

LEEDS STROKE REVIEW



Edition 21 - July 2005 Welcome to the latest edition of "Leeds Stroke Review"

This edition features an article on **“Development of an intelligent robotic system to aid physical therapy in stroke”** by Professor Bipin Bhakta, Charterhouse Professor In Rehabilitation Medicine, Academic Unit of Musculoskeletal and Rehabilitation Medicine, Faculty of Medicine & Health, University of Leeds. **“Positive Strokes – Changing Outlooks and Stroke Services Redesign”** by Debbie Neal, City-Wide Stroke Services Co-ordinator. **“Training in Stroke Medicine”** by Jonathan Cooper, Specialist Registrar in Geriatrics and General (Internal) Medicine Yorkshire Deanery Training Programme, St James University Teaching Hospital, Leeds. **“Early Supported Discharge – Measuring the Burden on Carers”**

If you would like to submit an article for the next edition of the Leeds Stroke Review please contact Olasupo Ogunyinka at the address below.

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Development of an intelligent robotic system to aid physical therapy in stroke

This project (funded by Department of Health NEAT program) involves the development of a robotic system that provides intelligent, interactive, safe movement treatment to help recovery of arm weakness after stroke. This research project is a multidisciplinary collaboration between Leeds West PCT, LTHT, School of Mechanical Engineering (University of Leeds), School of Computer Science (University of Manchester), Grampian Universities NHS Trust, and School of Psychology (University of Aberdeen). Up to 85% of stroke victims (130,000 annually in England and Wales) have arm paresis, of whom 25% reporting difficulty using their arm after five years. Recovery of arm movement partly relates to quantity of functionally relevant practice. Physiotherapists (PTs) carefully guide the arm allowing relearning of joint co-ordinations needed for functional arm movement. While beneficial, limited resource impacts on treatment quantity. A robotic device that helps PTs deliver more treatment would accelerate recovery of arm weakness. Such a device must (a) measure forces produced by PTs when guiding the arm through desired exercises, (b) actively control position of upper arm and forearm, (c) “sense” effort made by patient and alter amount of assistance, (d) be comfortable and safe, (e) be affordable and (f) be useable in patients with different amounts of weakness/spasm. Existing devices have limitations: they (a) often act at a single point on the arm, (b) use commercial robots and electric motors which makes them heavy and expensive, (c) are not able to sense and react to the patient’s changing efforts as they reacquire motor skills. The proposed system will address these limitations by using two cooperating pneumatic robots, linked to form a single interactive intelligent device, mimicking guidance of the arm as undertaken by PTs. The project has three phases: (a) develop a system which captures and copies how PTs guide the patients arm through the exercise while the patient remains passive - passive assistance. (b) develop a system which senses effort made by the patient while attempting to repeat the exercise and assists adjusts the assistance accordingly, interactive assistance, and (c) pilot clinical trial of the intelligent interactive system. The outcome of this project will be a co-ordinated pneumatic dual robot system with six axes of motion, which stroke patients with a wide range of arm impairments can safely and comfortably use in exercise therapy. The system will be portable, such that it can be flexibly deployed in physiotherapy departments.

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Positive Strokes – *Changing Outlooks*

Positive strokes – changing outlooks –the city wide group of service users and carers involved in the development of services for those with stroke, have been very busy over the last few months.

The number of stroke survivors and carers who regularly attend meetings has continued to increase, and going from strength to strength. Secretary Linda is finding it easier to take meeting minutes since the arrival of a lap top bought with a grant obtained through Voluntary Action – Leeds.

As well as direct input into redesigning stroke services, members of Positive Strokes have also been involved in:

- Helping to distribute the Positive Strokes information packs through the stroke wards in the hospital.
- Meeting and encouraging those with stroke still in hospital.
- Developing the layout and wording of the information handed out by the East Leeds Community Stroke Team.
- The interview process for staff for the East Community Stroke Team.
- Persuading shops in the Pudsey and Kirkstall area to leave wide enough aisles for wheelchairs and scooters.
- Producing a video in partnership with Leeds Metropolitan University to raise awareness of what it is like living with stroke. This will be used for staff new to working in stroke services and for health students.
- Talking to visitors to the Osmondthorpe Brain Injury Awareness Day in March 2005
- Being interviewed for "Frontline" – a journal for physiotherapists, about service users and carers being involved in service redesign.
- Working with researchers developing a protocol to evaluate the effectiveness of a toolkit to assess those living long term with stroke.
- Feeding back information received on the PS-CO Comments, Complaints and Compliments forms about current stroke services.

Stroke Services Redesign

The redesign of stroke services in Leeds has now stepped up a gear as it has become an integral part of Making Leeds Better.

All of the statutory agencies in Leeds have agreed a vision for the future of healthcare services in the city. The pathways have been selected because it seems likely in the future to involve a change in the mix between primary and secondary care services. Our assumption is that redesigning the patient pathway in this area will lead to significantly more care being provided outside hospital than now.

A number of pathway groups have been developed, one of which is the Neuro Care Group. This will be looking at a number of pathways for people with neurological conditions with the main focus being on stroke. Debbie Neal, the Stroke Services Coordinator, will be leading the development of the Neuro Care Pathways which will build on all the work done over the last three years overseen by the Stroke Programme Board.

Our assumption about resource is that the current requirements for the NHS in general to become more efficient and productive will continue. We are therefore expecting that in redesigning the pathway we will be able to improve overall efficiency and productivity whilst at the same time improving quality by providing faster access, closer to people's homes.

Work so far on the Neuro Care Pathways

An initial launch workshop for the Neuro care pathways work was held on April 14th at the Host centre in Leeds. Attendance was very good and included:

- Stroke survivors and carers (members of Positive Strokes)
- Voluntary sector representatives
- Managers and clinical staff from the hospital trust and primary care trusts.
- Making Leeds Better staff

In the morning there were a number of presentations on:

- Making Leeds Better
- Care Pathways

- Data about what happens to the Neuro care pathway group of patients at the moment.

In the afternoon, everyone worked in small groups to develop detailed suggestions of how the care pathways should look in the future, based on the framework of the Leeds Stroke Pathway. This information is being entered into a template which will form the final submission for the Neuro Care Pathways group which has to be completed by the end of July. A first draft will be circulated by email to all interested individuals and groups by the end of May for comment and further development.

The work of the Neuro Care Pathways Group is being overseen by a board, chaired by George McIntyre, Chief Executive of South Leeds PCT. This board will be meeting on June 15th and has representatives from patients and carers, health (hospital trust, primary care trusts and ambulance service), social services and the voluntary sector.

For further information or to get involved in the Neurology Care Pathways work, please contact:

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Training in Stroke Medicine

The devastating impact of stroke both nationally and worldwide is steadily being recognised. As the commonest cause of death and disability in the UK, accounting for over 5% of NHS resources, clear standards for stroke care have been implemented through, for example, the National Service Framework, Royal College of Physicians and in Scotland the National Clinical Guidelines for Stroke and the Scottish Intercollegiate Guidelines Network. To deliver good quality stroke care there must be exemplary training to meet these standards.

More recently, training in Stroke Medicine as a sub-specialty has been approved for trainees holding a national training number in other 'parent' specialties such as; Cardiology, Clinical Pharmacology, General (Internal) Medicine, Geriatrics, Neurology and Rehabilitation. As stroke encompasses elements of neurology, cardiovascular disease, ageing and rehabilitation, experience in these areas has been designed through a training curriculum, which broadly covers; acute stroke, stroke rehabilitation and stroke prevention. These training areas have a large degree of overlap and trainees will have different levels of experience depending upon their 'parent' training background, which will determine the duration of training (usually one to two years). As with conventional Higher Medical Training for specialist registrars, posts should be gained in open competition educational supervision and annual assessment are paramount.

As a specialist registrar in Geriatrics and General (Internal) Medicine in the Yorkshire Deanery, my interest in Stroke was developed through earlier training at Leeds General Infirmary and Bradford Hospitals Trust. I was able to consolidate this by the award of *the Stroke Association* funded Clinical Fellowship In Stroke, one of two nationally awarded fellowships annually. This was undertaken at Leeds Teaching Hospital Trust, incorporating St James', Leeds General and Chapel Allerton Hospitals, which in addition to the stroke services provided *all* of the important services and specialties to deliver the required training including; Geriatrics, Neurology, Neuroradiology, Neurosurgery, Vascular Surgery, as well as access to specialist clinics (for hypertension, epilepsy, thrombophilia, spasticity and specialist seating). Other specialties relevant to the training curriculum such as Palliative Care and Cardiology (with coronary care) are also provided in Leeds. Although a supernumerary post and with an emphasis on self-directed learning, I was able to concentrate my training needs in areas of inexperience. My first eight months were based at St James' ward 17 with emphasis on clinical neurology, 'young' stroke, (interventional) vascular imaging and neuroradiology.

Through ward rounds, multidisciplinary meetings, weekly neurovascular clinics and radiology sessions, I have been able to substantially develop my neurological clinical skills, neuroimaging reading and manage younger patients with conventional / 'rarer' causes of stroke. The final four months were based on ward 26 at Leeds General Infirmary and concentrated on 'older' patients with stroke and their rehabilitation including spasticity management. This was achieved by ward rounds, multidisciplinary meetings, neurovascular and stroke follow-up outpatients. There was opportunity to attach to vascular and neurosurgical teams to experience relevant surgical procedures from pre-to-post operative care. During this year I was also able to attend stroke reconfiguration meetings looking at the development of stroke services within the Trust, including the implementation of thrombolysis.

My training was based on the proposed curriculum for stroke medicine and was undertaken before specialty recognition, therefore I was not able to accredit my subspecialty training in stroke. Nevertheless it highlighted some of the deficiencies in stroke training from my 'parent' specialty alone, emphasising the need for a broad, good quality-training programme involving all aspects of cerebrovascular care. Furthermore it is my view that Leeds Teaching Hospitals Trust has the ability to provide a comprehensive training programme in Stroke Medicine. Currently training across the Yorkshire region is being developed, but is dependant upon the proposed training centres' ability to provide the majority of educational components required in the curriculum. Funding for such posts is another issue and may be provided by the Yorkshire Deanery. In Leeds at least, it is hoped that the training programme will be recognised and the first trainee will be in post later this year.

For more information about sub-specialty training in Stroke Medicine:

www.basp.ac.uk

www.jchmt.org.uk

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Early Supported Discharge – Measuring the Burden on Carers

Background

There is now good evidence to support the use of stroke specialist care in the acute phase to improve outcomes in terms of mortality and morbidity after stroke (Stroke Unit Trialists' Collaboration, 2004). Evidence also shows that the use of Early Supported Discharge by a stroke specialist team can reduce lengths of acute hospital stay by between 9 and 13 days with no negative effect on outcomes for the person with stroke (Early Supported Discharge Trialists, 2004). A recent Norwegian study demonstrated not only reduced lengths of stay but also increased independence at 1 year for those with stroke receiving extended stroke unit care i.e. ESD plus follow-up in addition to acute stroke unit care (Fjaertoft et al, 2003).

In Leeds, work is underway to develop a seamless integrated service for those with stroke. At present there are extremely limited community based stroke specialist services and a level of discharge for those with stroke to permanent institutional care much higher than the national average. Intermediate care teams (ICTs) across Leeds provide intensive home based rehabilitation to older people to prevent hospital admission or facilitate hospital discharge. East Leeds PCT are to

pilot an ESD stroke team working alongside the existing Intermediate Care Team. This will allow the relationship between the new stroke team and the existing ICTs and also the new team's impact on lengths of hospital stay to be clarified.

It is well documented that caring for those with stroke can affect the mental and physical health, emotional well-being and the quality of life for carers. In view of this any change to services that may possibly increase burden on carers should be carefully considered. Some studies of Early Supported Discharge (ESD) after stroke show a small, though not significant **increase** in carer burden, as measured by the Carer Strain Index. However a small but not significant **decrease** in carer burden was shown in recent studies by Teng et al (2003) and Fjaertoft et al, (2003) as measured by the Caregiver Burden Index and Caregiver Strain Index respectively.

There is however no consensus on the best outcome measure to use to assess carer burden nor on the best time to assess it, though it is generally recognised that it is highest in the first month after discharge. A measure is needed that can be administered by postal questionnaire linked to a system that is capable of accurately timing and evaluating its use (Leeds Stroke Database).

How to measure the burden on carers with the East ESD Community Stroke Team?

A huge number of different burden scales have been developed for use with different patient populations. A recently published review of measures of burden among caregivers of stroke patients, by Visser-Meily et al, (2004) was unable to identify the best measure to assess caregiver burden in stroke.

What has been used in trials of Early Supported Discharge?

Caregiver Strain Index
Sickness Impact Profile
GHQ 30
Caregiver Burden Index
SF36
GHQ28
Caregiver Burden Scale

What aspects of the measure are most important in this situation?

What it measures (content validity)

There are many aspects to carer burden that could be considered including carer's physical and mental health, financial circumstances etc. Not all measures look at all these aspects.

Whether it can detect change (responsiveness / sensitivity)

Visser-Meily et al, 2004 evaluated the clinimetric properties of a number of scales that have been used more than once in studies of stroke populations. Of the scales studied, **only the Caregiver Burden Scale, showed good responsiveness** though only in a single study, whereas the Carer Strain Index has not identified any statistically significant change in any of the studies on stroke in which it has been used (Visser-Meily et al, 2004).

How easy it is to use (utility)

Caregiver Burden Scale

No information found but appears to be a short fairly easy to complete questionnaire.

Caregiver Strain Index:

Post-discharge questionnaire can be completed in 10 minutes.

What do they look like?

Caregiver Burden Scale:

22 items grouped into five areas, (general strain 1 – 8, Isolation 9 – 11, Disappointment 12 – 16, Emotional Involvement 17 – 19, Environment 20 – 22). Each item is scored from 1 (not at all), to 4 (often).

Item	Score			
	Not at all (1)	Seldom (2)	Some times (3)	Often (4)
1. Do you find yourself facing purely practical problems in the care of your relative that you think are difficult to solve?				
2. Do you think you have to shoulder too much responsibility for your relative's welfare?				
3. Do you sometimes feel as if you would like to run away from the entire situation you find yourself in?				
4. Do you feel tired and worn out?				
5. Do you feel tied down by your relative's problem?				
6. Do you find it mentally trying to take care of your relative?				
7. Do you think your own health has suffered because you have been taking care of your relative?				
8. Do you think you spend so much time with your relative that the time for yourself is insufficient?				
9. Do you avoid inviting friends and acquaintances home because of your relative's problem?				
10. Has your social life, e.g. with family and friends, been lessened?				
11. Has your relative's problem prevented you from doing what you had planned to do in this phase of your life?				
12. Have you a feeling that life has treated you unfairly?				
13. Had you expected that life would be different than it is at your age?				
14. Do you feel lonely and isolated because of your relative's problem?				
15. Do you find it physically trying to take care of your relative?				
16. Have you experienced economic				

sacrifice because you have been taking care of your relative?				
17. Are you sometimes ashamed of your relative's behaviour?				
18. Do you ever feel offended and angry with your relative?				
19. Do you feel embarrassed by your relative's behaviour?				
20. Does the physical environment make it troublesome for you taking care of your relative?				
21. Do you worry about not taking care of your relative in the proper way?				
22. Is there anything in the neighbourhood of your relative's home making it troublesome for you to take care of your relative?				

Caregiver Strain Index

13 items, scored Yes = 1, No = 2

1. Sleep is disturbed
2. It is inconvenient
3. It is a physical strain
4. It is confining
5. There have been family adjustments
6. There have been changes in personal plans
7. There have been other demands on my time
8. There have been emotional adjustments
9. Some behaviour is upsetting
10. It is upsetting to find he / she has changed so much from his / her former self.
11. There have been work adjustments
12. It is a financial strain
13. Feeling completely overwhelmed.

Which to choose?

Confusingly the recent study by Kalra (2004) talks all the way through about the Caregiver Burden Scale and the scores 88 – 22 seem to indicate its use, although the reference at the end of the paper is for the Caregivers Strain Index. If they do mean the Caregiver Burden Scale that would probably be the best choice.

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THE EAST LEEDS COMMUNITY STROKE TEAM

DEVELOPMENT AND PROGRESS REPORT

The Community Stroke Team (CST) took up residence at York Towers, Leeds LS9 on 1st November 2004. The team have been accepting referrals since the 10 January 2005 following a period of planning, preparation and liaison with key personnel from the referring sites in Leeds Teaching Hospitals NHS Trust. The aim of the team is to facilitate patients with stroke to be discharged earlier from hospital and continue their rehabilitation in the most appropriate setting. This is mainly in the individual's home and their local community, although treatment is also undertaken in a newly designed therapy area within a local day centre (Firthfields) in Garforth Leeds LS25.

Input is provided based on "patient centred goals" which are reviewed on a fortnightly basis. As a means of addressing emotional, social and other needs individuals are also referred to voluntary agencies such as dysphasia support, neighbourhood network schemes. This can also assist in supporting individuals in being discharged from the Community Stroke Team.

Support is also given to carers which in some cases may have helped prevent readmission to hospital.

The team comprises of physiotherapy, occupational therapy, speech and language therapy, support worker and an administrator. So far we have accepted 25 referrals and discharged 8.

Wendy Wilson.