VSS NEWS
Volunteer Stroke Scheme

Issue 4 April 1989

Ann Kavanagh's Review

Visits in Dublin


Ann Kavanagh

In June 1988 I had occasion to visit most of our patients in both North and South Dublin. The trauma and heartbreak I encountered I shall never forget, whole families absolutely shattered by stroke. It has also had an indelible effect on me. Although I had a stroke myself in 1983, I never fully realised the extreme hardship other stroke victims suffered.

I found that many families were experiencing extreme poverty because the father in many cases had had a stroke, so the breadwinner was no longer able to provide for the family. In many cases where there was a wife and small children the wife was unable to take a paying job and the quality of life for all concerned was pretty dismal. I visited one family where the wife was confined to bed with severe arthritis, and the husband was confined to a wheelchair as a result of a stroke.

These two families illustrate just some of the problems that many people are unaware of. You could sense the feeling of hopelessness, the evidence of despair on the faces of fifteen and sixteen year olds, landed with these heavy burdens at a time in their lives when they should be carefree and happy.

ROLE OF VSS

Although the Volunteer Stroke Scheme helped by sending in a volunteer to help the stroke victim with speech problems, much more needeed to be done. The problems are many, but high on the list is the problem of economics. In the long term I would like to see VSS being able to provide respite accommodation for both victim and families alike.

Funding is the biggest problem. In 1989 we must launch a massive fundraising campaign to enable us to help the most needy. I would like to thank our small but hardworking fundraising committee. They have worked extremely hard to maintain the VSS

THE FUTURE

I am very heartened by the fact that our numbers are growing. Each month more and more people are being helped by the VSS. We are now in the process of expanding into Counties Waterford and Leitrim. I would like to see the VSS in every county in Ireland.

My sincere thanks are due to my very active and dedicated committee for all their support and encouragement in the past year. I look forward to expansion of the VSS in 1989. I have every confidence that we can face the stroke problems in all their starkness. In 1989 and beyond, realism, courage and good fellowship must be our watchwords.

Martin Donoghue

VSS extends sincere sympathy to the relatives of Mr Martin Donoghue, Ballindine, Co Mayo, General Secretary of the Disabled Drivers Association of Ireland. Martin died on 22 April 1989. He was an inspiration to many and will be greatly missed.

THE NORTH DUBLIN STROKE CLUB

Erica O'Mara

Our Club is now heading for its Third Birthday, which means a cake with three candles and a party. That birthday will mean a whole lot more than just a party to many people. Sister Margaret who runs the Centre had a wonderful welcome for us at the beginning, a welcome that hasn't dimmed. Most of our volunteers and some of our drivers have been with us all this time and along with more recent recruits deserve a debt of gratitude not easily measured in words.

The people who are the 'Club' are those who have had strokes and, on coming to the Club, the first thing that each one realises - perhaps for the first time - is that not one of them is unique when it comes to problems with stroke. All can see that there are others better than themselves or some worse. At the Club "better or worse" doesn't matter. What does matter is that one tries and for many people even to try is in some way to succeed. This can produce an atmosphere that has more than a bit of magic. A lot of caring and a great deal of laughter bring out effort not otherwise attempted.

We don't stop halfway for a break - we have one right at the start and it gets us all going with a will. Activities come next and are geared to people's differing abilities, with volunteers always ready with encouragement or a helping hand. Some weeks a table is set aside for working on specific speech problems. We have discovered that nearly everyone cheats at cards and that Bert can tell a group how to play Dominoes, without words. When he won he was, of course, accused of "fixing". Painting we are introducing gradually and we have just commenced our own physiotherapy programme with Maura's qualified guidance. There are times when we sit around an enlarged table and have a serious discussion on the problems of stroke. At last year's birthday four Club members were promoted to volunteers - a confirmation of the roles they had already taken on, John and Liam for their work in Club time, Enda as a driver and Bridie for her money making efforts.

Space does not allow me to mention everyone but as the goodbyes ring out at the end of the Club on Mondays, each goodbye is followed with a confident "see you next week" affirmed on someone's part with a vigorous nodding of the head that says it all.

STROKE - A PSYCHOLOGICAL PROBLEM YOU CAN HELP TO TACKLE

Siobhán Barry
Ted Dinan

We are indebted to Siobhán and Ted, doctors at St James's Hospital, for this challenging article. We hope that many of our readers will get in touch with them.

Siobhán Barry and Ted Dinan

WHAT IS A STROKE?

A stroke is a sudden attack of illness in the brain with loss of feeling, ability to move and often with associated speech difficulties. Deaths from stroke are the third most common cause of death in the western world after heart disease and cancer. In the city of Dublin in any given year, two thousand people suffer from stroke of whom one thousand will require a lot of help and six hundred sufferers will require continuous subsequent care. Although it is generally felt that stroke is a condition of advanced years, about a quarter of those afflicted are under the age of sixty five years. One third of those who suffer from stroke die within weeks of the event. For those who survive, the next few months are crucial in terms of restoring activity and independence. It can often take up two years before the stroke sufferer's full capacity is realised.

Among those who survive from stroke, just over a half return to a fully independent life. Some suffer loss of independence. This can be physical as well as psychological. The psychological changes are often the more significant and many people do not regain their previous level of functioning even after all physical disabilities have ceased to be a serious obstacle.

DEPRESSION

The most common psychological problem following a stroke is depression. It is often felt that this depression is a response to the handicap that the person now faces. There is also considerable evidence to suggest that the depression is directly due to physical damage to the brain caused by the stroke. Indeed research

carried out in the States has shown that those suffering from stroke have a higher incidence of depression than those who have similar physical disabilities due to orthopaedic problems alone.

Depression when it occurs following a stroke is indistinguishable from the type of endogenous depressive illness seen by psychiatrists. Features of this depression are that people may feel miserable and tearful. They often have a reduced appetite and may lose weight. Sleep is frequently decreased and generally there is an inability to concentrate. A generalised lack of interest in one's surroundings is also common.

This depressive mood which usually sets in within weeks of the stroke is often an important obstacle to the person's subsequent rehabilitation. Unfortunately this depression is often poorly recognised. It is also true that the form of depression which arises following a stroke can be extremely chronic and still be present and severe up to two years after the event.

MANAGEMENT OF DEPRESSION IN STROKE

The management of psychological problems following a stroke has a number of facets. Firstly, patients who have had strokes need to be sympathetically and carefully assessed. For those who have communication problems it will usually involve speaking to a close family member and getting some idea of the patient's recent decline in function. Those who suffer from depression following a stroke will not unfortunately recover with this approach alone. Such patients need to be treated with specific anti-depressant medication. The anti-depressant given needs to be effective and also to be given adequate dosage. This is something that comes within the province of a psychiatrist who is well used to treating such conditions. The evidence to date on treating those depressed following a stroke with anti-depressant medication is actually quite good. A significant portion of people recover fully from this depression within six to eight weeks of their starting treatment. It is extremely important that such people are recognised and that they are treated.

There is evidence that those who have a stroke affecting the left side of their brain, i.e. those with right-sided weakness tend to suffer from depression much more than those with strokes affecting the right side of their brain. However, possibly because of communication problems, those with left sided strokes have a much less chance of receiving treatment for this depression. Consequently, at present we at St James's Hospital are endeavouring to formulate a series of easy to administer tests which would enable us to measure the existence of depression in people who are unable to communicate their difficulties. We are doing this by carrying out a blood test on people who have been given a single dose of an anti-depressant tablet. We are most interested in pursuing this avenue of enquiry. To do so we would be greatly helped by having people volunteer to have this test if they have suffered a stroke and have not suffered from depression subsequently. Furthermore, it would also help us if people of a similar age to those volunteers suffering from stroke were themselves to volunteer to have the test done. We could then determine if there are differences between those who have and those who have not had strokes. Comparisons could be drawn between stroke sufferers who got depression and those who did not. By volunteering you can help doctors to get a better understanding of this problem. In time better systems of treatment will be developed.

If there are any queries regarding this or if people wish to volunteer for this form of testing, we can be contacted through the VSS Offices or by telephoning St James's Hospital 537941, ext. 2621.

YOU CAN HELP

SPORTS TALK QUESTIONS

To which sport or games do the following words apply?

1 Bully	15 Jack
2 Cradle	16 Christie
3 Grid	17 Edge
4 Fairway	18 Bridle
5 Dribble	19 Track
6 Bull's eye	20 Rubber
7 Cannon	21 Huff
8 Mate	22 Double word score
9 Tie-break	23 Hand-in
10 Cushion	24 Tack
11 Shuttle	25 Butterfly
12 Scrum	26 Jack-knife
13 Over	27 Crampons
14 Puck	28 Flush

See page 5 for answers.

THE VOLUNTEER STROKE SCHEME
FROM A VOLUNTEER'S POINT OF VIEW

Carol Madden

My first introduction to the VSS was when I heard Erica O'Mara speaking about the Scheme on the radio.

She explained what the Scheme was all about and, as she spoke, I was reminded of people I had read about or seen on television. These were people who had themselves suffered strokes and one of the main points which kept recurring in their stories was the fact that once you were discharged from hospital, that was the end of your treatment.

Many 'lofty' thoughts passed through my mind as I listened to Erica's voice on the radio. It was when she said the VSS needed more volunteers that I came down to earth with a bang. The interviewer asked what qualifications a volunteer would need and was told the only qualification was to be willing to help.

I thought of friends who had helped me on numerous occasions - each friend was different and had something of his or her own to offer but all had in common a genuine desire to help and be of use.

By now the 'penny had dropped' and I knew the Caring Society for which we all yearn can only be achieved when each one of us contributes our own little part.

Having convinced myself that surely I would have something to offer nevertheless it was with fear and trepidation that I approached my first meeting of the VSS. However the humour and light-heartedness of the group soon had me feeling at ease.

The next step came when I had my first introduction to a stroke person. This is an important day, you are meeting a PERSON who has had a stroke, not somebody who is identified by his or her former job in life e.g. a teacher, a builder, a shop assistant or a dentist; not somebody who is someone else's mother, father, husband, or wife. You are meeting someone who is a person in his or her own right, someone with his or her own hopes or fears, likes and dislikes, joys and sadnesses.

A year has passed since our introduction and if asked what we do during visits I could reply:

We talk together.
We go for walks and talk.
We do crosswords.
We do puzzles, a bit of writing.
Drink tea, go for the odd drive.
All this and so much more.

It is like trying to describe what you do when with a friend. Perhaps this is the whole point - you don't just visit a stroke person, 'visit' implies going to see someone. It is more than that. The time you spend with a stroke person is time spent "being with that person", learning to understand that person's needs and enjoying each others companionship.

I am glad I switched on the radio that morning.

I am happy to be part of the Volunteer Stroke Scheme.

IMPRESSIONS OF TIMES SPENT AS A STROKE PATIENT IN A REHABILITATION CENTRE

Peter Moore

After spending nearly six months in Jervis Street I was told that I had a place in a Hospital in Dun Laoghaire. At the time I felt very disappointed because I was due home that weekend. I imagined the place to be small but it was quite the opposite. My wife and son left me in tears for home. This bitterness was to last for my stay there.

I woke up at around half past seven after a sleepless night. I wondered what was ahead of me. First two men got me from bed. After that I got my first real look at the other patients. Each one was worse than me and I felt better. For the first time I accepted what I had. I had my breakfast then but I refused to eat the eggs and I felt like a rebel. After my breakfast I wandered around the hospital. I was still crying and I was trying to adapt to this new atmosphere.

At half past ten I was pushed down to the gym. The hospital was well built and very clean. It was here I hated the most. It was here I did exercises which reminded me of the Germans and their tortures. This continued until twelve. At twelve I made my own way to the speech therapist. I had one hour there which I enjoyed so much I wanted to stay there.

At one I took my dinner. I had to go down in the lift and take my place in a big queue. Everyone was pushing to get in to the canteen. After that day I arrived a few minutes earlier to avoid the rush. After my dinner I went back to my ward where I was advised to rest on my bed. It was all go in this hospital and at three o'clock I went to Occupational Therapy to do jigsaws. They must have thought I was thick!

At five o'clock I got my tea and waited for my son to visit me. My son came every second day and my wife on Thursdays. At the time I blamed them but my attitude soon changed. I cried when they were going but every weekend I went home. After six weeks there I had made some improvement. It was then I was told I would be moved to another hospital. I felt helpless.

The day my wife arrived and signed a form to take me home. I could not believe it. My sadness turned to joy. On that Friday I took one last look at the hospital and I bid it farewell. I realised that life can be very hard living away from home. I thank my wife and son and at the moment I am getting better at home.

VISITS TO STROKE CLUBS IN WATERFORD AND LEITRIM

Erica O'Mara

In June of 1988 I paid a visit to Waterford where Bridie Keogh and her assistant Pauline, both speech therapists, organise the Waterford Stroke Club along with a full committee. Walking into the Club the whole atmosphere was so exactly like our own Club in North Dublin that I felt very much at home and had many questions to answer about our own Club. Their Community Physiotherapist and Occupational Therapist were both there and attend regularly. We parted with promises to organise a joint outing if possible next summer.

In March of this year Margaret Tobin, a Club volunteer and also my very first volunteer, and myself headed for Carrick-on-Shannon, where Bríd Nolan, Patricia McLoughlin (Physiotherapist) and Nuala Lannon are in the process of organising a Stroke Club. So far several outings and a Christmas Party have been enjoyed but more regular Club meetings are now hoped for.

Both groups had a very warm welcome for us. We felt that we had made instant friends. The common bond of helping with the problems of stroke made a firm foundation for further contact and co-operation not only with Waterford and Leitrim but hopefully with other new groups around the country.

SPORTS TALK SOLUTIONS

1 Hockey
2 Lacrosse
3 Car racing
4 Golf
5 Soccer
6 Darts/archery
7 Billiards
8 Chess
9 Tennis
10 Snooker
11 Badminton
12 Rugger
13 Cricket
14 Hurling - Ice hockey
15 Bowls
16 Skiing
17 Figure skating
18 Riding
19 Athletics
20 Bridge
21 Draughts
22 Scrabble
23 Squash
24 Sailing
25 Swimming
26 Diving
27 Climbing
28 Poker

CAN YOU READ THIS?

Joan Monahan

For many stroke victims with dysphasia understanding those four simple words above would prove to be very difficult. We live in a world surrounded by the usual print from street and place names, to environmental notices like "Toilet", "No Exit", to directions on working items, on medicines, washing instructions, newspaper articles, letters, forms, books and texts for special study. Yet reading difficulties following a stroke tend not to be recognised and to remain hidden.

We think of the dominant stereotypes of handicap as someone in a wheelchair or with a stick. Disabilities that don't conform are often little understood by the public. One stroke victim with a reading disorder commented "It's there, but I can't figure it out" on trying to read a few single words. While another, reflecting on his initial attempts at reading after his stroke, puzzled "All those words. An article I tackled consisted of words which were in a complete jumble of letters signifying nothing".

This disability which can occur following a stroke is referred to as dyslexia. It is one symptom of a central language disturbance, brought on by a stroke or other brain damage, called dysphasia and which affects the comprehension of the spoken word, naming of objects, expressing thoughts, writing and

reading. Dyslexia may be defined simply as the loss or impairment of the ability to read caused by brain damage. A crucial consideration here is that the function of reading in the definition of dyslexia refers strictly to the comprehension or understanding of written material.

The ability to read out loud is often a separate function. If stroke persons can read out loud this does not mean that they can understand what they are reading. Conversely if persons cannot read out loud this does not mean that they do not understand what they are trying to read.

So how do we know what the stroke victim can and cannot read? What stages are involved in the reading process? It is only through careful assessments that we can identify the range and severity of the reading disorder. Investigation of the reading deficit is part of the total assessment carried out by the speech therapist using a standardised dysphasia battery. Specifically the test could contain a section enabling the therapist to survey reading comprehension of single words, sentences, short paragraphs and knowledge of the alphabet.

Reading is a very complex skill relying on the intact function of many different processes and dysphasia, in its various forms, may serve to dissociate these processes - sparing some and damaging others. Before working with letters and words one must check the integrity of the capacity to see and discriminate the basic elements of the written system i.e. letters as letters, words as words, numbers as numbers etc.

Assuming this is intact, we begin to investigate the reading comprehension of single words and the errors that may be made at this single word level. Some stroke victims make errors on words which look alike, e.g. selecting the word "leap" instead of "leaf" or "brown" instead of "broom". Others may make semantic type of errors e.g. choosing the word "train" for "jet", "brother" for "sister", "nozzle" for "hose" etc.

It is usually words that are in frequent use in the English vocabulary which the dysphasic person will find easier to recognise and read and which therapists will use in programmes to increase their understanding of single words. However, occasionally, longer and less common words that are specific to a person's occupation or lifestyle are more easily recognised and understood. One particular person who had been a musician found words like "music" and "saxaphone" much easier to recognise and read than words like "food" or "wall".

When someone has difficulty at this level of matching one correct word to a picture of the word or the real object, practice may begin with words that are as relevant as possible. Reading of words seen readily in the environment are important to learn early on e.g. toilet signs, stop and shop signs, banks etc. Pictures in magazines can be used effectively particularly with action type words like "put", "give", "turn" etc. These words are important for following written instructions e.g. "Turn the cooker on to 180°C"; "Put the cat outside" etc. Single word vocabulary training is helped by labelling objects around the house so that the person is exposed to the word and associations between the correct word and object is strengthened.

Beyond this one word level there is evidence that the reading of names of objects or items (so-called lexical words) uses a different mechanism from the reading of small grammatical words like "is", "so that", "under" etc. Often the relationship of these small words to the other items in the sentence is crucial to the interpretation of the sentence. e.g. "Put the money behind the clock" or "The dog is being chased by the cat". Some dyslexic people find these smaller words so confusing that they are unable to follow the sentence. One particular patient referring to the confusion caused by these small words said "I'm not sure what way they should go".

Once the client has a single word vocabulary of 50-100 nouns and verbs that can be easily understood we move on to phrases and sentences. This may begin by selecting pictures depicting images of noun-verb combinations, a woman cooking, a man gardening, that the person should know as separate words. A lot of different ideas and exercises exist to build up the person' understanding of short and long sentences. At a much later level tasks, such as identifying grammatical errors in sentences, can be useful as this demands very close reading and understanding.

Comprehension of written questions is one of the more difficult reading tasks for dyslexic readers. Yes/No questions about personal information are often the easiest to comprehend. "Wh-questions" (when, why, where) are often difficult to read and understand. With a person who can manage sentences/questions well it may often be the more complex grammatical structures in a sentence that can cause problems for them. It may be necessary to work on these before the stroke victim can cope with paragraphs from the newspaper or articles. Here we may wish to improve on the memory of what has been read and speed of reading.

However many of the people that we see for treatment will not be able to recover to their previous level of reading skill. There are a great many people in our population who do not have

occasion to read in their work or for pleasure and this impairment does not interrupt their routine. But for those people who did enjoy reading there are a few strategies which may assist. One is "Talking Books" which are taped editions of books. Stroke victims may prefer to recruit a friend or volunteer who will spend some time each day or week reading with them. Reading matter of any kind, especially social letters from family members, can be taped and played back while the words can be followed by the person.

In conclusion, to understand those simple words ***"Can you read this?"*** depends on many different processes working together. By identifying the extent of the problem and planning remediation programmes for family and volunteers we can help to make sense of that "jumble of letters".

£££££££££££££££££££

£ MONEY MATTERS £

£ John L'Estrange reports £

£££££££££££££££££££

1 The Eastern Health Board gave us £10,000 for 1988 for which we express our grateful thanks.

2 A wide range of commercial firms helped us, e.g. banks, building societies, insurance companies, travel agents, manufacturing firms and retail outlets. Companies who helped are listed in alphabetical order.
Abbott Laboratories, Allied Irish Banks, Anglo Irish Banks, Antigen.
Bank of Ireland, Bord Bainne, Burmah-Castrol.
Calor Kosangas, CBF, Ciba Geigy, Louis Copeland.
Dunnes Stores.
ESB.
FII.
Gallagher, General Motors Distribution, Glaxo, Guinness.
Insurance Corporation of Ireland, Irish Civil Service Building Society, Irish Permanent Building Society.
PMPA, Priority Travel Service.
Quinnsworth.
Roche Pharmaceuticals, Royal Insurance.
Smurfits.
Wellcome Ireland.
Our thanks are due to all these firms who answered our appeal.

3 We also acknowledge the proceeds of a variety of fund raising events organised by members of the VSS Committee and their colleagues and friends. The main events were:-
Bridie Kennealy's cake sale.
Irish Red Cross's contribution for a talk on VSS, given by our chairperson, Ann Kavanagh.
Raffle held by Ann Kavanagh in the Old Mill Pub.
A fancy dress ball hosted by HMV in the Mansion House, Dublin, music by Paddy Cole's Jazzband and the Pass Times from RTE.. Anne Copeland of the VSS did trojan work for this event, and it is expected to be a great boost for the treasurer.

4 Erica O'Mara visited the two new VSS centres in Waterford and Leitrim. These are the first centres outside Dublin to be organised. Each has a Club established and they are doing very well with their own fund raising events.

5 The VSS Membership is now approaching one hundred, and rising slowly every year.
BE SURE YOU ARE IN MEMBERSHIP.

Charlie Pride, American Folk Singer, entertained us at the Mansion House Dance on November 3 1988. Pictured here with his friends from HMV London and Dublin.

Volunteer Stroke Scheme
249 Crumlin Road
Dublin 12
Telephone 557455
Registered Charity CMY 6989

VSS News is distributed to all hospitals and Health Boards throughout the country free of charge. Organisations requiring copies of VSS News please contact the Editor at 249 Crumlin Road, Dublin 12 (Tel 01-557455), between 10.00am and 1.00 pm. on Monday, Wednesday or Thursday.

Aims of Volunteer Stroke Scheme.

1 To help people who suffer from speech and allied problems as a result of a stroke

2 To offer each patient a small team of volunteers who will visit singly for about an hour at a time on a regular weekly basis

3 To provide a club where patients can meet and be helped further.

4 To provide outings from time to time

5 To create a greater awareness and understanding of stroke through effective and relevant publicity.

Membership Application Form

Name.....

Address.....

.....

.....

Telephone.....

I wish to apply for membership of the Volunteer Stroke Scheme and I enclose a fee of £5.00 for 1989. Cheques payable to Volunteer Stroke Scheme.

Signed.....

Date.....

Please send to
Volunteer Stroke Scheme
249 Crumlin Road
Dublin 12