

Stroke patients in Glasgow are taking part in Britain's first trial of a new treatment which could help them recover from stroke.

Psychologists at Caledonian University hope to help patients reverse the brain damage caused by the condition using a simple treatment and a special glove. Now they are looking for volunteers who have had a stroke to take part in the first major test of the system. The study, called Constraint Induced Rehabilitation After Stroke, aims to gauge whether encouraging patients to use their weaker arm helps in their recovery. Researcher Stephen Butler explains: "Like all the best inventions, its really simple."

Patients wear a bulky glove on their good hand for eight hours a day, Monday to Friday, forcing them to use the weaker hand. This appears to help the brain by stimulating the area responsible for moving the affected arm. Earlier research suggests the treatment could help the brain make its own repairs. "Some people believe the brain can 'rewire' itself to bypass the affected area but there is a lot of debate about whether that is the case. Scans seem to show some recovery in some people who have this treatment and physiotherapy."

Patients will be visited by the researchers to check up on their progress over the stage when they wear the glove. During this time and afterwards, scientists will study how well patients can use both hands and a follow up check six months later should show whether any benefit lasts.

Restraint of the unaffected limb (constraint therapy) has been used by physios before, but this seems to be the first experiment in which the method and its efficacy is specifically measured. Earlier research in USA indicated that this sort of treatment may stimulate paralysed limbs even years after the stroke (see Journal of American Heart Association June 2000).

Scots
lead
the
way

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**STROKES HAPPEN TO
YOUNGER PEOPLE TOO!**

News

An unlicensed drug, which restored speech and movement to a helpless stroke victim within minutes, was last night being hailed as a **'miracle' cure**.

The relatives of 83-year-old Doris Holmes, from Bishop Auckland, County Durham, pleaded with doctors to do anything they could to save her, after she suffered a massive stroke. The attack, caused by a blood clot blocking the flow of blood to her brain, left her unconscious and paralysed down her right side. But after agreeing that she could be injected with an unlicensed drug widely used by American stroke specialists, her family witnessed an amazing recovery. "Within half an hour of this treatment the paralysis was gone. It was like witnessing a miracle," said Marilyn Weerasinghe, Mrs Holmes' daughter.

Doctors now believe the drug could save up to 10,000 patients a year from death or serious disability. While it has been used at the Freeman Hospital in Newcastle on a small number of patients, it is the first time the drug has hit the headlines in the region. Its startling success highlights how many lives could be saved if the clot-busting drug was cleared for use on UK stroke patients.

While the drug rtPA is licensed to treat UK heart attack victims, British doctors cannot use it to treat stroke patients, despite its use by stroke specialists in the US and Europe. It can only be used as a last resort with the consent of the patient's family. Crucially, it must be given within three hours of the stroke before brain damage occurs.

"My mother collapsed at 9.15am, she was injected at 11.30am and by 2.15pm she was sitting up in bed asking for something to eat. It was amazing," said Mrs Weerasinghe.

The unlicensed drug that cured stroke in 30 minutes

Dr Ali Mehrzad, who runs the stroke unit at Bishop Auckland General Hospital, paid tribute to Mrs Holmes' family for their "courage" in agreeing to the treatment. "It was a unique opportunity. The patient arrived within 45 minutes, I discussed the options with the family and they said go for it" said Dr Mehrzad. "It may be that we were just lucky but it worked in a way which amazed us all," he said.

The UK licensing authorities require more evidence of rtPA's safety and effectiveness, before giving it the go-ahead. The consultant, who plans to use the drug again in the right circumstances, said he believed that use of rtPA combined with faster hospitalisation of stroke victims could save up to 10,000 patients a year from severe disability or death.

Stroke charities are pressing for more specialist stroke centres to be opened across the country.

By Barry Nelson. Reprinted with permission from the Northern Echo. Barry is wanting to do a follow up article so if you have any suggestions or queries ring him on: **01325 5050 75**

The Placebo Effect – fake medicines can work!

Research done at the University of Texas shows that dummy treatments can have very physical effects on a patient. Scientists compared brain scans of depressed patients given the anti depressant Prozac with those of people given a placebo pill. After taking the tablets both groups show similar brain patterns. Again, patients told they were being given arthroscopic keyhole surgery for their osteoarthritis reported benefits two years later even though they had been given fake treatment.

Source - Dr Bruce Morley, Boylar College of Medicine, Houston, Texas

Live long and prosper

It could add years to your life – more even than not smoking or taking up exercise. Scientists at Yale have concluded that people with a positive attitude to getting old live an average of 7.5 years longer than those who take a gloomy view of ageing. “If an unidentified virus was found to diminish life expectancy by seven years, considerable effort would be devoted to implementing a remedy,” says the report in the *Journal of Personality and Social Psychology*. “In this case, one of the likely causes is known: societally sanctioned denigration of the elderly.” The study was based on data gathered in 1975 in Oxford, Ohio, when all the over-50s were questioned about their health, and asked to agree or disagree with such statements as “Things keep getting worse as I get older”. By tracing the histories of these individuals over the next 23 years, researchers calculated that the median survival for the negative thinkers was 15 years, while for the positive it was 22.5 years.

CHEERS!

Drinking beer and spirits may be just as beneficial as wine, says *The Times*. Several studies have shown that wine reduces the risk of heart disease and stroke by preventing blood clots. But now a Spanish survey of 19,000 adults indicates that it doesn't matter what form the alcohol takes – so long as it is drunk in moderation. Four out of ten non-drinkers defined their health as fair, poor or very poor. By contrast, only one in four of those who drank alcohol – beer, spirits or wine – gave their health such a low rating. “Consumers of any type of alcohol showed a lower frequency of ill-health than did abstainers,” said Dr Fernando Rodriguez-Artalejo, who led the study.

But do watch out — there are around 33,000 alcohol related deaths every year, with 25% of us needing a daily tipples and the rate of “laddette” alcoholism rising.



Supplements

Earlier this summer, an Oxford University research team concluded that vitamin pills had no health benefits. Now, the Food Standards Agency has warned that some supplements may actually be dangerous. The FSA has recommended a ban on the trace mineral geranium, which has been linked to kidney failure and damage to the nervous system, and has suggested setting intake limits on nine other supplements – B6, beta-carotene, vitamin E, boron, copper, nickel, selenium, zinc and silicon. The committee has also issued warnings about the potential harm caused by taking excessive quantities of vitamins C, B12, D, A and K. More than 1,000mg of vitamin C can cause stomach problems, while high levels of B6 have been linked to nerve damage. The committee agreed with the earlier study that most of the people who take vitamins and mineral pills are wasting their money.

Source: Daily Mail Aug 02

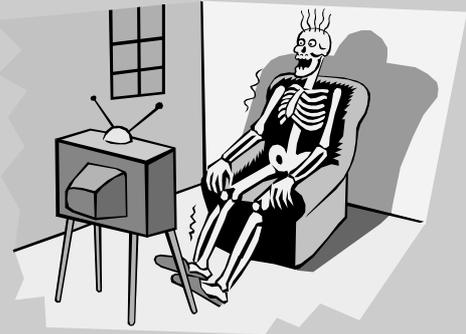
DVT

We've heard a lot about long-haul airline travellers suffering from deep vein thrombosis, but it seems travelling by road or rail may be equally dangerous.

A new study has indicated that a four-hour journey is as likely to cause a blood clot whichever of these means of transport you use. Anyone who remains immobile for that amount of time in a confined space is at risk, says French cardiologist Dr Emile Ferrari. He studied 160 DVT patients at a hospital in Nice, and found that 39 had recently been on a four-hour journey. Two had been on a train, nine had used a plane and 28 a car. By contrast, only ten of 160 patients with non-clotting blood disorders had recently been on a long journey.

News

Bingo may not be the most glamorous of hobbies, but it can do wonders for your brain. Tests have shown that playing bingo can improve the accuracy and speed of short-term memory, and help reverse some of the effects of ageing. A psychologist at the University of Southampton recruited 56 players and 56 non-players and divided them into four groups - young players, young non-players, older players and older non-players. She then tested their short-term memories, their ability to process complex information and their concentration. Overall, the bingo players performed significantly better than the non-players, and the older players performed better than the younger players. However, in tests to determine education levels, the bingo players - who were mostly manual workers - scored lower than the mainly middle-class non-players. The findings should help lay bingo snobbery to rest, although invented in 16th century Italy as a game for the intelligentsia, it is now perceived as an undemanding pursuit for working-class pensioners. Could it help those recovering from stroke?



Couch potatoes risk illness

Some 35,000 people in the EU each year develop cancer as a result of being overweight. So says the International Agency for Research on Cancer, based in France, who have discovered that the more people pile on the pounds, the higher their chances of developing breast cancer, as well as cancers of the womb lining, kidneys and oesophagus. With obesity becoming a virtual epidemic, the authors of the study say governments must motivate citizens to get off their couches – or face a global health crisis. “About half of the adult population of industrialized countries is insufficiently active in their leisure time and one-quarter to one-third can be classified as totally inactive,” says the report. “Avoidance of weight gain should become one of the mainstays of chronic disease prevention in modern society.” Inactivity can be a contributory cause of stroke.

Hard Week?

All work and no play doesn't just make you dull – it also increases the risk of heart disease and stroke. A Japanese study has concluded that men who work 60 hours a week are twice as likely to suffer a heart attack as those working a 40-hour week. The risk is tripled among men who get less than five hours' sleep a night for at least two days in the week. Scientists at Kyushu University say that, for good health, we should work no more than 40 hours a week and have at least two weekdays off a month. The study has led to concern about working conditions in Britain, where people work the longest hours – 43.5 a week – and have the fewest holidays in Europe, and where heart disease is the number-one killer. “This is an important study which raises serious concerns,” said Dr David Snashall, an occupational health expert at Guy's Hospital. “There is clearly evidence here that pushing people hard at work can trigger coronary heart disease”. Or maybe stroke?

Conference

This year's conference in Coventry was a great success. 160 delegates enjoyed the day, and some fifty stayed on for the dinner in the evening making a weekend break of the whole event. We were warmly welcomed to Coventry by Pru Poretta – **Lady Godiva** who gave us a very short talk on the legend of Coventry's most famous daughter.

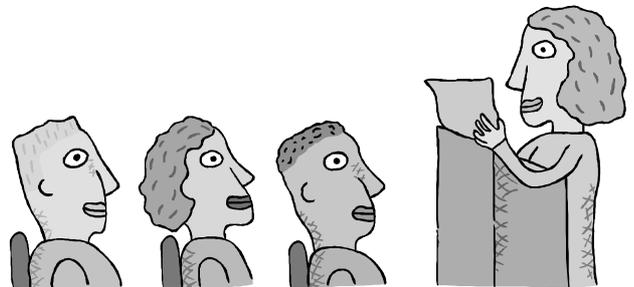
On behalf of the trustees **Donal O'Kelly** director, outlined the current status and services of Different Strokes (7,000 on mailing list; 30 classes around the country; 1,000 info packs sent out this year; 80 help line calls per week; 5,000 website hits per day) and future projects (children's conferences in 2003; exploring software to help people with aphasia; improving the delivery and management of the exercise classes).

Keith Wood our chairman summarized a satisfactory financial situation (income £192,789; expenditure £181,167) but warned that major grants ending in 2003 would need to be replaced. He expressed cautious optimism. We are now encouraging voluntary Direct Debits rather than charging obligatory membership subscriptions.

Geoff Durkin from Abilitynet talked about how PCs can be adapted to counter most disabilities. The mouse and the keyboard can be customized to the individual needs. Voice recognition systems (e.g. Dragon) are of tremendous use to stroke survivors. For any help with computer difficulties he invited Different Strokes members to ring their free advice and information service on 0800 269545. **Linda Holland**, project manager for the smart care programme, told us about the progress being made in improving stroke services in the Coventry NHS primary care group. Coventry PCG is one of six NHS trusts working together to improve the overall rehabilitation care for stroke survivors in the whole country. She emphasized that it was no longer acceptable for different professionals (primary care, A&E, Xray, stroke unit, rehab, intermediate care, community care) to defer responsibilities on to other fields of service; each must work together. Inefficient methods of administration/practice must be challenged and removed. **Phillip Cole**, a community money advisor, having apologized for Citizens Advice Bureaux being so busy and never seeming to answer their 'phone, told us how useful they can

be when it comes to filling in the complex forms that the Benefits agency always seems to demand. He also told us what to claim for and how to do it, and advised on key words to include on claim forms. He told us that 85% of appeals, where the stroke survivor attends with representation, succeed. So do appeal if you don't like the decision and take someone with you.

Leslie Childs, a consultant on disability issues could have covered all the law affecting employer and service providers had she the time, but instead limited herself to an excellent summary of what 'reasonable adjustments' needed to be made



under the Disability Discrimination Act. Professor **Karen Bryan** launched the publication of the Different Strokes 'Work After Stroke' document (please ring the office if you want a copy) and explained how members had contributed to the three-year research project (see page 7). Finally, **Louise Chadwick**, consultant at Leamington Spa Rehab Hospital, surveyed the progress of stroke medicine over the last year. She touched on FES (functional electrical stimulation) and how micro processors can be implanted in the muscle to stimulate movement in a "dropped foot". Ken, one of the first patients to be thus implanted, was able to give us a demonstration of his excellent walking skills! Dr. Chadwick answered all our questions and shared with us the novel use of the vibrator!

It was an excellent day, with something of interest for everyone. The catering was of the highest standard and coffee, tea etc was available throughout the day. In the evening an excellent meal was enjoyed at our first (but surely not last) annual dinner. **Very hearty congratulations are due to Irene Shannon, Mike Druce and the Coventry team.**

N.B. a fuller report is available if required — just ring central office on **0845 130 7172**

Aphasia

Reconnecting with life

'All I know is that I don't know what aphasia is'

'The brain is thinking. He cannot get the words out, but he's thinking'

'Living with aphasia is facing daily struggle – pain, confusion, isolation, anxiety - and learning and understanding within the social world'

About a third of people who have a stroke will experience aphasia, a communication disability affecting the ability to use and understand words. When words go missing the effects can be bewildering and life changing, not just for the person with aphasia but for everyone around them. Unlike some of the more visible changes caused by stroke, aphasia is a hidden disability. Most people don't know its name or how to react when they meet someone who has it. So people with aphasia risk social exclusion and isolation, not just from the loss of language (aphasia can affect talking, understanding, reading, writing, using drawing and gesture) but from the disabling effect of other people who have difficulty adapting their communication style or changing their low expectations of people with stroke and communication disability.

"Connect" - the communication disability network is a national charity, committed to working towards a world where communication disability is no longer a barrier to opportunity and fulfilment. Their website is: www.ukconnect.org or phone Carole Cross on 020 7367 0846. The Aphasia handbook, in easy to read format, is available through Connect. They are currently looking for new Trustees with aphasia – if you are interested contact: Hetty Webber at Connect (020 7367 0868) They are running the following events @ £5 per day.

- Ø Have **you** had a **stroke**? Do **you** have **aphasia**?
- Ø One of these **Connect** courses could be for **you**:

Courses for People with Aphasia and a relative or friend



Poetry and Aphasia

Wednesday 19th February 2003

Running Groups: a 2-day course

Tuesday 29th April 2003 and Tuesday 1st July 2003



Communicating differently through creative arts

Monday 28th July 2003

Computers and Aphasia

Monday 11th August 2003



A course just for relatives and friends

Long term caring and coping
Wednesday 4th December 2002

All courses take place at:
Connect, 16-18 Marshalsea Road, London SE1 1HL
Tel. 020 7367 0846 for more details

Work After Stroke

Research Project

**COMMUNITY
FUND**
Lottery money making a difference

503 of you wished to return to work after your stroke - only 211 (42%) of you were able to do so.

WHY???

What would have helped more of you to get back to work?

You told us

- ↓ More and longer term rehabilitation to tackle ongoing functional problems and psychosocial well being. Returning to work does not seem to be perceived as a "rehab goal"!
- ↓ Liaison between health/care professionals & employers to negotiate a staged return to work.
- ↓ Recognition that job centre staff targets lead to a gap in/and inappropriate provision for disabled people with complex and hidden impairments. Fatigue and cognitive problems often go unnoticed!

Research results will feature in detail in the next edition of the DS newsletter.

If you

- ↓ **have been on sick-leave from work for a long time and want to get back to work?**

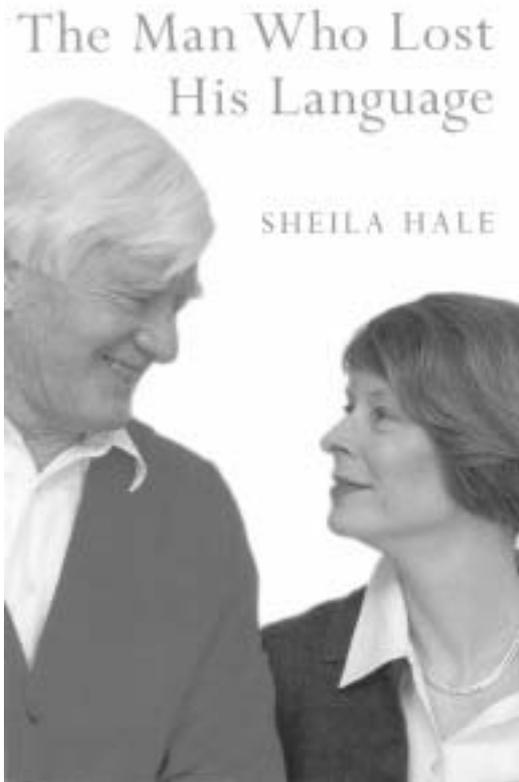
- ↓ have recently had a stroke and are thinking about work-related issues?
- ↓ **have fully recovered from your stroke but worried about coping with the demands of your job?**
- ↓ are concerned about managing work and your disability?
- ↓ **are wondering how to make a start in a new job?**

then contact us today on 0845 130 7172 or e-mail info@differentstrokes.co.uk and we'll send you a copy of our "Work After Stroke" booklet! Each section includes relevant information about employment-related services and resources, followed by examples of the varied experiences and advice of over **700 members** who took part in our research. Where we think they will be helpful we also include some perspectives of the employers we interviewed during our research with tips for dealing with them.

AND if you are a healthcare worker, you can't afford to miss our Employment Guide for Health, Social Care and Rehab Occupations, which will be available in the New Year!!! The Guide for Employers will also be available then.

Unemployment rates for people with disabilities are 2—3 times higher than in the rest of the working population. Britain loses nearly 1 day per week through illness resulting in an annual cost of more than £10 billion to the economy. Non disabled workers take an average of 14 days sick leave per year compared to 9 days for workers with disabilities. (Source - Shaw Trust)

Profile



Even a
great mind
 can suffer the
great insult
 of a
stroke

A book review by Robert McCrum

Stroke is the third biggest killer in the UK, after cancer and heart disease. In the time most people will devote to reading this review, at least one person in Britain will suffer a stroke, what doctors call an “insult to the brain”. And of those afflicted, one third will die. The brain-damaged survivors are a rag-tag army ranging from wheel-chair veterans to men and women with sticks to that tragically impaired minority who make an almost complete physical recovery but never recover the use of language, spoken or written.

Professor Sir John Hale was one of these latter stroke survivors. A brilliant Renaissance historian, with a wide circle of friends and acquaintances among the great and the good of British intellectual life, he was struck down at the age of 69 in 1992. His devoted wife Sheila found him on the floor of his study smiling “the sweet, witless smile of a baby”. After a period of dreadful anxiety she properly describes as “hell”, he was able to go home and, thanks to her refusal to write his case off as hopeless, slowly resumed some

kind of limited normality. Except he couldn’t speak. Hale’s “cerebral vascular accident” had so nuked the language centres in his brain that this brilliant, articulate and charismatic man was reduced to “Da woahs, da woahs, woahs, ach ga ga da woahs.”

The amazing thing about John Hale was that this didn’t seem to matter. Such was the charm and brilliance of his personality that friends and family (and even complete strangers) who spent time in his company often had the sense of having participated in a conversation. As Sheila Hale puts it: “His conversational behaviour is so natural that many people are persuaded that his voice, though evidently naked, is somehow clothed in meaning.”

It sounds weird, and it is, but I can testify from my own meeting with Professor Hale in 1998 (both of us the walking wounded from the battlefield of cerebral vascular disorder) that although he had indeed “lost his language” he had not lost his extraordinary powers of

Profile

communication. “There is something about his eyes and voice and body language” writes Mrs Hale, “that seems to speak more directly to their hearts than all the words with which he charmed and taught throughout his speaking life.”

This book raises some profound questions about the relationship of language to our humanity, questions that Hale himself would have taken pleasure in. Sheila Hale’s account of her husband’s post stroke experience is really two books. The part that moved me the most “a kind of love letter”, was the part that narrates the highs and lows of Hale’s affliction. Sandwiched within this is a long, well researched analysis, based on her own vivid experience of aphasia, as it manifested itself in John’s case. This will become required

reading for those who treat this dreadful illness and who try to grapple with the fathomless mysteries of the brain.

What unites these two narratives – the memoir of a life in extremis, and a wife’s painful quest for meaning – is Hale’s honesty and courage and her cool analytical prose. Her suffering as a partner might have inspired self-pity and destructive rage. Instead she has channelled her energies into one of the most remarkable additions to the literature of illness in our time, a book that can stand alongside Professor Hale’s own marvelous oeuvre.

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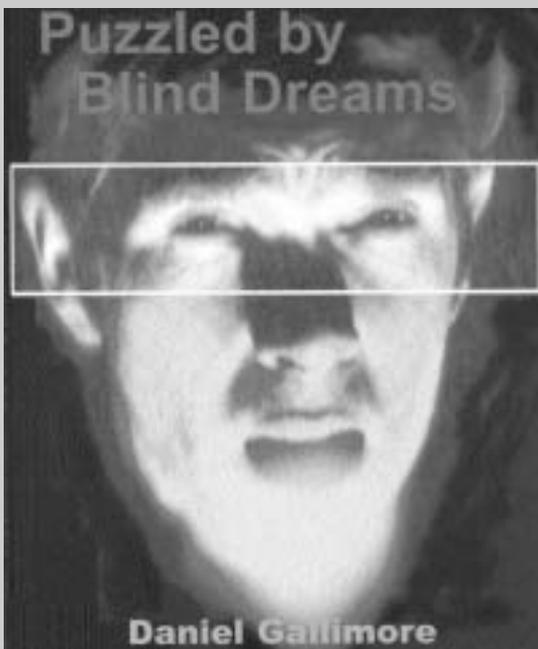
DANIEL GALLIMORE

PART TWO

(We profiled Daniels stroke in Newsletter 16)

Daniel’s mother Sylvie writes:- Daniel has battled bravely to get his life back on track and I think he has surpassed, mine and his father’s wildest dreams. He has started a Blind Awareness project called Have Stick Will Travel and raises money giving talks for individual blind projects. For example he has just bought the cricket shirts for the Avon Blind Cricket team. A couple of weeks ago Daniel received the Lord Mayor’s Medal here in Bristol mainly for his charity work.

Now, the amazing news, David Blunkett (Home Secretary) visited Dan. He telephoned and asked if he could call in and we obviously said yes. He stayed one and a half hours and was such a lovely man. No hidden agenda, no press. He has phoned Dan since and is sending him a Perkins Braille and operator because he says Dan needs one. He came with his driver, bodyguard and Lucy the dog, plus a car load of heavies, they were lovely and we fed and watered them all. Dan has promised to keep in touch. We now have unexpected friends in high places.



Daniel’s book, *Puzzled by Blind Dreams* (ISBN 1 85756 5118—Janus Book—£4.99) collects dreams he and others have had and to which anyone who has had the “near death” experience of a stroke may relate.

Future plans

Expansion of Different Strokes Exercise Classes

In 2000 a three year grant from the Community Fund allowed us to begin work to improve the co-ordination of our exercise classes throughout the UK, during which time the number of groups organising a weekly class has risen from 12 to 30.

For many stroke survivors, the **Different Strokes** exercise group plays an important part in the rehabilitative process. The class is led by a qualified exercise teacher, and in one or two classes that exercise teacher is a stroke survivor. As well as exercise and movement to music, the groups are encouraged to develop a social element to their activities, organising evening entertainment and 'away-days'. Stroke survivors, at any stage of recovery, feel at ease in the company of their peers and soon realise how much they can offer newly recovering stroke survivors too.

We want to expand the network and the necessary management and support functions to meet current and predicted demand, but realise that the current number of groups is stretching the present structure. As the number of groups has increased the Group Development Officer has spent more time travelling and has had less time to support existing groups and encourage new ones. There are a number of people who want to establish and co-ordinate groups in areas of great need, such as Ipswich, Lancashire, Northern Scotland and North Wales,

but we do not have the personnel to nurture new volunteer co-ordinators nor the infrastructure to support more groups.

We plan to appoint a Group Development Manager to replace the Group Development Officer. Over a period of three years the person appointed will recruit 10 part-time Regional Representatives covering the whole of the UK. The essential aspects of all these posts will be to support Volunteer Group Coordinators of both new and established groups, to develop communications between existing groups and to seek out Volunteer Group Coordinators in areas of need. We also wish to continue to offer 'seed support' for new groups by offering materials, venue costs, teacher fees and physiotherapist costs for the first 3 months. We would expect to have a minimum of 60 local groups after 3 years.

We are determined to increase the number of groups so that every younger stroke survivor in the UK has the opportunity to attend a geographically convenient exercise class. We are applying to the Community Fund for the necessary financial support.

We would love to hear your views on our planned expansion - write to Donal at the Milton Keynes office.



Some of our coordinators at their summer meeting

CLASSES AND CONTACTS

REGION	COORDINATOR	E-MAIL	TEL NO:
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Banbury	Sue Lovelock	banbury@differentstrokes.co.uk	01295 750 344
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Bristol	Bob Watson	bristol@differentstrokes.co.uk	01275 844 607
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FOR MORE INFORMATION ON YOUR NEAREST CONTACT/CLASS
PLEASE CALL CENTRAL SERVICES ON 0845 130 7172

Thanks to the Middlesex and Northampton groups
for their generous donations to central services

different Strokes

Support for Younger Stroke Survivors

The Role of Different Strokes Our Mission

Different Strokes helps stroke survivors of under retirement age to optimise their recovery, take control of their own lives and regain as much independence as possible by offering rehabilitative services, information and advice.

Different Strokes currently does this by:

- #####organising a national network of weekly exercise classes;
- #####providing practical, easy to use information for the recovering stroke survivor;
- #####offering the StrokeLine so that younger stroke survivors can speak to other younger stroke survivors on the telephone;
- #####keeping stroke survivors informed, through newsletters, an interactive website and other means, of developments relevant to them.

Different Strokes is run by younger stroke survivors for younger stroke survivors.

Susana Parker is a journalist writing a magazine article on women (15 – 40) and stroke. If you can help contact her on:
E.mail
s.parker@iol.pt

Dr. Sharon Dale Stone, associate professor in sociology in Lakehead University, Ontario, Canada is researching haemorrhagic stroke in women under 50. She had a stroke in childhood and has a particular interest. She will be in the UK in early December and would like to interview women willing to share their experience.

Ring her on 001 807 343 8530
or email
sharondale.stone@lakeheadu.ca

Disabled Person's Tax Credit

Dear Donal,
Only working part time due to my disability, I was pleased to hear that DPTC was a scheme specifically designed to help people with a disability in work by topping up earnings. I work 25 hours a week and working full-time I would be on £16,000 per annum. However as I don't my wage is considerably less and this is when I thought DPTC would help. It became clear I actually earn what DPTC consider too much to be entitled to anything. I feel that this scheme is totally unfair and discriminatory. If I hadn't acquired a disability I would be earning a lot more money than I do now. It seems that the Government have the attitude that a disabled person or the majority of disabled people can only aspire to the lower level paying jobs. The scheme should be more flexible so that if a disabled person had an income of £16,000 but could only work 25 hours they would still be entitled and be able to benefit from the scheme. The percentage increase should apply across the board so a person on £12,000 should get the same percentage increase as someone on £22,000 if not able to work full-time.

Yours sincerely
Julia Peel, (Cambridge)

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"Do it yourself" Therapy for Stroke Survivors

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- ψ Exercise all day without conscious effort

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