating in the Royal tent passed close by and then the Royal party. The beefeaters went off duty and the Mayor of Blandford and I decided we must make a move.

I felt quite important to step into the Mayor of Blandford's car—nicely announced, and be taken so kindly by her chauffeur and herself to Kings Cross station.

I got on the train and sank down on the seat, removed my hat and reflected on a very satisfying day. Tired but happy I arrived home having a wonderful experience to remember.

What do I remember most? The feeling of actually being in Royal company by invitation and the kindness of two complete strangers who with my good friends in the London office made what could have been a rather awe inspiring and lonely experience a very happy one.

FAITH M. SEWARD

Faith, who has spina bifida, is ASBAH's Education and Training Sub Committee Vice-Chairman, and Head Teacher of an Infants' School in York.

Hydrocephalus takes second place

I HAVE JUST been reading July/Aug LINK, and have read Mrs Phillips letter about hydrocephalus taking second place.

Like her I have a sixteen year old son who has hydrocephalus and I also feel that it is not mentioned as much as spina bifida. I too am asked 'What is the matter with him?' and when I tell them, I get 'What is that?' You can't keep telling people.

He is part blind, has brain damage and can't walk, and so on.

Like Mrs Phillips I think more should be done for these children.

Whatever Mark wants I get for him myself. I don't get a lot of help for him.

MRS MARGARET STIMSON
Charlton, London SE7

Unwrapping the holiday package

I THOUGHT I would write and tell you about the package holiday we took in Bulgaria with our son Paul, aged eight, who is confined to a wheelchair through spina bifida.

We flew from Gatwick Airport at 11.50 a.m. on a Saturday morning in May. We received first class service and help with our son and in no way can I find fault, indeed we were treated as VIP's.

As Paul is incontinent and we use a nappy roll we changed him in a disabled toilet at the airport, after which he had to wait until we reached Varna airport.

Going out the wheelchair was loaded in with the luggage and it was waiting on the tarmac when we carried Paul off the plane.

Unfortunately Varna is a very small airport with no facilities for the disabled. It took about 1½ hours to go through customs and then it was straight on a coach to the hotel. In all Paul had seven hours without being changed, his trousers were still dry!

The hotel bedroom was fortunately big enough for a wheelchair and we had our own bathroom with shower, which Paul hated! The hotel had two lifts to each floor but didn't extend to the top floor which was the breakfast bar, so Paul was carried up one flight of stairs (something that wasn't mentioned in the brochure.)

The weather was very good and we settled down to enjoy our holiday. No one was ill and the food was good. Children are allowed in all the bars and night clubs. Beach and sea were smashing. We used the local taxis to travel about in; they were cheap and much easier than the over-crowded buses.

When we came home a week later we had another 1½ hours queue through customs at Varna. We were given no help at all and trying to explain to some one who doesn't speak English that the wheelchair also had to go on the plane wasn't easy. I honestly thought they were going to leave it on the tarmac!

All in all we thoroughly enjoyed our adventure and look forward to another one next year.

MRS S. GODDARD
Garston, Watford, Herts.

French exchange

WE HAVE received the address of your Association as being of interest to our ileostomic children. Our Professor Pellerin is particularly interested in the problems related to such children.

Several of our families are willing to organise some exchanges with such children during the school holidays, and we would be grateful if you could help us.

MADAME VINTI, Surveillante Generale,
Service Due Professeur Pellerin,
Hopital Des Enfants Malades,
149 Rue de Sevres,
75015 PARIS, France.

***This letter was reproduced from the Ileostomy Association Magazine.**

One Child's Story

HOLIDAYS, hobbies; activity right for his age and a trip to Greece; teenage friends and growing independence; a car of his own and, eventually, responsibility for his own life. These are the usual stages in a very unusual process of growing up for William Bee. William was born in 1958 with a quite serious spina bifida condition, but no hydrocephalus developed. Here, in the second of three articles, his father, Mr W. R. Bee explains how the Bee family helped William tackle the business of growing up. These articles are the personal story of the Bee family. Their problems will differ from other spina bifida families. Solutions to problems are never universal. But there is encouragement in seeing others succeed and that is why we are publishing the story.

IN BRINGING up a family with a handicapped child one must always give a larger share of attention to that child and somehow make it up to the others. Will and Katharine have been expected to help about the house, with Kath let off lightly when her brother was laid up.

She had a truck to match Will's, a tricycle like his, and I made her a Wendy house and a doll's house to balance Will's planes and boats.

For family holidays we've found canal boats very useful (and an insurance against Will being in plaster). When he was older he learned to steer in and out of locks while the rest of us laboured at paddles and ropes.

Sometimes we rented cottages, and once on a farm holiday in the Lake District we had to spend a couple of days pulling the wheelchair up and down a one in five hill which had proved too much for the car. It drizzled on one of those days so we sheltered under an overhanging river bank, lit a camp fire, and had a splendid time watching the birds, fish and dragonflies, and throwing stones into the river.

We used to picnic a lot and became experts at finding places where we could park on a sheep-trimmed sward and play cricket which Will loved, or which had steep slopes nearby which he could climb, pulling himself up by the heather.

Boyhood hobbies

Like many fathers I tried to interest Will in my own boyhood hobbies—archery, catapult, stamp collecting, Meccano, model aeroplanes and radio controlled boats. We tried dinghy sailing and Scalectrix cars; he loved Action Man, chess was a success, and for years we played cricket and football adapted to his limits, but for the rest he humoured me. None of my old hobbies really gripped him, but at least he got a wide experience and I a lot of fun. We did succeed in getting both children swimming early and both are very much at home in the water.

My wife's mother bought the children a pair of tricycles when Will was about six, but to our great disappointment he couldn't manage to ride at all because his feet simply slipped off the pedals. We mentioned this to the head of his special school who produced a pair of adjustable footplates discarded by another family. These were easily fitted to his trike and he soon learned to ride.

For many years we shared family outings with both children 'a-wheel' We used to carry Will's on a roof rack and even managed to find a quiet and level road where he could join in blackberrying.

We tried, in bringing up the children, to help Will to gain the experiences appropriate to his age. For example, when he was tiny, we used to play tag with him on my shoulders which helped him to know what it was like to run and dodge and have the air rushing past his face. Later we steeled ourselves to let him race his wheelchair dangerously downhill, recognising that any other boy would be doing the same thing with a soap box, with his parents nowhere near.

School—and a trip to Greece

When Will was about nine he became conceited and contemptuous of the rest of his class in the special school at which he was a weekly boarder so that, after a talk with the head, who was very co-operative, he transferred to the local primary school. This was very good for him. He managed to hold his own and to complete his schooling with the rest of his class via the comprehensive school, where, again, he fitted in well.

When Kath followed her brother to the comprehensive we became aware that sooner or later she would ask to go abroad on a school trip, so when a friend who taught classics at a Grammar school asked Joan if any of us would like to make up the numbers on a trip to Greece we jumped at the chance.

Joan and I discussed carefully which parent should go with Will and decided it should be me—which was just as well because nearly everything worth seeing in Greece is on top of a mountain.

Informal social

It was a marvellous trip, we climbed to the Acropolis—and kept up with the party everywhere. Will developed a pressure sore almost at once, despite all my care, so we used the wheelchair or he went on my shoulders, and when this proved exhausting we bought a clothes line and the kids pulled us up the roughest tracks, with me steering the lurching chair on its back wheels.

Each evening was an informal "social" and I was soon able to withdraw into the background and chat with the teachers while Will played chess with all-comers or talked and sang with the other children.

William Bee at the wheel of his specially adapted car. With the car came freedom and independence.

Our group went one night to dinner at a Greek restaurant, Will drank a little too much beer and sparkled with tipsy wit. On the last night he compèred the children's concert from a wheelchair with great aplomb. It was a wonderful experience for him and a very good holiday for me.

We were extraordinarily lucky in the timing of this trip—Will was 14, old enough to mix well with the other children, just young enough to accept having me around. Our determination to keep up with the party ensured that we were accepted and helped, but without this it would (very reasonably) have been thought impossible for him to attempt the climbs, and certainly he would have come home with more and worse pressure sores.

But the trip was a new and experimental one with various odd people to make up the numbers, and I suspect that on a routine school trip a parent might feel very much an outsider and perhaps be forced into an over-protective role. I think the others may have gained something from Will's presence, and that experiments of this kind should be encouraged.

Teenage friends and a Bactric chair

The trip to Greece took place in the spring, and during the following term and the summer holidays two or three of Will's schoolfriends fell into the habit of calling for him and taking him out in his wheelchair. He could walk sufficiently well for them to enjoy themselves using the wheelchair only as a means of getting somewhere where they could lark about, and they often used to go swimming (we live at the seaside).

This was a very pleasing development, but we were concerned at Will's dependence on his friends. We solved this difficulty by obtaining a Bactric wheelchair for him via the Rowntree Trust. This was a huge success because it gave him as nearly as possible the independence of any boy of his age—he could call for his friends, they could walk longer distances, or he could go out on his own.

This gaining of independence at the right time, and in company with his schoolmates must have contributed a lot to the development and maturing of his personality. The Bactric chair was well suited to its purpose, though he turned it over once in the early days when speeding down a hill, but we weren't pleased with it in other ways. William's is prone to minor mechanical, and major electrical faults, the disc brake is poorly designed, and service is very expensive.

School books

As Will's studies progressed, so the number and weight of the books he had to carry increased in number and weight. He insisted on using a duffle bag like everyone else, and solved the weight problem by dragging the bag along the floor. This was expensive, and a nuisance because bags of reasonably good quality were hard to find. I tried rivetting a piece of hardboard to the bottom of the bag, but was eventually reduced to getting a hoop of metal made up to reinforce the hardboard.

A motor car and full mobility

When Will was born, my sister, who worked in the Health Service and forsaw the difficulties ahead more clearly than we did, opened a savings account for him, and this enabled us, when he was 17, to buy him a car. I was convinced that it would be possible for him to drive an automatic car without the need for hand controls, and the owner of our garage agreed after we had sat Will in the model we considered buying and checked very carefully.

We sent Will off to London—on his own—to the B.S.M. disabled drivers' consultancy service. They advised hand controls, but Will said they tested him rather less throughly than we had, so we decided to back our own judgement and ordered a Honda "Civic" automatic after we had checked that his wheelchair would fit through the hatchback.

I used Will's "Meccano" to make a mock up of the brake and clutch pedals and started testing. The car came a couple of months early, so we had the brake and clutch pedal positions altered a bit, and I was

Continued over page

Continued from page 11

able to start experimenting with Will driving on private land and we were ready for road tests by his 17th birthday.

I taught him to drive initially and we modified his driving aid as we gained experience, sometimes after quite alarming incidents—his foot once stuck under the brake pedal with the accelerator down! The final version was made entirely from scraps of timber I'd hoarded.

Will's left foot rests out of the way on a special platform, and his right heel is able to slide sideways in a groove. There is a rest for his right foot in the accelerator position, and a vertical member which serves both to keep his left foot safe and to prevent his right from moving too far when braking. The car has a false floor of hardboard to which two round steel studs are fitted, over which the base of the aid slides quite easily. With the aid removed the car is ready for any ordinary driver, and one is not aware that the pedal positions have been altered.

Once I was confident that Will could control the car safely we arranged lessons with an experienced instructor, with me giving him a lot of practise. After five months he passed his test at the first attempt, and some months later went with Katherine for a 700 mile tour of friends and relations and was really beginning to feel independent.

Driving Aid

The making and testing of his driving aid was not without risk but I'm convinced that it's been very well worth-while. I'm sure that it's very important psychologically that he drives an ordinary car without need for hand controls. Physically it's valuable, too, because he is using his right leg all the time he drives. He takes his boot off and drives in a plimsoll and the movement and sensitivity of his right foot (which is very limited) is improving as a result of the exercise.

The car gave him, of course, complete freedom to go out with his friends, and the independence which is so important at this age. We were particularly pleased, that during the marvellous summer of 1976 he often went off in his Bactric chair for a "walk" or a swim on his own. The Bactric attracts stares and curiosity, and it takes courage to expose a scarred and mutilated body in swimming trunks on a crowded seaside promenade, and we had been afraid that he might be tempted by the anonymity of a motor car.

Clothing problems

Clothes are a constant problem with physically handicapped children. Standard garments often do not fit, and they are subject to unusual wear and tear. I've described how Joan used to strengthen his garments when he was little. When he went into long trousers she had to develop a skill in tailoring to alter both trousers and then jackets to fit him. As he's matured the proportions of his body have departed increasingly from stock size.

Joan still alters his jeans and slacks, but he wears tailor-made jackets, and likes to have a tailor-made suit available. Oddly enough, it's very important that his pyjama trousers are altered, because with his left leg 2" shorter, he would be unable to walk in them. I hate buying clothes, and if not under wifely pressure, choose something as near as possible to the fashions of 20 years ago and sneak out of the shop, but Will knows what he wants, and persists, with great confidence, until he gets it.

Learning responsibility

We've always tried to think in terms of Will's overall development while dealing with day to day problems and encourage him to take his share of the responsibility. At 18, he signed the consent form for his last operation, and although we discussed it together, the decision to have it was his, and he planned his life to include it.

The recovery was extremely slow this time. After eight months he was only just able to walk sufficently well to go out occasionally with the help of friends, and it was another month before he started re-learning to drive. Will has set his own programme for walking practice.

We have always insisted on getting him out of hospital as soon as possible after each operation, Will having learned the physiotherapy exercises so that we could continue to do them with him, and I've grafted onto this programme a few general fitness exercises. It's gratifying that this time he included these in the programme, tough, but careful, which he followed with determination.

He is now living away from home and we are confident that he will cope. He has learned to treat his own feet. He should be able to check and rub them himself, helped by regular visits to a chiropodist, and, more important to gauge the amount of use they will stand so that he'll be able to adjust the extent to which he needs to use his wheelchair.

- **Mr Bee mentions several 'do-it-yourself' aids in these articles. If anyone wants to see plans of these or would like more information please contact Jill Vernon, ASBAH's Aids and Appliance Officer. She should be able to advise on the suitability of these for individual children.**

The third and final part of William Bee's story will appear in the next issue of LINK

Flexistand is firm favourite

A LONDON children's hospital has tested the Flexistand standing frame (see picture) with a range of spina bifida children, and is very enthusiastic about the results—most children complained bitterly when they were taken out of it!

The Flexistand looks attractive, is easy to move and to adjust, and is virtually impossible to tip over.

The stand is useful for very young children to give them their first experience of standing upright and they can then be left to play safely. It is also useful for the older child who may have difficulty with, or dislike, calipers. The child can join with others in a nursery group to play round a table, and can stand safely to join in other games—for example—learning to catch a ball.

As the frame can be modified or adjusted to take children of varying sizes and disabilities, it is likely to be particularly useful for day nurseries, schools etc. As with many other aids, the stand should only be used with the advice of a therapist, to ensure that the frame is adjusted.

The Flexistand was designed by Malcolm Johnston, working with the Newcomen Centre at Guy's Hospital, and it costs £43 + VAT. (incl. postage and packing).

Available from: Joncare,
18 Appleford Drive, Abingdon,
Oxon. Tel: (0235) 28120.

Chair gives support

THE TUB CHAIR, a well made sturdy chair, provides good back and side support and is ideal for younger children. The back and seat can be easily padded with foam.

The chair seat is 9" wide × 10½" deep, and can be ordered with seat height of 11" or 14".

Price: £8.52 including VAT. Post and packing £1.06 from: Newton Aids Ltd, 2A Conway Street, London W1P 5HE. (01-637 5962)

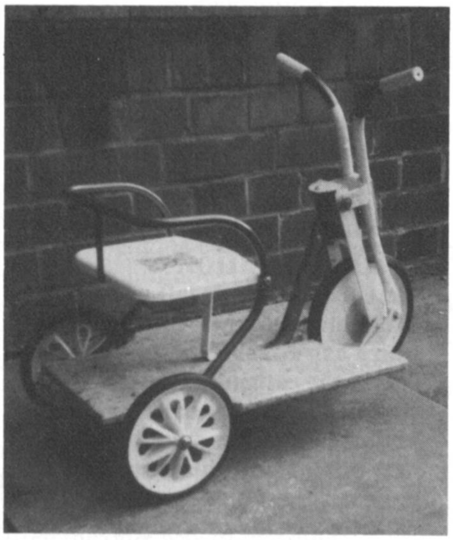
Small tricycles converted for young children

THE "HURSTWOOD" tricycle (mentioned in ASBAH aids and equipment booklet) is no longer available.

However, Keith Barnes, who makes an interesting range of wooden toys, has now taken over the conversion of small tricycles, particularly the Raleigh "Mini-Trike" (see photograph). The trike is converted so that it can be propelled by hand, and a basic footplate is also added.

You may need to modify the seat or footplate to suit individual children, but this is best done locally with the advice of your child's physiotherapist.

The trike costs £30 (including carriage charges) from Mrs Mavis Reynolds, 41 Hatherley Road, Sidcup, Kent. Tel: 01-300 5795.



Raleigh Mini Trike after conversion

Stayflex prevents caliper wear

WE STILL have supplies of Stayflex material available, (mentioned in LINK Sept/Oct. 1977).

This is a nylon material that can be ironed onto the inside of trousers, to prevent caliper wear so that clothing will last longer. The material is not available to the general public, so ASBAH has purchased a roll, so that we can send out smaller pieces to individual families, Local Associations, schools etc.

Send a stamped, self-addressed envelope, marked "STAYFLEX", to National Office, plus one extra 7p stamp to pay for the cost of each strip (15cm × 100cm) you order.

Jill Vernon
Aids and Appliance Officer

If you're 58 or under and severely disabled claim Mobility Allowance now.

If you are aged 58 or under (i.e. if you were born after 20 December 1919) you should claim Mobility Allowance now.

Claims can also be made for children aged 5 or over.

This is a benefit to help severely disabled people who are unable (or almost unable) to walk.

It is up to you how you use the Mobility Allowance to help you get about. The allowance is worth £10-a-week.

Fill in the coupon so that we can send you leaflet NI.211 which includes a claim form and tells you more about the scheme. Or you can ask at your local Social Security office.

Claim now for anyone aged 5-58.

To: Mobility Allowance Unit, DHSS, Norcross, Blackpool FY5 3TA.
Please send me a copy of leaflet NI.211 about Mobility Allowance.

Name (Mr/Mrs/Miss)____________________ Age______

Address____________________________

____

____________________ Postcode__________

Remember only claims for those aged 5-58 can be accepted now.
Others under pension age will qualify later. MOBH/L.I

Issued by the Department of Health and Social Security.

Use of catheters in patients with spina bifida

BY
A. M. K. RICKWOOD, FRCS
THE CHILDREN'S HOSPITAL
SHEFFIELD

IN PERSONS with spina bifida the nerve supply to the bladder is often deficient. From this two major problems may arise. The first, and more obvious, is incontinence of urine. The second is poor emptying of the bladder which can result in back pressure on, and damage to, the kidneys.

Any form of treatment for such a bladder should ideally overcome both these problems simultaneously. Unfortunately no form of treatment for such "neurogenic" bladder is ideal, but in recent years a number of techniques have evolved which offer patients the possibility of achieving dryness coupled with satisfactory emptying of the bladder.

Among these techniques are the use of catheters. A catheter is simply a tube which can be inserted, via the urethra, into the bladder and so empty it. It is most important to realize that not everybody with spina bifida and a neurogenic bladder is suitable for catheter management: some require no special treatment, others may be better treated in other ways, by surgery or drugs, for example. Yet others, potentially suited for catheter treatment, may not benefit from it.

Given that a person is considered suitable for trial of catheter treatment, the two alternatives are intermittent or continuous catheterisation. I will deal with these alternatives separately, giving some idea of the principles and practical considerations involved.

Intermittent Catheterisation

With this method a catheter is inserted into the bladder by patient or parent. The bladder is emptied and the catheter is removed. This process is repeated at intervals of, say, three to five hours. The object of the exercise is that the individual should stay dry between each catheterisation so that the interval between two catheterisations is adjusted to achieve this. If this is not achieved then there is no point in this management.

The typical person who benefits is one who can be expressed but only stays dry for, say, two hours or less because the bladder is not completely emptied by expression. Suppose the bladder can only be half emptied by expression, then if a catheter is passed and the bladder is completely emptied, it is possible to stay dry for twice as long. This method can only help when the bladder capacity is reasonably large. It is not necessary for those who can completely, or almost completely, empty the bladder by expression.

> 'No surgery is involved and nothing irreversible has been done'

Intermittent catheterisation has a more limited role in those who pass urine without expression, at fairly long intervals, but without any control. In this case, with the use of the catheter the time of voiding can be regulated.

Although intermittent catheterisation can be used for girls and boys, its use is limited further by three factors. *Firstly* the effort involved makes it unsuitable for very young children where incontinence is not a major problem. *Secondly,* the procedure must be painless; this is usually, but not always, the case. *Thirdly,* it is not usually suitable where there are already marked back pressure changes on the kidneys.

In younger children parents are taught the procedure, but older children usually learn to do it themselves. Various types of catheters may be used—the essential features are that the catheter should be large enough to drain the urine quickly, but not so large as to cause damage. The same cathether is re-used. An antiseptic solution is required to keep the catheter free of bacteria between each catheterisation. In the home or school environment it is impossible to make catheterisation sterile, but without over elaborate precautions it is possible to make the procedure adequately clean.

Two questions parents often ask. *Firstly,* can passing a catheter cause any damage? This is a possibility but is exceptionally rare. *Secondly,* won't inserting a catheter introduce infection? It should be remembered that this treatment is mainly used in those whose bladder empties incompletely, and this is a major factor in causing infection. In fact, by regularly and completely emptying the bladder, intermittent catheterisation may actually reduce or eliminate infection.

Continuous Catheterisation

Here the catheter is left permanently in the bladder, and the urine drains into a bag attached to the outside end of the catheter. This may be strapped to the upper leg or abdomen, and has a tap so that it may be emptied when convenient.

Because a simple tube type of catheter would fall straight out of the bladder, catheters used for continuous drainage incorporate an inflatable ballon at the tip which retains them in the bladder (this is the Foley type of catheter).

This type of treatment is usually less suitable for boys, but its use in girls is more widely applicable than intermittent catheterisation. For dealing purely with incontinence, its use is not limited by the capacity of the bladder, and it is particularly useful in helping incontinent girls with a small capacity bladder.

It is also very useful in girls who have back pressure changes on the kidneys as a result of poor bladder drainage, particularly when the pressure in the bladder is high. This is because the catheter keeps the bladder empty all the time. With continuous catheterisation, kidneys markedly affected by back pressure often return to normal within a few weeks.

Not all can tolerate a continuous catheter, and various problems may be encountered, especially with urine leaking round the catheter. These problems cannot be predicted in advance.

Because the catheter remains for long periods in the bladder it must be inserted in a sterile fashion, and this requires some expertise, and must usually be done by a nurse or doctor. Suitable arrangements can generally be made with a district nurse, school nurse or a local hospital.

Even with these precautions infection can be a problem, although it seldom gives major complications because drainage of urine is good. It can be minimised either by continuous antibiotic treatment or by washing out the bladder regularly via the catheter with a mild antiseptic solution. Parents usually learn to do this themselves.

The ordinary type of Latex Foley catheter soon becomes encrusted with debris from the bladder, and so requires changing every two to four weeks. If continuous catheterisation is successful, the newer but more expensive silastic Foley catheter is used, which only needs to be changed every four to six months.

This is a brief summary of catheter management. Obviously it is not perfect and requires some effort on the part of patient and parent. Often the only way of deciding whether the effort is worthwhile is to try it and see. Its great advantage is that no surgery is involved and nothing irreversible has been done. If it is successful much has been gained, but if not, nothing has been lost.

Christmas is coming . . . so don't forget to buy ASBAH Christmas cards.

The leaflet showing the cards and other seasonal buys is available from the Appeals Department.

Kate, back in 1974, when the crew of HMS Bacchante decided to 'adopt' ASBAH—just one of thousands of occasions that she personally attended.

Presentation at the House of Lords

OUR Vice President, Lady Masham very kindly arranged a happy afternoon at the House of Lords when Mrs Anne Wall who had given a substantial donation to purchase mobility aids was able to attend in person and hand over two Thistle trikes.

Esther's appeal nears £43,000

WE are still receiving donations and the total now stands at £42,782.

We must record our gratitude to Mr Higgon and the staff and pupils of Martindale School and, of course, the Hounslow Education Authority for allowing us to film the appeal there.

The children themselves played a very important role for it was their bravery that caught the viewers imagination, but the staff gave their time and patience so willingly and we are very grateful.

Hail and farewell

AS this is the last report I shall produce for LINK, I should like to take this opportunity of thanking all the members of ASBAH for their never failing friendliness and kindness.

I have enjoyed my seven years very much and was fascinated to see that in that time I have raised slightly over one million pounds. This shows what a very deserving cause ASBAH is.

I am now handing over to Miss Judy Kay who has been a most successful fund raiser, first with Action Research for the Crippled Child and latterly with the Bournemouth Symphony Orchestra. She is young and very charming and extremely capable and I am pleased to be handing over to someone who will I know be immensely successful.

KATE WHITE

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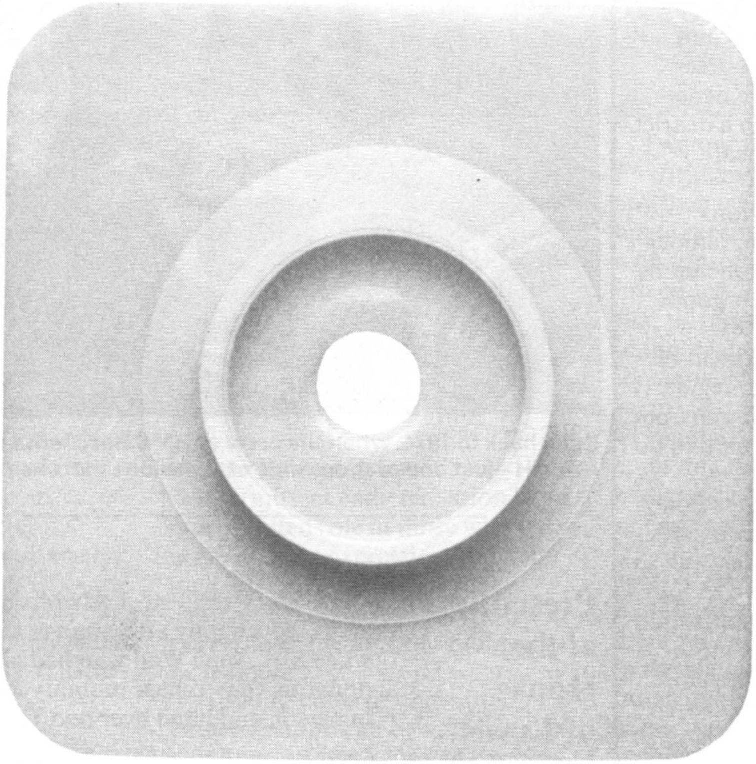

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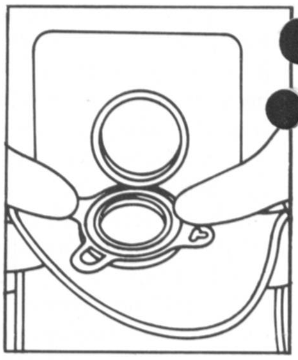
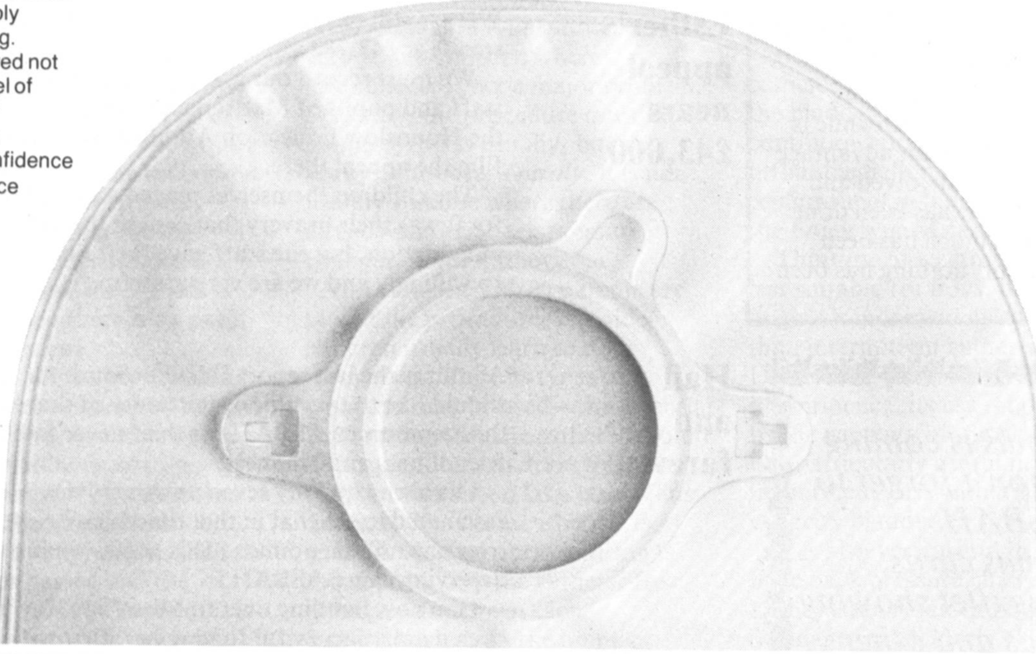


The colostomist, for example, may change pouches several times a day without the need to disturb the Stomahesive^{TM} base and its flange.



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CLASSIFIED 'ADS'

Adverts for next LINK must be in by October 1. The address is: LINK Advertising, ASBAH, Tavistock House North, Tavistock Square, London WC1H 9HJ.

Rate: £1.00 for up to 25 words. £2.00 for 25-40 words, £3.00 for 40-60 words. Please send remittance with your advert. You may like to pay for a whole year's advertising in one go.

HOLIDAY ACCOMMODATION

ISLE OF WIGHT: Brambles Chine. Holiday chalet. Open all year. Ring Mrs Gully, Seaview (I.O.W.) 3194.

SELSEY: Well-equipped specially designed, mobile home. 7-berth plus cot. Details (please send SAE) to: Mrs D. M. Driscoll, 26 Limes Avenue, Waddon, Croydon, CR0 4JX.

WINTERTON-ON-SEA, Nr. Gt. Yarmouth: 6 berth chalet, indoor swimming pool, shop, play areas. Details: Mr R. Morris. Tel: High Wycombe 32184.

ASBAH booklets etc . . .

Your Child with Spina Bifida, by J. Lorber, MD, FRCP	25p
Your Child with Hydrocephalus, by J. Lorber, MD, FRCP	20p
The Nursery Years, by S. Haskell, MA, Ph.D, and M. E. Paul, Dip.Ph.H	15p
Children with Spina Bifida at School, Ed. P. Henderson, CB, MD, DPH	30p
The Care of an Ileal Conduit and Urinary Appliances, by E. Durham Smith, MD, MS, FRACS, FACS, and others	15p
Clothing for the Spina Bifida Child, by Barbara Webster, SRN, RSCN	15p
Aids and Equipment	60p
Information leaflets	100 for £1.30

All available from ASBAH, Tavistock House North, Tavistock Square, London WC1H 9HJ. (Special rates available to Local Associations.) Please note that postage is extra. Allow minimum of 9p per booklet.

Scottish Spina Bifida Association Booklets

Growing Up with Spina Bifida, by O. R. Nettles, MCSP, ONC	20p

Available from: The Scottish Spina Bifida Association, 190 Queensferry Road, Edinburgh EH4 2BW (at special rates for bulk orders).

FUND RAISING AND PUBLICITY MATERIAL

Posters

Best Foot Forward 20 × 30 in.	**10p each**
Best Foot Forward 15 × 10 in.	**10 for 40p**
For local publicity 15 × 10 in.	**10 for 40p**
Car Stickers	**5p each**
Cards for Notice Boards	**10 for 10p**
Plastic Lapel Badges	**3p each**

All available from Appeals Dept.—postage extra.

The Appeals Dept. carries a range of fund-raising items, i.e. pens, balloons, calendars, matches, tabards, car stickers. Send for list and order form.

Flag Day equipment can be obtained direct from: Angal, 48a Holmbush Rd, London SW15 3LE (01-788 5464).

DON'T forget to send LINK an advertisement for your holiday chalet or caravan in time for the 1979 season. Advertisements for Nov/Dec LINK must be in by October 1, and for Jan/Feb issue by December 1.

WANTED

Old fashioned clothes. Victorian up to 1940. Please contact me before giving away Granny's old clothes, especially nighties and blouses. Cash paid. Please tel: 01-658 0660.

SERVICES

THE DISTRICT Advertising Company of EMI Elstree Studios, Shenley Rd, Borehamwood, Herts. WD6 1JG, offer a special service to charities. They produce telephone, address and notebooks free of charge, for fetes, bazaars and other events; fund-raising charts, with pockets for donations, which also help recruit membership and promote your cause, and are displayed in public houses, restaurants, on factory noticeboards and other prominent places; programmes for fetes, donkey derbys, bazaars and football matches etc. Calendars and Diaries can also be obtained, all free of charge. For further information contact Mr J. A. Alter, at the above address or tel: 01-953 1600 ext. 171.

FOR SALE

Tee Shirts: White Cotton with Green Family symbol and words Support Spina Bifida. £1.60 each 22"-30" £1.85 small, medium, large, plus postage. State size. From Mrs M. Humphreys, 27 Orchard Way, Holmer Green, Bucks, for Bucks/East Berks. ASBAH.

THE SHASBAH TROLLEY
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Standard model for children 1-5 years: £15 plus carriage.

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All enquiries to: Mrs K. Charrett, 46 Tillbrook Road
Regents Park, Southampton

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