

Association for Spina Bifida and Hydrocephalus/ASBAH

10p

Jan/Feb 78



Housing: Motability is launched: EMI Scanner offers new method of investigating hydrocephalus.

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THE RELIABLE SOURCE OF SUPPLY



IN A recent statement to the House of Commons on mobility for the disabled, Mr. David Ennals, Secretary of State for Social Services, said 'The House will be aware that the Mobility Allowance for the disabled went up substantially last month (November), from £5 to £7 a week - an increase of 40 percent.

The Government is convinced that a cash benefit is generally the most appropriate way of helping severely disabled people with their mobility. First, cash provides flexibility: it allows disabled people to make their own decisions

in ways that fit their individual needs.

And, second, a cash allowance does not discriminate unfairly against those who are too severely disabled to drive. The Mobility Allowance is paid to drivers and non-drivers alike. It has already brought mobility help to about 60,000 people who would have received no assistance whatever under the old scheme.

Double the money

'I am pleased to be able to inform the House that, with effect from July 1978, the rate will be £10 per week and will thus have doubled in less than a year. I know that this major boost in help for the disabled will be warmly welcomed, not only on both sides of the House, but also by the 100,000 people expected to receive the allowance when fully phased-in.

The Government has also decided that the new and higher level of Mobility Allowance should, in future, be protected against inflation. There will, therefore, be an annual uprating starting in November 1979. The Allowance will of course continue to be taxable, which ensures that it gives the most help to those in

greatest need.

Limit to government aid

'No Government can be expected to meet all the mobility needs of the disabled. It is reasonable for the disabled, like other people, to contribute to the cost of their own mobility. Any help which can be given to assist disabled people to make the best use of their resources is clearly very much to be welcomed.

'The House will recall that with this in mind I and my Hon. Friend the Minister for the Disabled have been engaged in discussions with a number of organisations and individuals over recent months. I am pleased to say that these discussions have now borne fruit.

Value for money

'At our suggestion, a group of prominent people drawn from the professions, from finance and industry, from voluntary bodies and from the trade unions, and chaired by Lord Goodman, has now set up a voluntary organisation (Motability: see story, page 4) for the United Kingdom, working in collaboration with the Government, to ensure that disabled people, both drivers and passengers, who want to use their Mobility Allowance to obtain a vehicle will get maximum value for their money in doing so.

The large increases in Mobility Allowance last month and next July, together with the formation of the new Motability organisation, mark a major advance in the provision of mobility for the disabled, drivers and non-drivers alike.

This is a field in which both the voluntary sector and the Government have a role. The Government will continue to fulfil its responsibility; and I am sure the House will wish to join me in welcoming the initiative of Lord Goodman and his colleagues and in wishing their venture well.

Correspondence to ASBAH at the National Office: Tavistock House North, Tavistock Square, 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: Mrs K M White

Liaison Officer: Mr H D Macfarlane

> **Education, Training & Employment** Officer: Mrs B Newman

Aids & Appliance Officer: Miss J Vernon, BSc.

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LINK Editor: Mrs S I Gearing

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THE NEW LINK

WELCOME to this new style LINK. Please let us have your views, news and letters. We cannot produce a good magazine without your participation.

The deadline for material is February 1 for the March/April LINK, and April 1 for the May/June issue, and so on.

Write to Mrs. Susan Gearing, Editor, LINK, ASBAH, Tavistock House North, Tavistock Square, London WC1H 9HJ.

The yearly subscription for LINK (UK) is £1.15, which covers the cost of postage. Views expressed in LINK are not necessarily those of ASBAH. While every care is taken to ensure the accuracy of information published in LINK the publishers can accept no liability.

FRONT COVER: To start the bright new LINK here is the bright and happy smile of 18 year-old Mary Boylan of Trafford ASBAH.

Motability brings new 'lease-a-car' plan

A NEW organisation — Motability — is being set up to help disabled people who choose to use their Mobility Allowance to help cover the cost of running a car. It will be a voluntary, non-governmental organisation which will supplement and not duplicate state aid

Motability follows general concern that while the Mobility Allowance — £10 a week from next July — is a big step forward in extending mobility to non-drivers, the phasing out of the invalid car which accompanies it leaves some disabled people worse off.

Charity

The organisation is being set up by Lord Goodman and other individuals at the request of the government. It will be a registered charity and will have the support of both government and opposition.

Motability will get administrative backing from the Government, including a grant towards expenses. Schemes of assistance which do not pay for themselves will be financed from voluntary sources.

It will work in conjunction with the Royal Association for Disability and Rehabilitation and the corresponding organisations in Scotland, Wales and Northern Ireland, and will seek assistance from other organisations working for the disabled.

Motability's aim is to help people obtain and run suitable cars, either as drivers or as passengers, where they are unable to drive and seek aid for this purpose. But it will be up to the disabled people themselves to decide whether they want to use Motability's facilities or to make their own arrangements.

Motability will have two main functions. The first, and the most important, will be the provision of facilities to enable disabled people to get the maximum value for money from their Mobility Allowance and other resources. It will give information and advice about the choice of cars and the adaptations needed to the normal controls. It will negotiate favourable financial arrangements and make them available to the severely disabled.

The most important result so far achieved in this field is that the clearing banks have agreed to make up to £100 million available on terms much more favourable than could be procured by any individual disabled person. This should enable Motability to work out a scheme for leasing cars at minimum cost, and in certain circumstances to purchase a car.

Secondly, as a charity, Motability will try to make provision for cases of hardship — where the disabled person cannot afford the full costs of the required mobility. Its capacity to do this will depend on the public response to appeals for funds.

Motability hopes to be fully operational and ready to receive applications by next July. At first it may have to operate a system of priorities dealing first with those who most need help. But the resources already offered show that no long delays should be involved for anyone.

THERE ARE now 16 ASBAH social workers throughout the country. The main areas served are: Buckinghamshire, Berkshire, West Surrey, North Hampshire, South Hampshire, Staines and Hounslow, West Sussex, East Sussex, Warwickshire (Birmingham), Warwickshire South, South Wales (Glamorgan) and South Wales (Valleys and Gwent), Manchester (Trafford), South Liverpool, North Liverpool, and Leeds and Bradford. A new worker is being recruited for St.

Helens, Lancashire.
Workers have considerable experience in social work, and before beginning their ASBAH duties they spend time at hospitals which specialise in the treatment and care of spina bifida and hydrocephalus, and work alongside social workers who have been dealing with the problems of

Social work aid proves its value

spina bifida and hydrocephalus for a number of years.

In 1973 there were two social workers. The expansion indicates a growing awareness of the need for many families to share their problems with somebody equipped to help.

Social workers attend conferences, give talks to local authority staffs and establish close links with hospitals and other statutory authorities, to create wider awareness of the needs of families.

Groups with disabled in mind

A growing number of organisations exist to help the disabled. Here is a brief introduction to some of them.

THE FORMATION of the National Disabled Passengers Association in May 1977 was a big step towards changing the situation of people who are too disabled to drive. In the past this group has been left out or given less state help with external independent mobility.

The newly formed Association wants to see the principle of parity suggested by the Mobility Allowance become a reality. It will represent its members at meetings and debates on independent mobility for the handicapped, and, for the first time, the needs and opinions of people too disabled to drive will be heard.

The aims of the Association include
— ensuring that the Mobility Allowance
is raised to a realistic level which will
provide the most severely disabled
person with adequate mobility; discovering the problems of mobility,
social and financial, of this group;
collating them and bringing them to
the attention of relevant government
departments. Where possible the
association will give advice and help.

If you are interested in joining send a SAE to: The National Disabled Passengers Association, 16 Calder Court, Britannia Road, Surbiton, Surrey.

Miss HILARY JONES Secretary NDPA

EVERY year, during the summer, Jet Set One, a group of 35 young and young-minded people, go on a light-hearted holiday/pilgrimage to Lourdes. The helpers come from all walks of life, the handicaps are many and varied. The party stays for a week at Hosanna House, a well-equipped hostel, five miles from Lourdes in a tranquil and picturesque setting.

Everyone enjoyed their week last summer and there was time for quiet reflection. One of the helpers was a qualified nurse, and it is hoped a doctor

will attend this year.

If you are interested, get in touch with me: Mike D'Alton, Jet Set One, 59 Silhill Hall Road, Solihull, W. Midland B91 1JT. THE NATIONAL Bureau for Handicapped Students was established with the main aim of improving opportunities in further and higher education for handicapped people. The bureau covers physical, sensory and mental handicap.

It aims to provide information on all aspects of education of interest to the handicapped student, to act as an information centre for the work being done for the handicapped by institutions in tertiary (further and higher) education, as well as other bodies, to promote good practice, and to coordinate, where appropriate, the work of other organisations. The services of the bureau are available to individuals and institutions.

A newsletter, Educare, is produced quarterly, with news of developments and research, as well as information on matters such as aids, grants, and facilities within tertiary education.

Subscriptions are: individual £5.00, student £2.00, and institutional £10.00 per annum. Members receive the newsletter and other reports and are eligible for election to the governing council.

Further information from: National Bureau for Handicapped Students, Thomas Coram Foundation, 40 Brunswick Square, London WC1N 1AZ.

INTERNATIONAL Pen Friends was founded in 1967, to promote international friendship. Now tens of thousands of members are corres-

ponding.

Profits from a stamp exchange scheme are given to UNICEF, to help underprivileged children.

For more information contact Ralph Power, International Pen Friends, 127 Lower Glanmire Road, Cork, Ireland.

In the meantime we have been contacted by a 13-year-old girl with spina bifida who would like to write to another girl with similar problems. Because her only handicap is incontinence, she is able to attend an ordinary school, and she lives in the Bedford area.

If you would like to write to her, please send your letter to National Office, addressed 'Pen Pal', via Information Officer.

THE PURPOSE of the Disabled Campers' Club, which is an independent charity, is to provide integrated, self-catering, camping holidays and to apply pressure on planners on behalf of disabled campers/caravanners. There is a free advice service to members, a news bulletin and the club hopes to issue a list of approved sites for members.

Enquiries (with SAE please) to: Mrs L. Strong, Secretary, Disabled Campers' Club, 28 Coote Road, Bexleyheath, Kent DA7 4PR.

Life really does go on

I THOUGHT that I would write to tell you about having to start a new life in a Cheshire Home after the sudden death of my father.

Luckily my parents had always talked about what would happen if anything happened to them and I was not able to look after myself. They said I would have to go into a home, and that I would be very well looked

No regrets

I have not regretted my new life for one minute even though it took some getting use to at first. I only hope that other parents of spina bifida children will discuss this point with their children because there is nothing worse than leaving the child in ignorance of the thing that is going to happen eventually.

Now a word for spina bifidas, do not be agraid of going into a home because in some cases you can be more independent than you can be at home. Some of these places have special equipment to make you more independent. And the staff at this home will only help you with things you cannot manage: you are expected to do as much as you can for yourself.

Visitors can come any day they wish and they can take you out for the day. All they have to do is to tell the matron or the person in charge so that they will know whether to save your tea for you.

If you have your own invalid car you can set off early in the morning and not come back until late at night, just as long as they have left a brief idea of where you are going so that if you break down you can be collected by the home's own ambulance.

I hope I have given you a brief idea of how good these homes can really be. I should also mention that I am a member of the Calderdale Association for Spina Bifida and hydrocephalus, and I hope that the members of the Calderdale Association will read this and realize that I have really settled down here at Spofforth Hall, thanks to the friendly staff and residents.

> PAUL JAMES CALLAGHAN Spofforth, Yorks

Finding the right answers

WHAT? WHY? HOW? These are the words that I uttered when my husband told me that the baby I had just given birth to had spina bifida.

I was so ignorant about spina bifida. I had always thought it was a really horrible thing. But I had given birth to a beautiful baby boy - he wasn't horrible and nasty. The truth was that I knew nothing of spina bifida and, therefore, I did not know that it is something which gives a person a handicap but is certainly not ugly or horrible as I had once thought. In fact there is a lot of beauty to be found in people with spina bifida.

Anxiety

After the initial questioning was over all I could think of was - please God, let my baby live. Whatever he hadn't got I would give him. If he couldn't walk then I would be his

In my anxiety to collect him from hospital I had forgotten to take his outfit of clothes. He was brought home in hospital clothes but I did not care. I soon got into the way of tending to a small baby again and I had a grand helper in his big sister who is a "model mum" at the grand old age of six.

At the Spina Bifida Club I met mothers and fathers and children of all ages. I found them really super and my daughter enjoys the company.

I have found this club invaluable as I have spoken to other families and learned of different problems that I may have to face and how to deal with them. I also enjoy helping with fund raising and other activities to help the children.

Worthwhile

There is no point in saying that life is as easy as it would have been if my son had not had spina bifida. There are the worries that one normally has and there is also the extra work involved with clinics, hospitals, physiotherapy, etc. But it is all worthwhile when your spina bifida child does something that you had been told might not be possible. There are things that he will never do but with the help of family, friends, neighbours and clubs like the one I attend, I will overcome any problems I have to face.

I am one of the luckier ones - my son may walk - but at least I now give a lot of thought to children and adults who are worse off - something which I never did before. They say there is a reason for everything - I guess this was God's reason for me.

> FIONA M. DENWETTE Stenton, Glenrothes

ROUND-UP

Queen Leanda — by popular command

THE PARENT Teachers Association of the village school organise the summer carnival in the Northants village of Brigstock, but it is the children who choose the Carnival Queen. And last year they picked seven-year-old Leanda Cooper who is confined to a wheelchair with spina bifida and hydrocephalus.

On carnival day Leanda's wheelchair was lifted onto a decorated float and she rode around the village with her two attendants. Another float followed, carrying the school children

in fancy dress.

On returning to the school playground Leanda was crowned by Dr. Robert Wigglesworth, a leading consultant paediatrician for Northamptonshire. He described Leanda as a girl with outstanding courage and ability.

Guide camp is a beginning

TWO TEENAGERS from the Huddersfield Association spent an enjoyable week at an experimental Guide camp for the able and less able guides of N.E. England. The camp was at Welburn Hall, Kirkbymoorside, N. Yorkshire.

Helen Wharam and Diane Brook took part in a variety of activities such as bell ringing, drama, craft and campfire entertaining, as well as taking an active role in the daily routine of the

The County Commissioner for the North-East has given the go-ahead for a similar event in the next year or so.



Is it on? Leanda Cooper being crowned Carnival Queen by Dr. Robert Wigglesworth, FRCP, DCH. See 'Queen Leanda — by popular command'. Photo: Northampton Evening Telegraph.

Sweet note of success

FIFTEEN-YEAR-OLD Jill Pepper of Flamborough is making a name for herself with her singing and guitar playing. After successes in talent competitions she was asked to take part in a Scarborough charity concert in aid of autistic children.



The five who cycled from John O'Groats to Land's End. See 'Long haul Photo: Southern Newspapers.

Happy seven go abroad

FOR THE first time members of Hull Association have ventured abroad. A party, including seven handicapped members, five children and two adults, travelled by North Sea Ferries from Hull to Rotterdam.

Mrs. Gerritje Brown, Association secretary and organiser of the trip said it was a success from start to finish. The cabins were first class, the crew very helpful; the hotel in Rotterdam had a lift and the food was very good. During the round of sight-seeing the whole party made it to the top of the Euromast — some 643 feet.

The trip was financed by local groups and organisations. Mrs. Brown is now planning a second trip for seven more members in May 1978.

Long haul up to £550

AT A DANCE held by the Southampton Association, five schoolboys from Glen Eyre School, Southampton, proudly handed over a cheque for £557.78, the proceeds of a gruelling sponsored cycle ride from John O'Groats to Lands End.

The five, Mike Watts, Mike Egan, Mike McCartey, Gary Cummins and Peter Baxter left Southampton on July 10 and arrived at Lands End on July 28. They were helped by Steve Cummins driving the mini bus which accompanied them and Derek Hayter,

navigator.

The money started the ball rolling on an ambitious project by the Association to raise £20,000 towards a work and social centre for physically handicapped youngsters. The foundations for this will be laid in 1978. Southampton feel strongly that handicapped youngsters should have the opportunity of doing a worthwhile job of work and the centre will cater for many different occupations suitable for handicapped people.

It's a real family effort

THE BUSINESS of sorting through old books in the Barnish family home in Weston, Notts., soon sparked off the idea of holding a jumble sale. Andrew 14, Wendy 13, Christopher 12, and Gary 8, roped in mum and dad and in due course £22.50 was raised and sent to the National Association.

Irish plan is to set example

THE IRISH Association for Spina Bifida and Hydrocephalus was founded in Dublin about nine years ago. It now consists of sixteen branches covering all parts of the country.

Among the schemes organised by the branches are pre-schools which provide physiotherapy, occupational therapy and Montessori teaching. The cost for all this, including transport, is met by the Association and only recently was there a grant from the State towards the cost.

A domiciliary physiotherapy scheme is also provided where the parent and child find it much more beneficial for the therapy to be given in the home rather than the hospital. A similar scheme in occupational therapy is also provided.

In some areas transport is provided or subsidised for children to attend schools and clinics. Christmas parties and summer outings are provided.

There is one great difference between the Irish and the British

Associations. Where the British Associations employ many social workers in order to obtain the maximum benefits available from the State, the Irish Association has adopted a different policy, namely to set up its own services and then encourage the local Health Boards to subsidise the costs and eventually, we hope, they will take over some of these services completely.

No social worker is employed by the Irish Association but we can pass on problems to social workers at the National Rehabilitation Board which is run by the State. In this way we can obtain help for Individuals but it does mean that the Association does not get information from the social worker which makes it rather difficult to follow up on these problems.

Relaxed

What we call "seminars" are held about four times a year. A team of professional people such as physiotherapists, occupational therapists, psychologists etc. spend one whole day in a hotel and each one individually interviews each child and its parents. Problems are discussed and advice given in a relaxed atmosphere.

The Association also provides money for research, interest free loans and grants towards cars to provide transport to places of employment, loans and grants towards house improvements and extensions to suit

the handicapped.

A pilot training scheme for spina bifida adolescents was held last summer. The scheme covered woodwork, metalwork and artwork and the theme was to discover the capabilities of the participants and to help the Association to plan for the future by providing employment or further training towards gaining open employ-

Crucial stage

The development of the Association is now at a crucial stage. Young children must still be catered for and we must increase our resources and efforts to cater for them in the future.

The real pressure, however, comes from the fact that so many of the young children who have been helped by the Association in the past are now in need of immediate help as teenagers about to take their place in the world with as much independence as possible.

> **GERARD COLLEY General Administrator**

Girls hop on a bus—50 times

SPONSORED walks, sponsored silences and sponsored games are common methods of raising funds but three girls from North London, Nicola Wood, Rachel Bromnick and Esther Bromnick opted for something different - a sponsored bus ride around London using Red Rovers.

They travelled on 50 different routes during their day of adventure and finished their trip in style on one of the famous Silver Jubilee buses.

Katherine Brace went as an observer and spent a lot of her time booking the girls' records as they swopped from bus to bus. Total raised by this novel experience was £70.

The girls were also very busy on a Jubilee boat trip on the Thames for the Central and North London Group when they helped with a party of 100. This party included a group of 12 in wheelchairs so they were kept very busy on board the catamaran Sue Rita. The rain and wind did not dampen the spirits of the group.



GOODYEAR Car Club has supported the Dudley, Wolverhampton and Sandwell Association for the past two years. Officials Mike Morris and Jack Lunt have organised social events and raised enough money to buy four electric wheelchairs.

Three of the chairs were presented by racing drivers Gunar Nilsson, Danny Sullivan and John Watson. Pictured (above) from the left Danny Sullivan, Bert Baldwin (Goodyear), Gunar Nilsson, Jack Lunt and Mike Morris (Goodyear) and John Watson.

The children are, from the left, David Smith, Lisa Welton and Jane Oakley.



Members of the Hull Association about to head for Holland. See 'Happy Seven

Medical

EMI scan offers new method of investigating hydrocephalus

ONE OF the major advances in the diagnosis and management of hydrocephalus in recent years has been the development of a magnificent x-ray apparatus called the EMI or CAT scan. 'CAT' stands for Computer Assisted Tomography.

X-rays taken with this apparatus will show up the size of the patient's brain, the ventricles within the brain, their size and shape and any other abnormal substance which may be there, such as a tumour.

It readily shows up hydrocephalus and shows its exact degree. The examination is totally painless and harmless and involves very little radiation.

The disadvantage, at the present, is that the patient has to hold still for about three or four minutes. This means that it is not possible to carry out this examination in a child under five years of age without an anaesthetic.

Valuable help

It is a useful technique for measuring the size of the ventricles in children with hydrocephalus. It can be done serially. Such an examination is a valuable help in determining the function of the shunt and the position of the catheter in the cerebral ventricle.

There is one other major disadvantage. The apparatus is extremely expensive and newer models may cost up to £300,000. There are only a few such scanners working in the country and there is severe pressure on all such units because they serve all the neuro-surgical and neurological needs of large areas.

The EMI scan is also a valuable research aid and has already resulted in striking discoveries in spina bifida children, which are the subject of reports being prepared.

New technique

In 1967, Godfrey Hounsfield CBE, FRS, originated a technique known as computed tomography or CT scanning which led to the development of the EMI-Scanner, a system which by combining sophisticated methods of X-ray detection with advanced computer technology, allowed the easy examination of soft-tissue structures in the human



The EMI-Scanner CT5005.
Photograph — EMI Medical Ltd.

anatomy, something not previously possible without the use of uncomfortable and sometimes hazardous procedures.

For examination on a CT scanner the patient lies on a couch while a gantry containing an X-ray tube and sensitive detectors (in place of the X-ray film), takes many thousands of X-ray absorbtion readings.

These readings are used by the built-in computer to calculate the various tissue densities and then present a picture of a cross-section through the area being examined on a television screen. In the latest systems the picture can be viewed within one minute of the start of the examination.

From a series of contiguous scans the computer is also able to produce pictures of vertical sections, thus giving the doctor 3-dimensional information on the tissue structures.

Areas difficult or impossible to see by conventional X-ray procedures such as soft brain tissue, the spleen, pancreas and details of lung tissue can be painlessly and accurately visualised. This vast amount of additional information assists the doctor in making a faster, more accurate diagnosis, leading to improved methods of treatment and a better chance of recovery for the patient.

Dr. JOHN LORBER MD, FRCP. Children's Hospital, Sheffield.

ASBAH Spring Conference: 'Towards Independence'

7-9 April. Roehampton, London

THIS looks like being another interesting and enjoyable Conference so do try to come along.

Robin Smith, Director of the Queen Elizabeth's Foundation will be the Conference Chairman, and Duncan Guthrie, Director of the Disabilities Study Unit will be the opening speaker.

Other speakers will include professionals who in one way or another are concerned with the welfare of those with spina bifida and hydrocephalus.

The Conference fee has now been fixed at £18 (inc VAT); £15 for young spina bifida adults aged 16–21. The fee for those accompanying conference members will be £15 for adults, and £12 for children under 12. These prices of course, include full board and residence. Booking forms are available (from mid January) from National Office.

PLEASE BOOK EARLY – if possible by the beginning of March.

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you can ask at your local Social Security office.

MOBILITY ALLOWANCE CLAIM NOW FOR ANYONE AGED 5-55.



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Name (Mr/Mrs/Miss)					
Address					
Postcode	Age				
(Remember only claims for the Others under pension age will	ose aged 5-55 can be accepted now. qualify later).				

THE FIRST two books came out in mid 1977 but some readers of LINK may not yet have come across them — and they are certainly worthy of a place on a good many bookshelves.

The Child With Spina Bifida by Elizabeth Anderson and Bernie Spain. Methuen. £7.50 hardback. £4.95 paperback.

THIS is an outstanding handbook — one of the most comprehensive studies of the spina bifida child, and it is aimed at helping parents as well as professionals.

The authors, Elizabeth Anderson and Bernie Spain — both well-known for their research work and their concern for those with spina bifida — have adopted a multi-disciplinary approach to this study.

Drawing on their own and other research, they provide a fully comprehensive and up-to-date account of the range of problems associated with spina bifida. They cover incidence and cause, physical problems, family difficulties, the needs of the younger children, choosing a school, learning problems and teaching methods, social and emotional stresses facing the young child and the adolescent, and the prospects for school leavers.

The authors make practical sug-

gestions for reducing or alleviating many of these problems.

My Children, My Children by Robert Reid. BBC Publications. £3.50. THIS book expands some of the ideas expressed in Robert Reid's BBC 1 Television series, and is a highly readable and absorbing study of attempts by scientists, engineers and the medical profession, to track down the cause and to alleviate the condition of spina bifida.

It is the human story of men and women involved in medical advances that can only be described as dramatic. They include people such as John Holter and Eugene Spitz, Ian Donald, David Brock and Roger Sutcliffe, Diana Marris, Muriel McKay, John Lorber, James Renwick and Alec Hamilton.

The book is a record of ingenuity, medical skill and personal determination, and it presents the implications of medical research real in human terms.

Directory For The Disabled by Ann Darnbrough and Derek Kinrade.

£4.25 from Woodhead Faulkner Ltd., 8 Market Passage, Cambridge CB2 3PF. LAUNCHED just before Christmas by Alfred Morris, Minister for the Disabled, this is a handbook of information and opportunities for the disabled and handicapped.

Reference copies are available at ASBAH National Office and the book should be in all the major public libraries. It contains an enormous amount of information on statutory services, benefits and allowances, aids, house and home, further education, employment, mobility and motoring, holidays at home and abroad, sports and leisure activities.

How To Push A Wheelchair by David Griffiths and David Wynne. Free from the Disabled Motorists Club, 6 Lime Grove, Oswestry, Salop SY11 2QE. (send s.a.e.).

THIS is not just a booklet for wheelchair 'attendants' but also for the handicapped person.

It provides much useful information to prevent the occupant of a wheelchair being deposited on the ground. It also presents information on dealing with kerbs, other obstacles and transfer from chair to car seat.

Appeals

Charities may get something for nothing

THE DISTRICT Advertising Company of EMI Elstree Studios, Shenley Road, Borehamwood, WD6 1JG, offer a special service to charities. They produce telephone/address books free of charge, getting their revenue from the advertisers in the book.

The book is nicely produced and can be sold at fetes, bazaars, coffee mornings throughout the year.

They are also in the process of producing a fund raising chart with a little pocket for donations, to be hung

in public houses, restaurants, canteen notice boards. This could be adapted for display in hospitals, clinics, etc. The editorial in the centre of the chart would be to your own wording and you could choose the colour.

Another service is the production of programmes for charity matches, fetes, etc. If any Association is interested they should write to Mr. J A Alter at the address given above.

As this is the first Link of 1978 we send you our very best wishes for a fruitful and rewarding year. We plan to step up our programme of fund raising events and to attract more regular subscribers. We have an expanded team to cope with the extra workload. Here it is:

Mrs Maisie Burgess: trusts and wills; Cathy Holder: my personal assistant; Valerie Hunter-Brown: special events organiser; Percy Cox: assistant appeals organiser; Geoff Towler: appeals office manager; Daphne Smith: direct mail assistant; Ted White: volunteer (direct mailing); Mrs Mary Whitehead: volunteer (direct mailing).

Would you please write to us if there are any ways in which we can be of help to you in the activities you are planning. If we don't have what you want we are always willing to make enquiries to see if it is possible to get it

1978 PROGRAMME

Pigeon Show at Blackpool – 21/22 January.
'Crown Jewel Ball' at the Dorchester – 16 March.
BBC1 T.V. Appeal – 19 March.
Harlequin Ball Dinner/Dance at the Savoy – 23 May.
Albert Hall Concert – 2 October.

KATE WHITE:

A home worth living in...

THE PROVISION of 'accommodation' is accepted in our society as a basic obligation, met in shapes, sizes and materials to suit taste, environment and circumstances, some selected or accepted happily, others imposed.

A handicap is a criterion accepted by all concerned with housing as justifying special considerations, of as much importance as finance are the emotional and social implications of the provision. A home is not a utility. It is a place where a family or an individual is able to experiment, to exercise individuality and to achieve the maximum quality of independence.

There are those for whom support must always be provided, firstly by parents and later by statutory or voluntary bodies. The articles contained in this issue of LINK tell of the Acts of Parliament in the terms of which some provisions for the disabled are made.

However, some houses, many privately owned, cannot be adapted for a disabled adult and the need to move presents the implications mentioned above. Our Association is able to help by finding an adviser, independent and informed, competent to see the entire issue and be flexible.

Independent disabled individuals and married couples, where one or both partners are handicapped, have accommodation needs which are being met as often by Housing Associations as by Local Authorities. Our Association has decided not to form a Housing Association but to co-operate with the specialist groups, using the expertise available. It is hoped the Local Associations will unite with Housing Associations at local level, encouraging the provision of units to meet special needs.

Our Association accepts its responsibility to advise and take action, on behalf of the disabled of all ages, in this important field of accommodation.

H. D. MACFARLANE Liaison Officer THE HOUSING Act 1974 contains provisions for the welfare of registered disabled persons. From the Act, two main grants emerge: intermediate grants and improvement grants. Both grants were introduced primarily for the improvement of older 'eligible' property, but now include 'eligible' persons — registered disabled persons.

It would be reasonable to assume that any property, not being council owned, would attract some form of grant aid. Make the fullest enquiries if you think that you may be eligible. It is important to note that these grants are in addition to help which may be available under the Chronically Sick and Disabled Persons Act 1970 and are not subject to testing of your income and savings.

How to apply

Your application for either intermediate grant or improvement grant will be made usually to the local Environment and Health or Housing Department, before applying for help under the Disabled Persons Act. In many cases the Social Services Department will help you to make both your applications. Remember that you should still receive a grant under the Housing Act 1974 when the Social Services Department are unable to give a grant under the Disabled Persons Act, due to lack of funds. If you are an owner/occupier you will be required to certify that you intend to remain at the improved address for a period of five years.

Intermediate grants bring some of the basics within reach

The intermediate grant relates specifically to toilet, wash basin, bath or shower, kitchen sink and hot and cold water supply. Where any of these items (known as standard amenities) are not *readily* accessible, due to disability, a grant may be paid in respect of additional items which *are* readily accessible.

The important point is that the existing item is not *readily* accessible. While a disabled person may quite

comfortably be able to climb stairs to the toilet, lifting him/herself from step to step in a sitting position or walking with calipers, this cannot be regarded as a readily accessible toilet. Therefore, a grant should be payable in respect of an additional toilet at ground floor level. Similarly, where a disabled person normally sleeps upstairs and climbs the stairs as before, he/she should be eligible for a grant in respect of a toilet upstairs, where the existing toilet is at ground floor level.

Shower aid

While bath aids may prove of great value to some disabled persons, these usually prevent a person from being fully immersed in the bath water. In these cases, therefore, a grant should be payable either for a shower over the existing bath, a shower to replace the existing bath or a shower in addition to the existing bath.

The same principle would apply to a wash basin. The hot and cold water supply would of course be included with the appropriate fitments but there is a grant for this as well. A grant should be payable for a more suitable type and more 'readily' accessible type of sink unit to replace an existing sink unit. Occasionally it is necessary to disturb an existing item in order to provide room for other items. A grant should therefore be payable for the disturbed item.

Actual cash

With Intermediate grants, limitations are placed on the amounts payable in respect of each item. The actual cash you will receive will be half the cost of the work or the following fixed amounts, whichever is the less amount:

,	TOOL MILLOWA
Toilet	£135.00
Bath or Shower	£ 90.00
Hot and Cold Water	
Supply to Bath or	
Shower	£115.00
Wash Basin	£ 35.00
Hot and Cold Water	
Supply to Wash Basin	£ 60.00
Kitchen Sink	£ 90.00
Hot and Cold Water	
Supply to Kitchen	
Sink	£ 75.00

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Improvement grants help you adapt for a smoother life

This Improvement grant is given entirely at the discretion of the council concerned and is restricted to properties with a rateable value not exceeding £225.00 (£400.00 in Greater London). While the Act states that a grant is payable for work required for the welfare, accommodation (and employment) of registered disabled persons, welfare and accommodation could be taken as meaning any work which provides for the safety, comfort and convenience of a registered disabled person.

In most cases, (but not all), there is a limit of 50% payable. Or, as in the earlier grant, half the actual cost of the work, whichever is less. This grant can cover, a bathroom as before, ramps, widening of doors, levelling floors, handrails, lower or raised switches and plugs and many other items.

Normally there are conditions relating to the age, life and condition of the house, which have to be complied with, but, in the case of works for registered disabled persons, many councils now use their powers to waive these conditions. (Though it is sometimes convenient to have your home improved at the same time).

A booklet entitled 'Housing Grants and Allowances for Disabled People' has been published by RADAR at 25 Mortimer Street, London, W1N 8AB.

If you would like further details or have any queries in connection with these grants please write to the Chief Executive Officer at the Association headquarters, Tavistock House No.th, Tavistock Square, London, WC1H 9HJ, or contact your local assocation.

W. L. GRADWELL, M.I.O.B. Disabled Living Adviser, Trafford Social Services



Crossroads signposts way to keep families together

THE CROSSROADS Care Attendant Scheme was set up in 1973 to give practical help to families caring for the disabled at home. It aimed to show the need for this kind of help, meet the need, and prove that disabled people, given the right kind of help, could be successfully cared for at home.

The Scheme is registered as a charitable trust, and was sponsored in Rugby, Warwickshire, by ATV Network Ltd., who originally donated £10,000 to cover a two-year pilot project. The Department of Health and Social Security (DHSS) gave a further grant

Pat Osborne, Director of the Crossroads Care Attendant Scheme with Noel Crane.

of £5,000 in March, 1976, to cover one more year.

The name came from the ATV serial, "Crossroads". Noel Crane, a young, severely disabled person, contacted the studios about their portrayal of a newly disabled person. He subsequently met the producer of the programme and the medical adviser.

Care attendants are a combination of nursing auxiliary and home help. A trained nurse is responsible for the grass roots running of the scheme and the attendants, as part of their training, spend a week in the community, with district nursing sisters, visiting all types of homes and families.

Much emphasis is placed on attitudes, rather than on technical procedures, as we want the attendants to learn these from the disabled themselves and their raltives.

Originally we intended to place an attendant in the home of a disabled person in an emergency. However, it soon seemed wrong to keep the attendants on a register, waiting to be called upon and we changed our thinking and aimed at prevention.

Regular support

The attendants now go into homes on a regular support basis, and the scheme, while not replacing the district nursing sister, home help or auxiliary, provides help in hours which are mostly regarded as unsocial — late at night, very early in the morning, at weekends and during public holidays.

We have had very few emergencies, and we believe that by giving this small amount of help, on a regular basis, emergencies have in fact been prevented.

The peace of mind which the relatives now have cannot be over estimated. The big difference to them is that they can have help WHEN THEY WANT IT. To know that somebody will visit, at a given time, and do something practical, as well as talk and listen, means very much to them.

We have served a wide range of age groups and encountered many different problems. Help has been given to parents of handicapped children and in the first two years we were able to assist 28 families. We made 3,000 visits.

The Scheme has stimulated interest on a local and national level, and many reports and surveys now recommend the setting up of this type of operation.

The DHSS, in 1977 granted £10,000 to the Crossroads Scheme which has enabled it to have a national base and a full-time organiser.

How to link with housing associations

'SPECIAL PROJECTS: Through Housing Associations' is a very useful guide produced by the National Federation of Housing Associations. It contains basic information, primarily for voluntary groups, explaining how they can liase with housing associations to provide accommodation for disadvantaged groups, whether it be a hostel for disturbed teenagers, a home for elderly Asians or flatlets for the disabled.

This guide might set local ASBAHs wondering if they could become involved in providing accommodation for some of their members!

The guide explains how housing associations operate and how they are financed. It covers the housing association grant, special projects, and gives advice on how a voluntary group should go about establishing a link with a housing association. The guide is available from: National Federation of Housing Associations, 86 Strand, London WC2R 0EG.

We are now active on three fronts: Locally - for the year 1977/78 Warwickshire Social Services granted £5,000, which not only gave the Crossroads Scheme a great boost, but has set other areas thinking about following their example.

Nationally – We believe that this is a project which falls clearly between both Health and Social Services Departments; it is an obvious candidate for joint funding. The attendants' duties lead to a saving on demand for residential care and long-stay hospitalisation. They supplement domiciliary statutory

services.

EEC Project - £100,000 has been granted to the United Kingdom, by the Social Affairs Directorate of the EEC for a research project which will investigate ways of keeping severely disabled people in their own homes. Housing, in its many facets - mobility, wheelchair, adapted - will be researched together with the provision of domiciliary care of the Crossroads type.

An occupational therapist will assess housing needs and about £30,000 will be used to carry out

structural alterations.

Three years

Four areas have so far been chosen to participate in the programme and in each of the areas the Social Services Departments have agreed to finance Crossroads Schemes. The project will last for three years and up to £5,000 per year, provided by the Social Services Departments, will be matched by the DHSS.

The Housing Development Directorate of the Department of the Environment will be administering EEC housing research grant and there will be a sub-contract with the Care Attendant Scheme

Trust.

When Noel Crane picked up the telephone to criticise a small part in a popular television series, he could have had no idea of the results of his action.

The original grant from ATV afforded a chance to sort out the problems. Now we will use the next three years to produce not only evidence of our research programme but also practical help for disabled people wishing to stay in their own homes.

PAT OSBORNE SRN, NCDN Director Crossroads Scheme.

Mrs Osborne will be happy to forward booklets giving details of the Crossroads Scheme: Mrs Pat Osborne, SRN, NCDN, Crossroads Scheme, 11 Whitehall Rd., Rugby, Warwicks CV21 3AQ.



IN THE kitchen of one of the specially designed flats at Whitby Court, Holloway, North London. . . .

Thanks to co-operation between the local authority and John Grooms Association, 12 flats for the disabled have been incorporated into this new local authority housing complex, which comprises a total of 64 dwellings for rent.

It is an important principle of the Whitby Court Scheme that the disabled people are not grouped together in a separate building. There are three blocks of flats - a two-storey, a three-storey, and a four-storey block - and the disabled flats occupy the whole of the ground floor of the three-storey block, and alternate flats on the ground floor of the four storey block.

Ten of the special flats are for one or two people and two are for up to four

people.

All the flats are designed for use by chair-bound disabled, whether living alone or as one of a family. But the emphasis is on independent living and there is no warden on call.

John Grooms' first housing project at Finsbury Park was sheltered housing, with a warden, and having gained experience in the pilot scheme the Association was anxious to take the concept of independence for the disabled person one stage further in this latest scheme at Whitby Court.

Photo: John Grooms Association for the Disabled.

EVEN with the best of intentions things can still go badly wrong for the disabled when it comes to housing. Moves by central and local government, voluntary agencies and sometimes social workers which are all designed to help can sometimes, quite perversely, have the opposite effect. Below ANTHONY BASSETT, parent of a spina bifida child, writes of his own experiences in this respect. It is a sorry tale. Happily it is not typical. We publish it not to deter others from seeking help but to warn them that the path to a better home may not be a smooth one and to offer the help of National Office should difficulties arise.

A family's struggle for a better home

PARENTS of handicapped children should start planning for the future when their children are still babies. It can be a long time between the planning stage and the finished product, especially if a local authority is involved. Housing is something which needs to be thought out carefully.

A great deal depends on the extent of the child's handicap, the area in which the family lives the financial situation of the family and on the amount of assistance available from

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government, local authority and charity sources.

When our daughter was born in 1964 we lived in a semi-detached house which was some distance from the shops and schools. By 1966 we realised that, owing to her disabilities, it would be advisable for us to find a bungalow or ground floor flat.

In 1968, with the help of a member of the Association, we found a bungalow which we could just about afford.

By 1972 we started to realise the difference between coping with a handicapped baby and a handicapped young child. Before these problems became too great we decided to ask the local social services department for assistance in extending the bungalow to give our handicapped daughter her own room and also to adapt the toilet and bathroom. We were offered a loan by the county council of £3,000 to pay for the adaptations.

A social worker from a Trust visited us and offered to have plans drawn up by an architect friend. We thought this was wonderful at the time as prior to that time we had really wondered what social workers did (and we still wonder what they do).

Responsibility

A year passed and there was the question of who should pay the architect's fee. The Trust said it was the council's responsibility. The council said it employed its own architects and would not pay for an independent architect.

The County's architect drew up some plans and one of the designs was chosen. By this time, however, the estimated cost of the proposed adaptations had increased — according to the County's architect — to £6,000. It was also a new financial year for the County Council and it was at this point that the Social Services Committee, in its wisdom, decided that it could no longer offer us the original loan; this was despite the fact that this loan had been offered in writing and had been accepted in writing.

It was suggested that our handicapped daughter should be placed in hospital for long stay care. This was presumably because it would then transfer the financial responsibility from the County Council to the National Health Service. It seemed that the welfare of the handicapped child and its family was the last consideration of the Social Services Committee.

Surely there is something wrong with a system that makes it acceptable to spend £3,000 per annum on keeping a child in hospital when a loan of that amount, or slightly more,

would enable a child to remain at home and in the community. It seems common sense that with a redistribution of finance an enormous amount of money could be saved.

Having argued with the County Council, involved the press, radio and television and having taken the matter to the all-party group of MPs concerned with the handicapped, the Minister for the Disabled, the national Ombudsman, we got nowhere. Not being able to afford to take the Council to Court we decided to solve the problem ourselves.

It was now 1974. The plans were modified to keep the cost down. The work had to be done in slow stages, as and when the money was available. A loan from the local Spina Bifida Association enabled us to buy the building materials. The Family Fund offered a grant towards storage space for the wheelchairs and other equipment but would not make a grant towards the extension as it held that this was the County Council's res-

ponsibility.

Under the Housing Act 1974, the Housing Authority for the Council can make grants to cover circumstances such as ours. However, the rateable value of the bungalow was above that set down in the Act and we were eligible for a small grant for the bathroom conversion only — payable on completion of the work. The officers from the Environmental Health Department were most helpful and sympathetic, but they obviously had to conform with the criteria laid down in the Act.

September 1977: the adaptations to the toilet and bathroom were complete and a shower had been installed. The extension is complete except for the ramp into the garden. The project has cost to date about £1,500; the grant under the Housing Act was £175; the social services committee decided to match this with £175.

The worry anf frustration of dealing with the social services department, the Trust and supervising the project must have taken ten years off our lives. It took five years to do what could have been done in three months. Our handicapped daughter is still living at home with us.

What can the Spina Bifida Association do to ensure:

- the Chronically Sick and Disabled Persons Act is worth the paper it is written on?
- the criteria in the Housing Act is amended?
- there is some system for the redistribution of finance to give the greatest benefit to the handicapped and their families and the greatest saving to the nation?

Volunteers provide some of the best answers

SOME OF the best housing schemes — whether for purpose-built flats, or converted, specially adapted property — are provided by voluntary housing associations such as the Habinteg Housing Association and John Groom's

Finding out the full range of housing available in any area is no easy task.

The local authority housing department will be able to put you in the picture about its own schemes which are suitable for the disabled, but it may not be so knowledgeable when it comes to schemes run by housing associations. The planning department or the local authority, or even the social services department may be able to help.

The Housing Corporation — Head Office, Maple House, 149 Tottenham Court Rd., London W1P 0BN provides lists of associations carrying out charitable housing schemes as well as those doing co-ownership schemes, but their list is not fully comprehensive as it is made up of the associations it funds.

Information

Other schemes are funded by local authorities and are, therefore, not included in the Housing Corporation listing.

The National Federation of Housing Associations does not carry an all-purpose list, but the nearest it gets to this — in the London area only — is the London Housing Association Annual Report which provides some information about associations working in the various boroughs.

The next Report should include a breakdown of the kinds of accommodation likely to be available for the coming year, and one section refering specifically to specially designed accommodation for wheelchair users.

Do not forget that your own local ASBAH — and in particular the local ASBAH social worker if you have one, are there to give advice and practical assistance and help with regard to housing and house adaptations.

National ASBAH keeps up-to-date with the housing scene and Mr.
Macfarlane, the liaison officer, will do all he can to give advice and support as needed.

CLASSIFIED 'ADS'

HOLIDAY ACCOMMODATION

PRESTATYN: Two well-equipped 6-berth caravans. £25 (off peak £12.50). Mrs. Taplin, Colonial House, 63 Corporation Street, Manchester M4 3DT.

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

Two bedroomed chalet, four—six berth, situated at **BASHLEY PARK** in the **New Forest**. Telephone: evenings only Portsmouth 68193.

CHRISTCHURCH: 6/8 berth Caravan. 1 mile from sea. Near New Forest. Club House. Mrs. D. Collier, 2 Barnard Close, Nythe, Swindon.

WITHERNSEA: Well equipped 6 berth chalet at Golden Sands Chalet Park. Shop. Licensed club. Play areas. Amusements on site. Details send SAE to: Mrs. P. O'Callaghan, 14 Dyer Lane, Wheatley, Halifax. Tel: 0422 56402.

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 Mr. F. Smith, 102 Bowyer Drive, Cippenham, SLOUGH, for Bucks/East Berks. ASBAH.

ASBAH booklets etc...

Your Child with Spina Bifida, by J. Lorber, MD, FRCP				20p
Your Child with Hydrocephalus, by J. Lorber, MD, FRCP				15p
The Nursery Years, by S. Haskell, and M. E. Paul, Dip.Ph.H Children with Spina Bifida at Sch.		n.D, 		15p
Ed. P. Henderson, CB, MD, DPH The Care of an Ileal Conduit and		 v Ann	 Jiances	30p
by E. Durham Smith, MD, MS, FI	RACS,	FACS	S, and	
others Clothing for the Spina Bifida Chil				15p
by Barbara Webster, SRN, RSCN				15p
Aids and Equipment Information leaflets			 100 for	
All available from ASBAH, 30 De W1N 2EB. (Special rates available Please note that postage is extra.	to Lo	cal As	sociatio	ns.)
per booklet. Scottish Spina Bifida Association	Bookl	o te		
Growing Up with Spina Bifida,	DOOKI	ers		
			:	20p
Available from: The Scottish Spin 190 Queensferry Road, Edinburgh				
rates for bulk orders).				
FUND RAISING AND PUBLICIT Posters	Y MA	TERI	AL	
Best Foot Forward 20 x 30 in.			10	p each
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stickers, etc. Send for full list and order form.

The Appeals Dept. carries a range of fund-raising items,

such as pens, balloons, calendars, matches, tabards, car

THE CLASSIFIED advertising section is something new for LINK' and we do hope that your 'ads' will come pouring in!

It will take in 'ads' not only for Holiday Accommodation, but also for articles For Sale or Wanted, For Hire etc. Let us know what you want to advertise and we will let you know if you can!

Rate: £1.00 for up to 25 words. £2 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.

Adverts for March/April LINK must be in by February 1, and for May/June LINK by April 1, etc. The address is: LINK Advertising, ASBAH, Tavistock House North, Tavistock Square, London WC1H 9HJ.

Letter

WHEN I moved to West Sussex in February, 1972, I was so pleased to be able to join a group and meet other families with similar problems instead of feeling completely isolated.

I am sure that I speak on behalf of many parents who will agree that social worker Sue Newham, who has recently retired, will be greatly missed in West Sussex. She had that very special quality of always being the same each time she visited in spite of a very tight schedule. She was also a very good listener — a very important factor. When problems arose one knew that she would go away and do her utmost to solve them, and this gave one support and confidence which is so necessary when looking after a handicapped child

MARGARET J. CARROLL Chichester, West Sussex

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Mrs S. G. Plymouth.

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Mr R A Frake, 11 Scott Close,
Wallisdown, Hants.

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HUDDERSFIELD Mrs J Brook, 11 Standiforth Rd., Dalton Huddersfield, W. Yorks. HULL & DISTRICT Mrs G D Brown, 233 Cranbrook Ave., Hull HU6 7TX. Tel: Hull 857165.

JERSEY Mrs M V Houze, 46 Don Street, St. Helier, Jersey, Channel Islands.

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LONDON SOUTH Mrs Glazebrooke, 10 Freshwater Close, Tooting, SW17.

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23 Melbourne St.,
Mansfield Woodhouse, Notts.

MIDLAND Mrs D Britt, 1075 Warwick Road, Acocks Green, Birmingham B27 6QT. Tel: 021-707 2930.

NORTH EAST (Northumberland) Mrs E Grant, 27 Redwell Rd., Prudhoe, Northumberland

NORTHAMPTONSHIRE Mrs A Hardy, 28 Eastbourne Ave., Corby, Northants.

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