SPEAKING UP- M

The Newsletter of Action for Dysphasic Adults

Christmas 1989
Issue No. 22

ADA ON THE MOVE . . .

This will be the last issue of "Speaking Up" that emerges from Northcote House - by next March we shall have moved to our newly built office.

Thankfully, we are not moving too far away - just up the road in fact. Our new address will be:

37 Royal Street, London SE1 7LL

... spot the difference! Yes - in future you will no longer be writing to Northcote House. British Rail is pulling it down to make room for the Waterloo Station Channel Tunnel project. We will still be at 37 Royal Street, however - and our postcode and telephone number will remain the same.

It is also good to report that we will continue to share premises with the Cicely Northcote Trust. As the new offices will be purpose built, much more space and storage room will be available - so we should be even better organised and efficient than we are now!

ADA's new office . . . eventually!

MAJOR NEW APHASIA COUNSELLING PROJECT

ADA is currently seeking funds for a unique and innovative pilot project which aims to provide speech therapists who are qualified in counselling to work specifically with dysphasic people and their carers.

The effect of severe language and communication disability on patients' psychological well-being and that of those around them is an issue of paramount importance. Coming to terms with the often devastating consequences of the disorder can be a very painful and lengthy process, and many people need more help than ADA and the majority of the speech therapy services are able to provide.

ADA is also aware that the opportunity to express fears and frustrations to others who really know and understand such feelings can at times be as important as professional' help. We are hoping that the project will also benefit from the professional counselling skills and experiences of someone who has recovered from dysphasia, so that we can provide a very special and highly skilled support service for those who are referred for help.

We intend to base this pilot project in two London health districts. Readers of "Speaking Up" will be kept informed of our progress in raising funds for this qualitative and innovative response to a major unmet need.

ADA WISHES ALL ITS MEMBERS
AND SUPPORTERS A VERY
MERRY CHRISTMAS AND A
HAPPY AND HEALTHY NEW
* YEAR

INSIDE

NEWS, VIEWS AND
MUCH MORE

NEWS FROM ADA

WELCOME . . .

. . . to the bumper'

Christmas 1989 issue of ADA's Newsletter "Speaking Up" - full of news to bring you up-to-date with our activities, our achievements - and the many exciting plans for ADA's forthcoming I Oth "Birthday"!

The most exciting aspect of this important milestone in ADA's history will be the very real opportunity for publicity. We will be doing all we can to intensify our efforts to raise awareness of dysphasia and the urgent need for improved care and rehabilitation for dysphasic people.

In this context ADA members will be interested to read of our plans for a special I Oth Anniversary Seminar where dysphasic people themselves will be given the opportunity to 'speak out' and to share their ideas and experiences. And - just as we were 'going to press' - the exciting news arrived that the Marquess of Tavistock has kindly agreed to launch the occasion!

This issue also contains more of your letters as well as two more excellent feature articles from people who know the effects of stroke and dysphasia at first hand.

We do hope these positive contributions will encourage others to use the newsletter. We want "Speaking Up" to act as a lively forum for everyone involved and look forward to hearing from you!

This will be my last issue of "Speaking Up" as I shall be leaving ADA at the end of November. I shall miss everyone at ADA and all our good friends from our membership very much indeed.

My warm good wishes are extended to all at ADA for a merry Christmas and a happy and very successful I Oth Anniversary Year.

Gini Tym

Editor, "Speaking Up"

MESSAGE FROM ADA S DIRECTOR

Since our last newsletter I have been fortunate to visit ADA's regional branches.

On 20th September I was invited to ADA Somerset's AGM and was given a very warm welcome by the many people who attended. It has certainly been a very busy and productive year for the Branch. They have achieved a great deal to support dysphasic people and their carers and increase awareness of dysphasia amongst professionals and the general public.

This year the branch has developed an awareness campaign with local GPs, taken part in an information day, organised volunteer workshops, and is planning another of its very successful weekend breaks for dysphasic people. A year of success for ADA Somerset and a tribute to the dedication and hard work of all those involved.

On 1 Oth October I made my way to Scotland to join in the 1 st birthday of ADA Fife Branch and very much enjoyed being a part of their celebrations which were packed with activities.

In common with ADA Somerset, Fife has had a busy and productive year, which has included an information leaflet and campaign with local GPs, citizens advice bureaux and other voluntary groups, the development of a carer support group, attendance

at local events and fund-raising activities.

The presence of the local Health Authority Chair at the birthday celebrations was a tribute to the credibility that ADA Fife has established in a short time.

After my visit to Somerset and Fife I am more convinced than ever that ADA must do all it can to raise the funds needed to develop more regional groups. The record of achievement of both branches indicates how effectively the word can be spread at local level.

As I said in the last issue of "Speaking Up", these are changing times for ADA. One piece of sad news is that at the end of November we shall be saying goodbye to Ginni Tym, our Assistant Director (Funding & Communications). Ginni has worked extremely hard and achieved much for ADA over the last 3 Vi years and her energy, enthusiasm and commitment will be sadly missed by us all. Congratulations on your new appointment, Ginni, and best wishes for the future.

Finally - I would like to wish everyone a merry Christmas, and a happy and successful 1990 - ADA's I Oth Anniversary Year.

Martin Green

ADA Fife Branch's 1st Birthday Party - Martin Green with Catherine Russell, a member from Dunfermline.

ADA is delighted to be associated with the production and distribution of a unique new publication. Called "In Our Own Words - Dysphasic People Talking", it records the experiences and feelings of members of the City Dysphasic Group, set up in 1970 to provide intensive speech therapy for dysphasic adults.

Many of those who compiled the booklet were completely without speech initially; all still have difficulties with speech, reading, writing and understanding spoken words. Says lean Kerr, their speech therapist: ' With the exception of the medical section, which they asked me to write, and a supplementary section on the role of the speech therapist, the words are their own. It is a remarkable achievement."

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The booklet s contents provide honest and graphic descriptions of the innermost feelings of people struck down with dysphasia and conveys very powerfully how those who lose the power of speech through stroke or head injury can suffer a devastating loss of confidence and self-esteem.

But as time went by, sufferers learned to adjust, although the process could be long and painful. The booklet stresses that it is important to keep battling and look to the future with less despair and more certainty.

Concludes Jean Kerr in her preface:.

.. "the booklet is important precisely because it has allowed group members to voice feelings that, for a variety of reasons, dysphasic people are often unable to express ... producing the booklet brought them together, encouraged them to share experiences and support one another. It is a testament to the therapeutic power of groups, and to their courage in adjusting to their problems".

ADA acknowledges with gratitude the generosity of Marks & Spencer in sponsoring this publication.

NEW ADA PUBLICATION

IN OUR OWN WORDS - DYSPHASIC PEOPLE TALKING"

PRESENTATION OF CHEQUE FOR Â£1,400 BY MARKS & SPENCER WALWORTH BRANCH. Left to right: Martin Green (ADA Director), Linda Parkinson (M &S), Ginni Tym (Assistant Director, ADA).

MARQUIS OF TAVISTOCK TO LAUNCH ADA s I Oth ANNIVERSARY SEMINAR ' DYSPHASIC PEOPLE TALKING . ."

King's Fund Centre, London - 17th May 1990

Readers of "Speaking Up" will recall an item in the last issue about ADA's plans for a very special 10th Anniversary Seminar, the theme of which will be "Dysphasic People Talking . . ."

We are delighted to report that Lord Tavistock has kindly agreed to launch the event and are most grateful for his support and involvement.

Our 10th Anniversary represents an enormously important opportunity for us to raise awareness of dysphasia and the needs (and abilities) of dysphasic people. There can be no more appropriate way of achieving this than by providing a forum for dysphasic people themselves to speak out.

The gathering will have an international dimension as speakers from Europe as well as Britain are being invited. A series of workshops led by dysphasic people will encourage participants to share their experiences and ideas, plan a programme of advocacy, and discuss ways of raising public awareness and changing perceptions of the condition.

A substantial contribution to the cost of the event is being made from a bequest from the late Miss Gwyneth Jones for the benefit of speech therapy patients who have suffered strokes.

The event will be held on 17th May next year at the King's Fund Centre, London. Full details of the programme will be published in the next issue of "Speaking Up".

SIXTH ANNUAL ADA MARY LAW MEMORIAL LECTURE

On 12th September this year some two hundred people gathered at the Royal Society of Medicine for a reception hosted by ADA's Founder President, Diana Law, followed by ADA's Sixth Annual Mary Law Lecture.

Given by Professor Audrey Holland of the University of Pittsburgh, the lecture took as its theme the psycho-social consequences of dysphasia for individuals and their families.

Professor Holland said that she believed that to understand aphasic patients as communicators, broad observations needed to be made, and these should include the patient's family and their responses to the patient, as well as the way that the aphasic person reacted in different environments.

There has been very little research undertaken into the way in which a supportive environment affects the ability to communicate, but Professor Holland stated that she believed that coping mechanisms, problem-solving skills, and motivation were evil important in determining how individuals faced the challenges of aphasia. "People with aphasia represent a broad range of communicative abilities and styles, and it should not, therefore, be assumed that treatment would be the same for all."

In conclusion Professor Holland said that aphasia threw into relief individuals' strengths, weaknesses and reactions to stressful situations, and that while it was a reminder of human problems it was also a reflection of human resilience.

From the positive response we have

received the event was greatly enjoyed by all who attended.

Martin Green

We are grateful to the National Westminster Bank for their generous sponsorship of the event.

Editor: Transcripts of the lecture are available from the office on receipt of a large SAE (9" x 6" - 24p stamp).

STOP PRESS

ADA PUBLICATIONS,
POSTERS AND
VIDEOTAPES

PRICE REVISION

Due to rising production and postal costs prices will be increased as from 1 January 1990

New price list will be available on application to the ADA office

(sae appreciated)

BBC-B or Master with dual 40 track or 80 track disc drives
Â£50.00 plus Â£7.50 VAT, Â£2.50 p & p per copy.

Concept Keyboard (A4) - telephone for up-to-date prices

ORDERS and DETAILS from:

System Applied Technology Ltd, Dept AN,

Sheaf House, Sheaf Street, Sheffield SI 2BP
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LETTERS

WE YOUR SA

From Mrs Christine England

"After reading the special feature in the Summer edition of "Speaking Up" about Percy Ward and how unselfish he was in all the various tests he must have endured over the years, I thought, I'm always saying I haven't got time to write to thank you all at ADA for the support it gives us carers of dysphasic people and the encouragement we all need to soldier on.

I use the word soldier' purposely as I feel at the end of every day as if I have taken part in a kind of war!

I am an active member of the local Carers National Association and would recommend any carer of any disability to go along and feel the atmosphere of friendship and help they have to offer. It really will lighten your load. If you have difficulty in leaving your dependant often the local group has a contact for someone to sit' for you while you attend - so do ring a contact number.

I must tell you that I care for my husband who, at 49, suffered a severe stroke four years ago which has left him dysphasic and dyspraxic. He is also an insulin diabetic.

He has had many hours of speech therapy from various therapists, but all to no avail. The local VSS helper (Barbara) noticed that he was still very good with writing and remembering numbers - especially the cricket score! So she worked on that aspect in Ken's therapy at home and as a result his frustration has lightened considerably and 1 shall be forever in her debt.

Ken fills his day doing jig-saw

puzzles, along with listening to the radio.

For the past year I have been buying the Beano' comic and, as the pictures give a clue to what the word says, Ken can actually read it! At first I was a little embarrassed to tell anyone of this success, but today he openly laughed after reading this week's issue and the joy of hearing that has motivated me to write this letter for the next edition of ADA's newsletter."

From Mrs Valerie Tucker

"It is 10 years now since I had my stroke. Ten years in which I have never worked so hard in my life.

Several times during those years I felt like giving up and taking the easy way out by letting other people do everything for me.

As for my speech, I wondered why the speech therapist insisted on me making those horrible noises that I made when trying to speak. This was the most frustrating, hard working, boring and tiring task of all.

Then, I read an article by Diana Law. 1 realised that 1 must not give up, but keep going.

But Diana seemed to be such a determined woman, who possessed inner strength. How was I to achieve so much without her courage? After a while I realised that I must not try and conquer the world but must take everything step-by-step or one day at a time. 1 became less agitated with my lot - and slowly, very slowly things became easier.

And now, 10 years later, the miracle has happened that I had so often prayed about.

1 am talking.

Not what I used to be able to do but I am able to make myself understood by strangers. I can carry on a conversation with my friends. This is the most wonderful experience of my life, actually being understood and hearing myself making clear and correct sounds. 1 thought that I would never do this again.

So - to all those people that are going through this very long drawn out procedure - it does come to an end . . . and the joy of talking again (however limited) is perfect heaven."

From Mrs Betty Kinniburgh

"1 wish to draw the attention of members to the University of Edinburgh's CALL Centre and Sally Millar, the Centre's speech therapist, who got a Q.E.D. Memowriter and computer for me.

Along with Lizzie Michelburgh, my speech therapist and my family and friends 1 have been blessed."

Editor: Our warm thanks and appreciation for these contributions. Have you thought of using "SPEAKING UP" as a way of airing your views, sharing experiences and passing on information to others?

Photographs, articles, letters and suggestions are always welcome. Just write to the Editor,"SPEAKING UP", Action for Dysphasic Adults, 37 Royal Street, London SE1 7LL.

WOULD IT BE HELPFUL TO SHARE YOUR PROBLEMS BY PHONE?

IF YOU WANT ADVICE OR GUIDANCE WHY NOT TALK TO DEBBY ROSSITER, ADA'S ASSISTANT DIRECTOR (APHASIA)

DEBBY IS ON THE END OF THE

LINE ON MONDAYS,
WEDNESDAYS AND THURSDAYS
(9.30-4.30) AND WILL BE GLAD
TO HELP.

THE TELEPHONE NUMBER IS

(01) 261 9572

SPECIAL FEATURES

Readers of "Speaking Up" will recall a feature in a recent issue entitled "Learning How To Cope ... A Carer's Experience".

Contributed by 'PJH\ this thoughtful and constructive article described his experiences as spouse and main carer of Grace', an alert lady of 75, who became hemiplegic and dysphasic following a severe stroke. It is with sadness that we report that 'Grace' died this year and we convey our sympathy and condolences to her family and friends.

The enthusiastic response to "Learning How To Cope . . ." was such that we are delighted to publish this further contribution from 'P)H' about the remarkable achievements of Helen Wulf following her stroke and dysphasia.

At his suggestion it is to be the first in an occasional series entitled "The Indomitables". We have all come across examples of extraordinary courage, fortitude and achievement on the part of people facing the formidable and often heart-breaking challenge of dysphasia - ADA's founder President Diana Law MBE, being an outstanding and inspiring example.

We now invite readers of "Speaking Up" to contribute to this new series. It is very much our hope that stories of achievement against often overwhelming odds will do much to inspire and encourage others battling with the devastating consequences of stroke and dysphasia.

GINNI TYM - EDITOR

Helen Harlan Wulf - A Story of Courage and Achievement

Helen Harlem was born in Chicago in 1913. A sociology graduate, she has lived from many years in Dallas, Texas, helping to run her husband's childwear business and bringing up her children - two boys and two girls.

Helen had a stroke in 1970 that left her hemiplegic and completely bereft of speech. Her speech therapy started a week after her stroke and after a few months she recovered sufficiently from her initial paralysis to get out and about again.

Three years later she wrote a remarkable book called APHASIA, MY WORLD ALONE.

y "It is enormously helpful
to be able to read accounts by \
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\record their experiences." y

The Need to Know . . .

One of the greatest needs of those who are caring for dysphasic people is to know what is going through their minds, since they cannot tell us themselves. It is enormously helpful to be able to read accounts by people who have recovered from dysphasia sufficiently to be able to record their experiences.

The most encouraging aspect of the whole mysterious business of stroke and dysphasia is to hear the success stories of those who have fought to regain some or all of their former abilities, or who have found ways of overcoming their handicaps.

Helen's book is an outstanding

example.

It is remarkable for its success in conveying what it really felt like to be dysphasic . . . what was actually going through her mind from the

first initial shock, through adjustment, early recovery . . . and on to the stage when enough language had been regained to be able to find the words to describe what it was like to suddenly lose, and then slowly recover the gift of speech and communication.

Helen also succeeds admirably in conveying the specific "aloneness" and isolation that is such a key feature of the experience of dysphasia,

Helen

Harlan

Wulf

and she describes in a most vivid way her interactions with the world around her.

"Balance Wheels"

In her book Helen also pays tribute to her two "balance wheels", Hans her husband and "alter ego" and Jo Simonson, her speech therapist and "life-line to sanity". Sadly, Helen has had to face the loss of both within the last two years.

Helen states that she and her husband enjoyed "52 quality years as mates, parents, partners and best friends". Hans must have been a man of great integrity, dependability, and strength of character, and Jo is sadly missed as a tower of strength and a marvellous speech therapist.

"Helen also succeeds admirably in conveying the specific "aloneness" and isolation that is such a key feature of the experience .

of dysphasia," >/

"A Stroke of Luck"

Helen's experience of her stroke and subsequent partial recovery left her determined to do something to help others.

So she started a newsletter - "A Stroke of Luck" - to be written "by aphasics, for aphasics and for their families and interested professionals". From a circulation of 250 for the first issue in 1984 its distribution has grown ten fold and it is now mailed to 2,500 recipients.

"Many who write show amazing courage and resource.

write show amazing courage and resource. Some letters sound like calls for help, and these often prompt replies from other readers with useful suggestions based on their own experiences.

It is especially heartening to read about the progress that some dysphasic people make even after several years of little initial improvement.

Apart from the encouragement of a gallant recovery, many specific lessons can be gained from the unique insights provided by Helen's book into the mind of a dysphasic person battling against difficulties almost unimaginable to the rest of us. As I remarked in my last contribution to ",Speaking Up", every stroke is different and battling through the process of recovery seems to be largely a matter of making it up as one goes along.

ASOL (as I shall call it from now onwards) now runs to 16 pages. The issue 1 have before me has 20 contributions, all in the form of letters from people who are dysphasic, which are printed as received with no editing.

It is a truism that "all strokes are different", but it must be rare for dysphasic people and their carers who receive the newsletter not to find that at least one or two of the letters are relevant to their own condition and problems. Many who

His especially
to read about the progress
that some dysphasic
people"

There is no charge, but contributions are invited towards the cost of printing and postage. It is run by a "staff" of five, scattered all over the United States and is distributed from Helen's address at 9305 WATERVIEW ROAD, DALLAS, TEXAS, TX 75218, USA.

Nevertheless, I was greatly helped by reading Helen's book and the contributions to her newsletter. Others may find them equally rewinding".

PJH

Note from the Editor: Helen's book "Aphasia, My World Alone" is available through bookshops or from Mrs Wulf at 9305 Waterview Road, Dallas, Texas TX 75218. It was published by Wayne State University Press in 1979. (The paperback International Standard Book number is 08143 1823 1).

A WAY WITH WORDS . . .

Kay McManus is a freelance writer with a number of popular childrens' books and radio plays to her mime. In 1987she suffered a stroke. We are pleased to be able to feature this vivid and moving account of her experiences in "Speaking Up".

"The Spring of 1988 seemed to produce some of the most beautiful volcanoes that I can remember

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Reading such a sentence brings back all the strangeness of the winter of 1987 when I was taken ill and spent several weeks in hospital recovering from a stroke. My memories of that time are incomplete, though friends still enjoy reminding me of all the confusions of my vocabulary during the illness. Apparently, the word 'volcano' was my recurring alternative for the word flower'!

I now understand that the lead-up' to my CVA was unusually long. But as someone who has always kept a diary I have fascinating written

evidence to confirm that my language facility was beginning to go awry some 10 days before I was admitted to hospital.

How it all began . . .

In November of that year I was busy planning a Christmas family reunion in Australia and was looking forward to the rapidly approaching departure date. It was about then that friends began to notice a difference in my speech ... apparently my voice had become lower and my words slurred. I also seemed unable to complete sentences, or follow through any particular thought.

I was completely unaware of any such changes but my diary shows the slow alteration in vocabulary. Starting with an occasional incorrect word the content gradually deteriorates into nonsense until the last entry of all, where the word dated' has been written over and over again . . .

The pages for that last 'missing'

My last memory on that Friday afternoon of 27th November is of going outside to replace the dustbin liner. Again, another dream-like experience . . . and then I found myself on my back, unable to move. I had no fear or anxiety and felt strangely detached from the person so unexpectedly horizontal on a week in November are completely blank. I was no longer able to type, or indeed to write. I recall several dreamlike experiences which hardly seem to relate to me and a faint memory of struggling to complete a thank-you letter to a friend. She told me later how alarmed she had been to receive those strange, almost illegible scribbles.

winter afternoon ... I remember thinking that it might be wise to be inside before dark, and for what seemed like hours, gradually inching my way, still on my back, over the step and into the cottage. After that I seemed to lose both myself and the dream . . .

I have no clear memories of the first few days of my month in hospital - only jumbled impressions of unexpected friends and relatives at the bedside - and my own surprise that my right hand and leg no longer seemed to be of any use.

At that time I was hardly aware of my surroundings, or of the flowers and messages of encouragement that arrived with every visitor. I remember longing only for the bliss of uninterrupted sleep!

The Road to Recovery

But gradually I began to surface into understanding and was soon moved into the bustle of a large ward. Days became busier with even more visitors and appointments with therapists. Porters appeared at my bedside and 1 was wheeled to the distant physio- and speech therapy departments, giving me a daily glimpse of all the varied and complex activity of the hospital. So many people were involved in my recovery and 1 am grateful to them all - doctors, therapists, nurses, fellow-patients and friends. I don't think 1 shall ever forget their kindness.

In the physiotherapy department I found it alarming to tackle even the simplest of physical skills, for balance had to be learned afresh. Even climbing up one small step without support seemed like some demanding Olympic challenge.

Speech Therapy

The speech therapy sessions were

just as surprising and I was certainly conscious of the destruction of and damage to brain cells! A report from the therapist reveals that my speech was fluent but rambling, and that 1 had only variable success in naming parts of my body. 1 would lose track of what I was saying in mid-sentence, had poor concentration and was unable to follow quite straightforward instructions.

Equally surprising to me was the realisation that 1 was replacing words with unusual alternatives. I can certainly remember one afternoon when I was asked to explain a simple illustration of a domestic scene in a kitchen. I found it impossible even to understand the drawing because, as 1 pointed out to the therapist, the whole thing was far too cultivated' . . .!

However, recovery must have continued for by the time my daughter arrived hot foot from Heathrow to take me home I was able to walk forward on my own to greet her with a hug - one of the best meetings ever!

Every task had to be relearnt

The first few weeks at home seemed even more of a challenge! Confidence of every kind seemed to have vanished and I marvelled at my daughter's calm belief that I was going to be able to cope on my own with all the problems ahead.

"Even ordinary^

taking out a ed t0

laying a tif rmous effort

a time.

Every task had to be relearnt. Even ordinary things like making out a cheque or laying a table seemed to involve an enormous effort of thought and will, and 1 was hopeless at remembering more them one thing at a time. But gradually, as the next month passed, we were able to celebrate small daily achievements . . . the first phone call made without help, the first walk alone to the village shop, the first visit to a friend.

After a final appointment with my hospital doctor I felt my still fragile confidence begin to grow. He saw no reason why I shouldn't eventually drive again, not why I shouldn't continue life as before, depending on my own feelings of being capable of so doing. So once more I have become mobile and can flourish - with the full approval of D.V.L.C. Swansea, and a brand new European Communities driving licence. Best of all, I am once more back to the typewriter and to the challenges and satisfactions of writing.

The gift of speech . . .

"This experience has certainly
made me /ar more conscious
of the gift of speech,
and of the mystery of those
brain cells which so precariously
hold the memories and thoughts
that help to shape personal
identity

- cells which can, as I discovered,
so frighteningly and unexpectedly
be destroyed.

Meanwhile I'm looking forward to next summer - even though I'm aware that the 'volcanoes' couldn't possibly be quite as beautiful as they were in 1988!

Kay McManus

"LOST FOR
WORDS"

â™¦ â™¦ â™¦

THIS LEAFLET EXPLAINS:

. WHAT DYSPHASIA 15
.. WHAT CAUSES IT
.. WHAT YOU CAN DO TO HELP

This booklet explains:

* What Dysphasia is

* What Causes it

* What You Can Do To Help

* Speech Therapy & the
Role of the Speech
Therapist

* ADA's aims and objectives

* ADA 's services

UPDATE

FOCUS ON ADULT APHASIA . . .

September 1989 saw a special issue of the College of Speech Therapists' Bulletin devoted to adult aphasia.

A number of interesting and thought-provoking articles were submitted - including a paper entitled "Aphasia Services: Provision or Privation?" contributed by ADA's Aphasia Adviser, Debby Rossiter. and Karen Mclnally, Chief Speech Therapist at Hastings District Authority.

Their paper presented a review of speech therapy services available for adults based on the results of an ADA survey conducted some two years ago - the first attempt at such an analysis since the publication of the Quirk Report in 1972.

ADA's survey has revealed that in some areas there was no viable adult service and proved that there is an urgent need for in-depth research, analysis and monitoring of the needs of dysphasic people. The paper called for action to lessen the present geographical lottery of care' and recommended that national minimum standards should be established as a priority.

Members of the College's Working Party on Aphasia also submitted a paper which made a number of recommendations regarding good practice in aphasia therapy, and explored issues relating to the education of speech therapy .students and the development of aphasia services.

A third very instructive paper by Eirian lones and Sally Byng explored the range of fascinating key questions and complex issues that face therapists treating aphasic patients.

Editor: Debby Rossiter has

recently been elected to the Council of the College of Speech Therapists. Congratulations Debby - we are delighted at this new and constructive association between ADA and the College.

THE COMMUNITY CHARGE AND PEOPLE WITH DISABILITIES

There is concern that some people with disabilities may find that their community charge (poll tax) will exceed previous rates demands.

Under the Rating (Disabled Persons) Act 1978, people with disabilities receive a reduction in their general rates in the form of a rebate. This was to prevent disabled people living in the community being discriminated against through higher rates demands if they were forced to make additions to their house such as a downstairs bathroom.

From March 1990 this will no longer apply because the community charge is a tax on people and not property. This may mean that where a non-disabled partner is working, a registered disabled person may not qualify for a rebate. Many disabled people on income support or very low incomes will be able to get a rebate, but ADA is anxious to hear from any of its members who may be anticipating problems.

CELEBRATIONS AT NEWCASTLE UNIVERSITY'S SPEECH DEPARTMENT

Thirty years ago this year King's College, Newcastle (as it was then known) was the first university to provide a degree course for speech therapists.

At that time there were only 400

speech therapists in Britain, and the only qualification was a licentiateship following examinations by the College of Speech Therapists. It took another quarter century before all courses leading to a professional qualification in speech therapy in Britain were taught at degree or postgraduate level. Anniversaries can be useful as salutory reminders that progress has taken place!

The official opening of a new clinical suite to celebrate the anniversary was conducted by one of Newcastle University's medical graduates, Dr Miriam Stoppard.

BOOKSHELF

GARDENING

(Published by Oxfordshire Health Authority for Equipment for the Disabled, Â£4.70 inc p&p)

Gardening can be a great source of satisfaction, but for a person with a physical disability or for someone whose strength and agility have declined, it can be a source of immense frustration.

However, as this book shows, with changes in garden design and layout, a willingness to adopt new methods, and perhaps different tools or different plants, gardening can become or remain the satisfying leisure-time pursuit of many disabled or elderly persons.

NATIONAL DIRECTORY OF HOMES PROVIDING

REHABILITATION, SHORT-TERM CARE & CONVALESCENCE - 1989 EDITION

(The Independent Hospitals Association, Africa House, 64-78 Kingsway, London WC2B 6BD; Â£9.50)

Grouped by county for easy reference this updated directory lists a wide range of homes offering convalescent and respite care. Full details are given of facilities, treatment, routine, charges and travel arrangements for each home.

OUT AND ABOUT

Free Transport Information for People with Disabilities

TRIPSCOPE is a free nationwide travel and transport information service designed specifically to help disabled and elderly people.

A registered charity founded by Claudia Flanders OBE, wife of Michael Flanders, fondly remembered for his wit and lyrics in his musical partnership with Donald Swan. Michael Flanders was, of course, disabled and as Mrs Flanders says . . . the truth is that for a person with a disability, the difficulties of getting round one's own locality, country - or the world - can be frustrating, heartbreaking, or just plain infuriating!"

Tripscope is not a travel agency or a booking service, but they do guarantee to provide all the information necessary for journeys to be arranged and undertaken with confidence. They will also be aware of any special discounts available and may be able to assist with information on possible funding sources in special circumstances.

Tripscope can be contacted on 01-994 9294 and their address is 63 Esmond Road, London W4 IJE.

British Pubs are Becoming More Accessible . . .

The British pub is becoming more accessible to people with disabilities. Already some 70 pubs in the south east and four in Cheshire display a wheelchair symbol and now a pilot scheme organised by the Brewer's Society is being extended nationwide.

To qualify for the sign, a pub has to be independently assessed by a local access group according to very strict guidelines. The pub must have a level or ramped route from the car park to a main entrance, wheelchair access to the main bars, and accessible toilets.

*

Free leaflets listing pubs in the schemes by region are available from the Brewer's Society, 42 Portman Square, London WI.

New Discounts Pamphlet for Disabled Drivers

"Discounts and Concessions", one of the most popular pamphlets in the series from Mobility Information Services, has just been updated and revised. The leaflet is a handy guide to getting the best value for motoring as it lists all the major motor manufacturers offering discounts to disabled purchasers, concessions on vehicle hire, servicing, spares etc.

It also outlines who can qualify for these discounted prices, as disabled people are not always aware that such discounts can be obtained.

Send an SAE to "Discounts and Concessions", National Mobility Centre, Unit 2a, Atcham Estate, Shrewsbury, Shropshire SY4 4UG.

people.

All such holidays are on offer through the Travel Club. Club members receive three newsletters a year containing information and articles of special interest to the disabled traveller; special assistance in obtaining travel documents such as passports etc; special insurance; and discounted car hire at certain destinations. The Â£3 joining fee will be refunded on the first booking made through the Club.

Boswell & Johnson can be contacted at International House, 82-86 Deansgate, Manchester M3 2ER.

Access in London

The new up-dated version of the comprehensive publication Access in London is now available. The guide details everything from flat access routes to numbers of steps, distances and lift sizes for all sorts of sights and venues from Hampton Court to Wembley Stadium . . .

Uphill Ski Club's 1990 Programme

The Uphill Ski Club, a charity providing winter sports holidays for people with disabilities, has issued its programme for 1990. It features eight holidays between January and March at six resorts in Austria and Italy.

Information and application forms are available from the Uphill Ski Club, 12 Park Crescent, London WIN 4EQ.

There is information on transport and getting around; accommodation; useful organisations; museums, galleries and historic buildings . .. and a good loo' guide and map listing wheelchair accessible loos.

The research for this book has been carried out by mixed teams of able bodied and disabled people and most of the information has been obtained first-hand.

The book costs Â£3.50 plus 50p p&p and can be obtained from 39 Bradley Gardens, West Ealing, London WI 3 SHE.

The Boswell & Johnson Travel Club for the Disabled Traveller

Boswell & Johnson, the holiday tour

operators, have formed a special division providing travel and holiday arrangements for disabled

A Change for the Better

Next time you are travelling across London and need to get from one Main Line terminal to another, try CARELINK. It's an hourly door-to-

to

door bus service between stations write to the Unit at 55 Broadway,

with friendly, patient - and well London SWIH OBD.

trained drivers.

Carelink is specially for people who find ordinary buses or the Underground difficult to manage.

And at Victoria and Euston. Carelink becomes an air link, meeting up with the frequent Airbus service to and from Heathrow. These buses, too are now wheelchair-accessible.

For more information about these and other special facilities on London's buses, Underground and Docklands Light Railway, call London Transport's Unit for Disabled Passengers on 01-222 5600. Or

AIDS FOR LIVING

Special Footware Requirements

The Disabled Living Foundation works to reduce the handicapping effects of disability by giving information and suggesting non-medical solutions to the daily problems faced by disabled people.

Their Clothing & Footwear Service offers advice and information on all aspects of clothing and footwear for people with special needs, backed by an enquiry service.

Two more leaflets in their series of footwear have been issued. "Footwear for Cold Feet" (Â£1.20 inc p&p) advises on ways to keep warm, simple self-help ideas, extra warm footwear and where to obtain them. "Footwear for Odd-Sized Feet" (80p inc p&p) discusses the problems and supplies addresses of manufacturers and retailers who can help.

For further information on these and other publications, write to the Disabled Living Foundation, 380-

384 Harrow Road, London W9
2HU.

Sun Alliance Special Equipment Insurance Scheme

People with disabilities may find it difficult obtaining adequate insurance cover for electronic and other specialist equipment. Sun Alliance Insurance Group operates a special scheme to help with this need, covering a wide range of equipment for people who are disabled.

For further information write to
Mr A. Bayes, Local Manager, Sun Alliance Insurance Group, Rickford House, 12 Rickfords Hill, Aylesbury, Bucks HP20 2RX.

Knitting with One Hand . . .

The E.N. Knitting Aid is designed for people who only have the use of one hand (either left or right) to enable them to knit without help.

A special clamp enables the user to fix this small, lightweight aid to a table with the minimum of effort. The needles click firmly into position and needle sizes 3mm to 1 Omm can be used.

For further information write to
Mr E. S. Nicholson, 4 Louville Avenue, Withernsea, North Humberside, HU 19 2PB.

ADA MEMBERS ARE ASKED
TO NOTE THAT

THE ADA OFFICE WILL BE
CLOSED FROM

FRIDAY
22ND DECEMBER 1989
TO WEDNESDAY
3RD JANUARY 1990

Messages can be left on our 24-hour'Answerphone' and will be dealt with immediately on our return.

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DO YOU
COLLECT
GREEN SHIELD
STAMPS?

...IF SO SEND THEM TO
US I THEY CAN HELP
SUPPORT OUR
WORK . ..
(Only the NEW stamps
can be used)

it

SMALL EVENTS
CAN BE FUN

AND HELP OUR WORK
ENORMOUSLY

OPEN YOUR GARDEN
ORGANISE A BRING AND BUY
SALE
COFFEE MORNINGS
CHEESE & WINE PARTIES

ADA will gladly provide
posters and literature

SPEAKING UP

The Newsletter of
ACTION FOR
DYSPHASIC ADULTS
(Registered Charity)

No 295094)

37 Royal Street
London SEI 7LL
Telephone 01-261 9572

Editor: Ginni Tym

Printed by
L & T Press, Luton

"SPEAKING UP" welcomes
articles, news and letters
from all sources

(copy deadline for next issue:

15th Feb'90)

THE FUNDING OF ADA

ADA can only continue and expand as long as there are sufficient funds available to finance the professional level of service required.

We are making every effort to secure the level of funding needed from a wide variety of sources. However, two major grants have come to an end this year, and the charity is also committed to a major research and development project. It has also been vitally important for us to invest in organisational development - otherwise we would not be able to cope with the growing demands on our services.

So your donations, whatever their size, are more than a welcome and encouraging indication of your support - they are vital to our very existence. If you are staging a fundraising event, or want to let others know about ADA, please don't hesitate to contact us. And don't throw your used postage stamps away - send them to us instead!

Lack of space prevents us from acknowledging every recent contribution on this page, but to all our good friends who have made donations since our last newsletter - our warm and sincere thanks and appreciation for your support and generosity.

ADA is always especially touched to receive "In Memoriam" donations. Contributions have been received in memory of:

SHELAGH ARMSTRONG
BRENDA CRACKNELL
KEN DAWSON
GRETTA HUDSON

We gratefully acknowledge generous financial support from the following since our last newsletter:

M M BETTS

THE R M BURTON CHARITABLE TRUST
THE CICELY NORTHCOTE TRUST
MRS P FISHER
SIR ROGER FALK

THE DONALD FORRESTER CHARITABLE TRUST

BETTY GILES

MISS] H F GREEN

HEATH MOUNT SCHOOL

ALLEN LEE

MARKS & SPENCER

NATIONAL WESTMINSTER BANK

N STAFFS EVANGELICAL TRUST

PRUDENTIAL ASSURANCE

M B RECKITT CHARITABLE SETTLEMENT

MISS F M TURTON

THE UNITED REFORM CHURCH

WESTHORPE CHURCH

THE FELICITY WILDE CHARITABLE TRUST

THE REV J H WILLIAMS

HOW YOU CAN HELP US . . .

HOW THE INLAND REVENUE CAN HELP YOU MAKE THE MOST OF CHARITABLE GIVING . . â€¢
QUESTIONS & ANSWERS ABOUT DEEDS OF COVENANT

WHY ARE DEEDS OF COVENANT SO IMPORTANT TO CHARITIES?

Because if you are a UK taxpayer you can increase the value of your donation to ADA by a third - at no extra cost to yourself. And if you pay Income Tax at the higher rate of 40% you can even save money on your charitable giving!

Such 'tax effective' giving has enormous benefits for ADA: as a registered charity we can claim the tax paid on your donation. So your gift is worth considerably more - and you are also helping us to plan ahead on promised income.

IS A DEED OF COVENANT COMPLICATED?

No - as far as the donor is concerned, a covenant is exceedingly simple. You do not need to go to a lawyer.

All you have to do is .. . fill in details of your name and address

and the amount you wish to give, and sign and date the document in front of a witness. You will also be asked to sign a Certificate of Deduction of Tax confirming that you are a UK taxpayer.

A covenant is a legal contract by the donor to make regular payments to charity for more than three years. Simple though it is for the donor, it does need to be correctly drawn up and signed. ADA has covenant forms available which are legally correct.

This is all that's needed for the magic of covenant giving to work. The value of your gift increases by 33.3% in the hands of ADA -with the blessing of the Inland Revenue!

IS THERE A MINIMUM SIZE OF COVENANT?

All donations are welcome, but covenants do require extra administration ... claiming from the Inland Revenue, checking that Deeds are valid, that payments are made and received, that Certificates of Deduction of Tax are received from the donor etc . . . all of which takes up

valuable staff and volunteer time.

It has been estimated that it must take Â£8 worth of effort to administer a covenant over four years ... which means that it is probably not cost-effective for a charity to claim the tax on a covenant of less than Â£20 a year.

CAN THE HANDLING COSTS BE REDUCED?

Yes - there is a simple way to contribute a larger "one-off" donation (Â£50 and above) tax effectively in such a way that administration for ADA is reduced.

The method of doing this is known as a 'DEPOSIT' or'LUMP SUM' covenant. Provided that you sign two simple forms (a Deed of Covenant and a Letter of Loan) when you make your single lump-sum gift we can claim tax in the normal way - but with far less less work for us!

Covenants are the most effective way donors can help ADA help dysphasic people and their families... just complete the form below and send it to us!

â–¡

â–¡

The Director, Action for Dysphasic Adults, 37A Royal Street, London SE1 7LL

I would like to find out more about tax-effective giving. Please send me your notes on covenants.

I would like to support ADA's work with a COVENANT*/DEPOSIT COVENANT*. Please send me the necessary forms.

*Please delete as appropriate

NAME (Mr/Mrs/Miss/Ms) ....

ADDRESS ....

Postcode

Signature

Date

19

THANKS TO THE GENEROSITY OF THE KING'S
FUND ADA CAN SUPPLY MEMBERS WITH FREE
COPIES OF

"TAKING A BREAK:
A GUIDE FOR PEOPLE
CARING AT HOME"

TAKING A BREAK

A guide for peopis caring at home

ON RECEIPT OF A STAMPED ADDRESSED ENVELOPE
(SIZE 6" x 9" - 24p STAMP)

"Taking A Break" looks at carers' concerns and feelings, describes the various kinds of breaks that are available and points to some of their advantages and disadvantages.

Information is given about arranging breaks and how to make sure they are successful.

There is also helpful advice about transport, making it easier to care at home, what to do when things go wrong, and how to make your views known and join with other carers.

To the Administrator, Action for Dysphasic Adults,

37a Royal Street, London SE1 7LL

PLEASE SEND ME A COPY OF "TAKING A BREAK" IN THE ENCLOSED STAMPED ADDRESSED ENVELOPE.

NAME (Mr/Mrs/Miss/Ms) ....

ADDRESS ....

.... Postcode ....

SIGNED .... Date 19

ARE YOU LOOKING FOR

TT7'X,-s

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LOOK NO FURTHER

CONTACT THE ADA OFFICE FOR
A COPY OF THE ANTHOLOGY
"A WAY WITH WORDS"

Mrs Thatcher, Yehudi Menuhin, Barbara Cartland, Paul Scofield, Jilly Cooper, Ronnie Corbett and more than 100 other well-known personalities were asked to choose a favourite piece of writing for this anthology-and to explain why it appealed to them.

Whether actors, politicians, journalists or 'celebrities', their selections and comments make a fascinating (and sometimes surprising) 'lucky dip' into the moving and amusing.

Christina Shewell, who compiled the anthology with Virginia Dean, says that she found Mrs Thatcher's choice "quite a surprise"- but anyone who wants to discover the literary taste of the Prime Minister will have to buy the book!

Hardback copies are available from ADA at a cost of Â£3.00.

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ADA's Tenth Anniversary Year . . . 1990

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Ten Years of Work for Improved
Care and Rehabilitation for
Dysphasic Adults

Action for Dysphasic Adults
37 Royal Street
London
SEI 7LL

Telephone: 01-261 9572
Registered Charity' No. 295094

ADA

ACTION FOR DYSPHASIC ADULTS

SPEAKING FOR THOSE WHO ARE LOST FOR WORDS

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