

Report on Conference “Stroke is a Medical Emergency”
held at the Redworth Hall Hotel, Newton Aycliffe, on
Friday December 1st 2006

APPENDIX 1

Background

The County Durham and Darlington Acute Hospitals Patient and Public Involvement Forum was established at the end of 2003 and has now operated for over three years. Its members are from varied backgrounds, but all have been active in the voluntary and community sector in various ways. Most have direct experience of the NHS as patients. The Forum looks at different aspects of services provided by the Trust, responding to the concerns of patients and the public. It has produced reports on hospital catering, maternity services, and fire safety, and has established working parties to consider diabetes and the involvement of young people. The Forum meets monthly and is always keen to receive applications to join from interested members of the public.

One of the projects which Forum members have been concerned about is the issue of stroke and its treatment. One Forum Member, Marilyn Weerasinghe, sits on the Clinical Action Team for Stroke which has been established by the Acute Trust in conjunction with the County Durham Primary Care Trust. Its objective is to encourage joint working between the two Trusts to deal with the whole issue of stroke – its prevention, treatment and aftercare. A local MP , Helen Goodman, who represents Bishop Auckland, sits on the Public Accounts Committee, which recently produced a report (Select Committee on Public Accounts Fifty-Second Report) identifying the considerable costs to the country and to the NHS of stroke (£7 billion and £2.8 billion respectively) . The Report recommended that if stroke, which is the third biggest cause of death in England after heart disease and cancer, was given a higher priority, not only would many lives be saved, but the economy would benefit.

A Sentinel Audit in 2003 recommended that all hospitals should have a specialist stroke department. At present, of the three main sites in the Co Durham and Darlington Acute Trust, only Bishop Auckland has a unit, as yet incomplete, which is largely due to the enthusiasm and commitment of one specialist, Dr Ali Mehrzad. Bishop Auckland has also developed a Thrombolysis Therapy Unit, one of a few in the country and the second most active in the North East. The Trust has also appointed a Coordinator for Stroke Services Jayne Nicholson, whose role is to raise the profile of stroke treatment and to develop relationships with the Primary Care Trust.

Marilyn had reported back to the Forum about the activities of the Clinical Action Team and Jayne has spoken to Forum members. As a result of this the Members decided to convene a special conference to bring together as many people as possible who worked with different aspects of stroke. The aim would be to both try and raise the profile of stroke within the NHS and also to encourage joint working in order to improve prevention and after care, as well

as the actual treatment of stroke. Marilyn and Jayne worked with the Forum Coordinator to arrange the Conference.

The Conference Itself

The Conference was supported by the Commission for Public and Patient Involvement and took place at Redworth Hall Hotel, Newton Aycliffe on December 1st 2006. Over 70 people attended, drawn from the NHS, voluntary sector, local authorities and other PPI Forums. What was particularly pleasing was the fact that some GPs attended, as they are in the front line of dealing with stroke. (A copy of the programme is attached as Appendix One)

The principal speaker was **Dr Ali Mehrzad**, the Stroke Specialist from Bishop Auckland General Hospital, and a strong advocate of improving stroke services. Dr Mehrzad first of all gave an update on the Management of TIA and Stroke. TIA (or a Transient Ischaemic Attack) is often known as a mini-stroke. About 20% of stroke victims present with this warning symptom. Rapid intervention after a TIA can prevent a stroke. Stroke affects 120,000 patients annually in the UK and is the leading cause of disability and the third most common cause of death. Sixty-five percent of patients will be dead or dependent in 6 months. The rest will either have a mild disability or make a complete recovery. Analysis of stroke units has shown that acute care in a stroke unit for a few weeks after the event is associated with about 35% relative risk reduction in mortality and improved prospect of independence and returning home. Britain is behind her European counterparts, most of whom treat stroke as a medical emergency. There are 1200 strokes in County Durham every year, and this would require 4 stroke physicians. At the moment there is only one, Dr Mehrzad.

The Conference was also addressed by Howard **Tighe** who had survived a Stroke and then made a recovery and gone on to run a successful business. Although he still has some physical impairments this does not prevent him pursuing an active lifestyle. **Kath Toward** also spoke. She ran a farm with her husband and was very active in the community. She then had to cope when he suffered a stroke, and made the point that support and aftercare were not adequate. Caring for a stroke sufferer puts a tremendous burden on their carers and family.

Gerry Hehir described the Stroke Survivor programme which is managed by Co Durham PCT and delivered by Teesdale Council Leisure Services. So far 14 Stroke Survivors have benefited from the programme. **Jayne Nicholson**, The stroke Services Coordinator for County Durham and Darlington Acute Hospitals Trust spoke about the need for all parts of the NHS to take responsibility for dealing with Stroke. Her main point was that Stroke is a Medical Emergency, and not something which once it has happened doctors and health practitioners can do little about. There needs to be much greater public and professional awareness of the signs and symptoms of Stroke/TIA. Also more resources should be put into assisting stroke survivors and helping their rehabilitation as 45% are unable to live independently.

Helen Goodman M.P. described how she had become aware of the problems with stroke when she was involved in the Public Accounts Committee investigation (Fifty Second Report). A greater priority is given in the UK to cardiac problems – there are almost twice as many patients per stroke specialist compared to cardiac ones. Four times as much money is spent on cancer treatment compared to stroke. Yet early intervention and treatment could prevent stroke and save lives. Not only would this help patients, but would save the NHS and the economy money. The other big concern she had was the lack of help to carers when stroke patients are discharged. 50% of carers do not receive needs assessments. Stroke survivors who live on their own are a particular problem. About half of stroke patients receive rehabilitation services that meet their needs in the six months following discharge falling to 25% twelve months after discharge. Helen acknowledged that more needed to be done, and in particular carers needed more help and community services needed to be improved.

Dr Mehrzad concluded the Conference by talking about the Primary and Secondary Prevention of TIA and Stroke. Apart from the behavioural changes which people should make, such as reducing smoking and alcohol consumption and engaging in more physical activity, Dr Mehrzad described clinical trials of various drugs and forms of surgical intervention designed to reduce the incidence of stroke. Aspirin can be combined with other drugs for example, and Warfarin is best for older people.

Points Arising from the Conference

The Conference was intensive, with a wide range of speakers. There were opportunities for questions, but time constraints meant that there were not many opportunities for discussion in groups. To counter this an extensive questionnaire was issued, to which there was a good response, (see appendix one) and the results are analysed below. The main points which came out of the Conference were as follows:

- The Prevention, Treatment and Aftercare for Stroke have been neglected in the UK where much more emphasis is placed on dealing with Heart Disease. As one speaker said, Stroke is a Brain Attack as distinct from a Heart Attack.
- Early intervention can save lives and reduce the harmful effects of a stroke. Stroke should be treated as a medical emergency requiring hospital treatment, rather than something where no action can be taken.
- The issues of prevention and aftercare, as well as treatment, mean that the Acute and Primary Care Trusts must work together, and also involve local government and the voluntary sector, particularly regarding after-care.
- More resources need to be put into helping carers and the families of stroke victims.

- There is a need for more specialist stroke units in hospitals and more specialist physicians.
- Stroke needs to have a higher priority, as it does in most other European countries. Money needs to be more effectively spent.

Analysis of the Questionnaires

As mentioned above, the organisers felt the best way to accurately gauge feedback was through issuing a thorough questionnaire (see Appendix Two). There were over 70 people present, and 50 questionnaires were returned, a response rate of approximately 70%. This shows a considerable degree of interest by the participants, and a desire to take the ideas discussed at the Conference forward. The organisers stressed that the PPI Forum would use the results to draw attention to the issues raised in the Conference.

The first part of the evaluation form asked for comments on the Conference organisation, and used a five point scale, the top one being Very High, and the fifth Very Low, with the third point as Average. The scores were as follows:

Table 1

	V High	High	Average	Low	Very Low
Chairmanship	6	34	10		
Admin/Org	10	35	5		
General Format of day	8	37	4		
Content	11	33	5		
Lunch	13	27	9		

Table 2

As regards the usefulness of the day, respondents were given a choice between four options: Very useful, fairly useful, Not Very useful and Not at all useful. The results were as follows:

Very Useful	Fairly Useful	Not Very Useful	Not at all useful
26	19		

Some people did get to the end of their questionnaires!

It was very pleasing to the organisers to note that regarding the overall organisation of the day, the results were weighted heavily towards Very High and High, with none in the bottom half of the scale. Similarly a majority found the conference very useful, and no one thought it not to be useful. The resources and effort put into it had been worthwhile.

The bulk of the questionnaire was constructed in a qualitative rather than a quantitative manner. Respondents were asked to give their answers to five questions as follows:

1. What was the most important issue the Conference highlighted for you?
2. How will the Conference influence the way you work?
3. What do you think the NHS priorities should be regarding stroke?
4. Any other suggestions as to future actions to deal with stroke?
5. Suggestions for other health issues which CPPIH could address.

I shall summarise the replies. All the points are valid but do not represent a collective view.

1 What was the most important issue the Conference highlighted for you?

Networking and coordination between services. There was concern that patients and carers would expect services which they would not receive. Some respondents stressed that the Acute Trust should brief patients on what services they were entitled to and how they could access them. A minority of respondents felt that existing services were not being recognised, and that efforts were already made to coordinate aftercare services.

Some respondents were concerned that thrombolysis was being promoted as a treatment, but this did not always work with all patients.

There was also a concern that since the majority of conference participants were from the Bishop Auckland area not enough attention was given to what happened at UHND.

There was also concern about the statement that ambulance crews were not trained to deal with stroke

The majority, however, felt the main issue highlighted by the Conference was the need for adequate aftercare services, and the need to better coordinate them.

2. How will the Conference influence the way you work?

There were several very encouraging comments such as "Inspirational – but the problem is lack of time, staff and money", and "A morale boost"..

The majority of respondents made the point which was the main theme of the Conference, that they would become more aware of the importance of stroke, with such comments as "I shall get the FAST message across." The organisers had been keen to target GPs, so it was particularly encouraging where respondents who identified themselves as GPs said that they would become more aware of the need to treat stroke quickly, and would also make themselves more aware of local services.

A significant minority said they would become more aware of the need for good aftercare. Some of these were not health service practitioners, and

these people said they would campaign for it in other bodies where they could make their voices heard.

The issue of UHND was mentioned – how their services had to be publicised more.

Overall the feedback indicated that the main message of the conference, that stroke treatment had to be taken more seriously, had got across. There was awareness too of the need to put more resources into developing aftercare.

3. What do you think the NHS priorities should be regarding stroke?

The majority of answers stressed the importance of improving aftercare in the community. Several therapists described their difficulties with lack of resources and said there was a need to train more therapists. More therapy in the community would mean patients did not have to stay in hospital so long, and would be better for the patients. Earlier discharge, however, meant a greater burden for social services, and this had to be recognised. There were also comments that the service needed to be equal everywhere. One social care worker stated how she had tried to support a stroke sufferer, and had not been able to access any physiotherapy through the NHS. This had caused the family considerable distress.

Several respondents stressed the need to educate both the public and NHS professionals about stroke. There needed to be more training for GPs and paramedics. The public too needed to be aware of the significance of stroke and know how to deal with it.

The issue of more resources was raised several times, as one would expect.

4. Any other suggestions as to future actions to deal with stroke?

There was a considerable amount of unanimity. Many respondents wanted information about stroke available in as many ways as possible – through schools, leisure centres and GPs surgeries. There was a feeling that there should be closer working between the Acute Trust and community agencies. “Discharge from hospital should not mean goodbye” as one participant put it.

Although practically everyone wanted more resources put into community care, several made the point that this should not be at the expense of facilities within the Acute Trust. The point was also made that services should be equally available to everyone. This particular respondent repeated the point several times, so there may be a particular issue here.

5. Suggestions for other health issues which CPPIH could address.

The following suggestions were made:

- Care of people with Chronic Obstructive Pulmonary Disease (COPD) (2 respondents suggested this)
- CHD and obesity
- Smoking and alcohol in young people.
- Mental Services for young people.
- Future of LINKs

- Care in the community
- Elderly in hospital
- Living Wills/DNR forms
- Addiction problems

These issues can be addressed by forums when resources and time allow.

The Way Forward

The Forum will work with the Acute Trust to take the issues raised at this Conference forward. It is important to stress that many of these are national issues, and the Forum should not be seen as simply expecting the Trust to do things when resources may not be available. Nevertheless the Forum's role is to raise awareness of an issue.

The points which emerge from the Conference are as follows:

- The Forum should campaign to raise awareness of stroke.
- Stroke must be treated as a medical emergency. Early intervention can save lives and reduce the impact of stroke.
- All stroke patients in County Durham should have access to treatment in an acute stroke unit.
- The Forum should work with the Trust to improve stroke and thrombolysis at BAGH and ensure that these facilities are available to all stroke patients in County Durham.
- The PCT, Acute Trust and Social Services must work closer together on both the prevention and after care of stroke.
- More needs to be done to help with the aftercare of stroke sufferers and their carers.
- The need for more resources has to be directed at the Government.

The Forum will draw up an Action Plan as to how to deal most effectively with these issues.

David Taylor-Gooby