WHAT MAKES A GOOD STROKE SERVICE AND HOW DO WE GET THERE?
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Each of the following sections sets out what was considered to be key elements in achieving a good stroke service, some examples of good practice, some information about further work underway and possible sources of help.

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INTRODUCTION

This review was developed from an initial discussion paper presented at a workshop earlier this year. The workshop's aim was to identify some of the key success factors in developing a high quality stroke service.

The workshop took as its basis the current clinical evidence for stroke services, set out within the Intercollegiate Working Party for Stroke national clinical guidelines published in 2000 by the Royal College of Physicians. These guidelines are reflected in the National Service Framework (NSF) for Older People, published in 2001. The NSF stroke standard translates the guidelines and further evidence based practice into a four year plan and concludes with an expectation that every person who has a stroke will be seen by a specialist stroke team and have access to a specialist stroke service by 2004. The workshop considered what other practical advice could be offered on how to achieve a good stroke service, which would meet the needs of people who have had a stroke.

The themes in the initial paper arose from a series of visits to, and discussions with, staff working on stroke units which had been commended for their work. These were then further explored at the workshop and some additional areas have been introduced. Local circumstances and models of stroke care vary enormously but, despite that understandable variety, when attempting to explain the apparent success of some services, there are a number of recurrent themes.

These are:

- the need for vision, drive and leadership
- having a inter-agency and interdisciplinary strategic view
- ensuring the right workforce is in place with the right skills and competencies
- developing a care pathway
- the need to have primary care engaged
- involving users and carers
- long-term social and psychological effects of stroke must be considered
- participation in research and development
- effective use of IT
- establishing a clinical governance framework
- ensuring effective management of change.

Following the workshop, we decided to consolidate the work into a document setting out:

- key elements considered necessary in achieving a good stroke service
- some examples of good practice
- some information about further work underway or possible sources of help, and
- contact details of people who were involved in the process.
This document is designed to provide this. It is in no way designed to be prescriptive – it is there to provide information to those who would find it helpful, not as a blueprint. It is also a living document. In this fast-moving world, issues and information of relevance today will not necessarily be those relevant tomorrow.

However, in the light of the Older People’s NSF milestone for April 2004 (requiring all general hospitals caring for people with stroke to have a specialised stroke service) it would seem timely and helpful to consolidate as much information as possible in order to direct people towards useful resources and expertise.

We would like to thank all contributors for their time and efforts in the development of this document.

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VISION, DRIVE AND LEADERSHIP

Strong leadership is important both for strategic planning and for clinical service delivery. A mixture of management and clinical skills seems to be required. Arguably, any profession involved in stroke care could take on this leadership role. In the visits and subsequent workshop discussions, it was agreed that generally a medical consultant with responsibility for stroke often acted as the catalyst for change by formalising this leadership responsibility. Perhaps this leadership role will change as consultant therapists and consultant nurses become more widely established but at present those services not yet able to achieve the NSF stroke standard might consider developing a medical consultant post to take responsibility for implementation. However, the need to have a strong interdisciplinary team should not be underestimated and can be very powerful in influencing decision makers (illustrated by the second example below).

Examples

In NorthEast Devon, the current stroke service dates from the appointment of the consultant geriatrician leading on stroke. There is also a stroke co-ordinator who is central to the provision of organised stroke care. (Beacon site details in Appendix B)

The Royal Free NHS Trust Stroke Service (STEP- Stroke Treatment for Every Person) was established in November 2000 and comprises 12 acute stroke beds and 15 rehabilitation beds. The Unit functions across two sites (a mile apart), but operates very much as a single unit, with some staff working between both sites. The STEP team, which won an award in 2001 for their teamwork and contribution to patient care and is regarded by the Trust’s Chief Executive as an “exemplar of MDT”.

The team believes that the whole is greater than the sum of its constituent parts and this has meant that decisions and developments are team, not individually, driven. This approach can have the advantage of not having one person singled out, and the team is not dependent upon one driver. The STEP team uses the RAID model to engage other staff, and it gives high priority to a weekly one-hour meeting to ensure that they have a forum for planning, discussion and reflection. (Contact Cherry Kilbride, details in Appendix A)
Current work/information of interest

The NHS Leadership Centre

The NHS Leadership Centre was created as part of the Modernisation Agency to support NHS staff to achieve sustainable service improvement. Working with the Older People's National Director and the Older Peoples Care Group Workforce Team, the Centre is currently focusing on developing local leadership capacity and capability for older people's services. See Appendix 3 for more details, or contact Christina.Pond@doh.gsi.gov.uk. More details of the leadership programme can be found on www.modern.nhs.uk.
INTER-AGENCY AND INTERDISCIPLINARY
STRATEGIC VIEW

In general, in order to achieve a good quality stroke service a high level group of all interested players is needed to develop and implement a strategy. The group typically needs membership drawn from the strategic health authority, social services, primary care trusts, community services, hospital trusts, voluntary sector and people who have had a stroke. Each will provide a different but valuable perspective. Leadership of this strategic group has varied but often there has been a smaller core group, meeting more informally to construct a clear vision of the purpose and shape of their stroke service, and this has formed the basis for debate and discussion. Service users are also forming a part of those core groups. In some areas the strategy group has subgroups to take forward work on specific issues such as information to patients, user involvement, long term care, etc.

Example

In 1997 Wiltshire Health Authority (as it was then) established an operational development group reporting to the Wiltshire Elderly Services Steering group. They were responsible for preparing options for service reconfiguration, making recommendations regarding commissioning decisions, monitoring services and designing change in each PCG area. This provided strategic overviews that helped to drive and develop the now established stroke rehabilitation service. (More details can be found through contacting Bath stroke service see Appendix A)

- Current work/information of interest

Influencing strategic planning can be achieved through recognising available levers for change. The following are levers which call for stroke to be identified as a local priority and which could help influence strategic planning.

The Third National Sentinel Audit of Stroke

The Audit, carried out by the Clinical Effectiveness and Evaluation Unit of the Royal College of Physicians and led by the Intercollegiate Working Party for Stroke, has given a detailed picture of the way hospitals provide care for stroke patients. The first two Audits (in 1998 and 1999) showed serious variations in the standard of care for stroke patients between hospitals, and the continuing audit is a major factor driving improvements in care. More NHS Trusts took part in the 2001 Audit than in the previous ones, so the results are not directly comparable in all categories, but it is clear that - although many have made progress in every area of care - some hospitals are not reaching acceptable standards. The Audit also demonstrates that many stroke services do not have the capacity to ensure that all those admitted with stroke have
access to this type of care. Although 75% of hospitals now have a stroke there is still insufficient capacity. The next Audit is planned for April 2004.

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Local stroke audit results, particularly if sub-optimal, can be used as a powerful stimulus to develop a strategic plan to make the necessary improvements.

**Government Priorities/Monitoring**

Implementing the Older People’s NSF is one of the top priorities for the Department of Health. The document *Improvement, Expansion and Reform: the Next Three Years*, which sets out the priorities and planning guidance for 2003-2006, is published on the Department of Health web site at [http://www.doh.gov.uk/planning2003-2006/index.htm](http://www.doh.gov.uk/planning2003-2006/index.htm). The NSF stroke milestone for 2004 is one of the priorities identified. Health and social services are, and will continue to be, monitored against the NSF milestones and in terms of quality of stroke care. We are currently considering the development of new stroke performance indicators, so that we can monitor performance once the 2004 NSF milestone has been met. In order to meet central performance requirements, services will need to be provided in line with the stroke standard in the NSF.

**Information of Interest**

**National and Primary Care Trust Development Programme (Nat PaCT)**

**PCT Commissioning Project**

The Department of Health and NatPaCT are working with 7 pilot PCTs to help them to commission in order to deliver on the requirements of the Older People’s NSF. One of the projects will look specifically at commissioning to deliver on the stroke standard. In order to achieve this, there will need to be an inter-agency strategic vision, with interagency planning and commissioning. For more information, contact Jane Allberry: Jane.Allberry@doh.gsi.gov.uk
WORKFORCE MATTERS

Having the right people, with the right skills, at the right time is an essential element of implementing the stroke service model set out in the NSF. Research also shows that a co-ordinated specialist inter-disciplinary team is an important feature of good stroke care.

There are shortages of key professionals in many areas, and the current shortage of therapy staff is a nationally recognised problem. Some services have addressed therapist shortages by using generic therapy assistants, trained and supervised by therapists. Research has also shown that as a result more therapy time can be devoted to each patient, including at weekends. Other services have aimed to integrate therapy into the care provided by all staff – which has the advantage that patients can benefit from therapeutic activity on a continuous basis.

There are also problems with inadequate medical time, for example to run TIA clinics with sufficient frequency to enable rapid access, and inadequate staffing to meet recommended standards for access to scanning. The medical input associated with stroke services is considerable (TIA clinics, stroke units, review clinics) and the British Association of Stroke Physicians (BASP) has suggested two full time consultants are needed per service to meet this challenge. Currently most stroke services are provided by consultants who have commitments in addition to stroke e.g. geriatric medicine, neurology. Very few are full time stroke physicians. However, many services may be able to make progress by utilising local opportunities to reconfigure existing consultant physician job plans, to release at least some designated sessions for stroke care.

There is a need for more training about stroke care for all staff, particularly where patients are not in specialist stroke units. Recovery is quicker and complications are avoided by staff adopting the correct approach throughout the whole of the patient’s journey – this includes staff in ambulances, A&E and acute assessment wards. There are examples of different initiatives to ensure an adequate level of knowledge and skills among non-specialist staff, including in-house training, courses run by the Stroke Association (contact details can be found in Appendix C) and university modules. You can contact your local work force confederation for details of courses running in your area via http://www.wdconfeds.org.

There is a further development need in that many hospital staff are familiar primarily with providing acute care services and do not have experience of the long-term issues that people who have had strokes have to deal with. This means that the workforce is often geared only to dealing with short-term issues. There are relatively few personnel available with the expertise to enable people to deal with the life changes stroke can bring or the long-term emotional consequences of stroke.
Examples

The Bradford changing workforce pilot is exploring new ways of working in the care of stroke across health and social care teams. The principal players are the Bradford Hospitals Trust, the three Bradford Primary Care Trusts and Bradford Social Services. The benefits expected from new ways of working are greater continuity of care for patients, faster access to treatment, fewer communication problems and unnecessary re-assessments, less pressure on scarce staff resources and greater staff satisfaction. (More details can be found by contacting Philip Shields, details in Appendix A)

Further work in Bradford has shown how physiotherapy-led training for stroke unit staff can be delivered as a routine in-house training programme and is associated with care quality improvements. Contact Anne Forster (a.forster@leeds.ac.uk) for more details

A one year multi-disciplinary stroke course has been developed in the University of Leeds. It is delivered by stroke specialists and is designed to improve stroke care in all settings. Contact Anne Forster a.forster@leeds.ac.uk for more details.

In Northumbria the establishment of the ENB 923 course in stroke care and the Foundation course in stroke care have provided the service with highly trained staff, with some lecturers being ex patients and carers who are keen to share experiences with professionals. (Beacon site contact details in Appendix B)

- Current work/information of interest

Older People Care Group Work Force Team (CGWT)

The Older People CGWT is a multi-disciplinary advisory body set up to support the National Workforce Development Board (NWDB) in drawing up national workforce strategies. It also aims to support the Older People's Services Taskforce in delivering service improvements for older people through care-centred workforce planning and development.

Its approach is to consider the skills and competencies needed in the workforce to deliver patient centred services. The Older People CGWT works closely with the Health and Social Care policy leads within the Department of Health and Workforce Development Confederations (WDC) to encourage innovations in human resources fields such as recruitment and retention, pay, education and training, new roles or skill-mix. It also links with the other CGWTs to ensure that cross-cutting issues, such as primary care or public health, are fully explored, and that changes in service delivery that could benefit several CGWT areas at once are identified.
The CGWT has identified issues around General Hospital Care (NSF standard 4) and Intermediate Care (NSF standard 3) as two of its key priority areas for 2002/03. These areas include the care of patients who have had strokes. Work in these areas includes identification of emerging workforce pressures and examples of new ways of working. The new ways of working that have been identified have been disseminated through the CGWT’s website.

The CGWT has commissioned the development of a Skills and Competencies Framework, identifying the skills and competencies required to deliver services to older people to the standards defined in the Older People’s NSF. This framework will also provide a tool for local service and workforce planners. The tool will help WDCs to commission relevant education and training programmes in relation to the Older People’s NSF priorities.

More general information can be found at: http://www.doh.gov.uk/cgwt

The Changing Workforce Programme

New roles for staff can provide better care for patients, meet critical staff shortages and create better jobs and careers for staff – for a summary of new roles in stroke go to the NSF Older Peoples website: http://www.doh.gov.uk/nsf/olderpeople.htm

New ways of working need both permission and protection and must be supported at operational and strategic levels. The NHS Changing Workforce Programme has been set up to promote the concept of new ways of working and to help healthcare providers introduce and test new roles. There are currently 13 pilot sites covering most clinical conditions and staff groups. The team also offers the Toolkit for Local Change, a process built around a full-day workshop which helps to turn local service pressures into ideas for new roles which can be tested; facilitation and materials are provided free of charge by the team.

For more information please contact:

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ESTABLISHING CARE PATHWAYS

Carefully designed care pathways ensure that all patients get the best quality service to meet their needs. (Details of stroke pathways can be found in the NSF, page 70)

A major product from the strategic group in many areas has been a jointly agreed stroke care pathway. This is not the integrated care pathway (ICP) describing intended care for individual patients, which many practitioners have become familiar with in recent years. Rather, it is a flow diagram defining the interconnections between stroke service components. Obviously not all components will be in place at the outset, but the plan allows a medium term understanding of a whole systems approach to stroke care. One of the concerns voiced at the workshop was the need for these care pathways to be created for long term care of stroke patients and their carers and not finish on discharge, which is what is found in the majority of cases (see example 4).

Critically, the stroke care pathway must relate to local circumstances – it builds on existing strengths, key people and available components. It allows reconfiguration where possible and identifies gaps which require new resources. A stroke care pathway for a rural district is necessarily different from that of an urban district.

Delivering person-centred care should be a fundamental principle in establishing the care pathway. It can also provide a common focus and ‘belief system’ for organisations and teams. When achieved, it is an important success factor. Therefore it is essential that local care pathways include people who have experienced a stroke as well as family members perhaps as well as someone from the voluntary sector. They will provide a different but valuable perspective.

Examples

*The Wirral Stroke Service* uses an inter-disciplinary care pathway to ensure that simple effective treatments are put into practice to benefit patients. (Beacon site, contact details in Appendix B)

*In North East Devon*, a pathway for stroke care across organisational boundaries, based on evidence practice, has been produced. The model of stroke care allows delivery of consistent good practice for patients both at home and in hospital, either in local community hospitals or in the central acute stroke unit. Providing stroke rehabilitation in community hospitals and in the home reflects the rural environment and the local health-care culture. (Beacon site, contact details in Appendix B)
Trent StHA has highlighted the need for an integrated Primary Care Pathway, ensuring that long-term care is also incorporated. Within the health communities a great deal of care pathway mapping has taken place, in order to develop protocols for stroke prevention, detection and management between primary and specialist care. (Contact details in Appendix A)

In May 2001 a multi-agency group was set up to develop a Community Stroke Pathway for Northumberland and North Tyneside, to extend the in-patient stroke pathway which had already been implemented across Northumbria Healthcare Trust. This group is in the process of identifying a joint health and social care pathway for all aspects of community based care and treatment, including standards for multi-disciplinary rehabilitation and longer term support and review. The pathway will also include a standardised assessment, a model for care co-ordination and a patient-held information pack (tied in with the development of the Single Assessment Process for older people). A pilot of the Community Stroke Pathway is planned for early 2003. (For more information contact Marie Watkins, details in Appendix A)

- Current work/information of interest

Most of the stroke services which have been awarded beacon status in the past have excellent examples of care pathways. Contact details can be found in Appendix B.
PRIMARY CARE CONTRIBUTION

Stroke care must cut across primary and secondary care boundaries. Primary care services must be engaged in the pathway and understand their role in prevention strategies and access and also to ensure appropriate follow up and support on discharge. Primary care is meant in its widest sense, involving the whole team – for example, practice nurses can be key in providing primary and secondary prevention care, physiotherapists can organise exercise on prescription at local gyms. Counsellors can offer support for longer-term emotional issues.

When a patient is discharged, alternative environments for ongoing care need to be considered. Assessment and ongoing rehabilitation are often better provided in other settings e.g. own home, housing based intermediate care, care homes and community hospitals, with nurse/therapy led services. If a stroke has altered someone’s level of independence significantly they need time and a different environment, other than acute care, to decide what is best for them and their carers.

Examples

In Bournemouth, GPs fax details of people suspected of having a TIA through to the hospital, so that outpatient appointments can be sent out quickly to the patients. (Contact details can be found in Appendix B)

Hull’s Stroke Association is running the Preventing Stroke and Saving Lives Project - this is targeted at people who have experienced a TIA and aims to provide an intensive follow-up service to limit the risk of stroke by providing a programme of lifestyle change, guidance and advice. The service is part of a multidisciplinary primary care team involved in the investigation and management of TIA patients within the pilot area. The project is based at Primary Care Trust level and working with GP practices and the community. It is also offered to the patient’s family so that they can encourage the patient and also to limit the risk of stroke to other family members. (Contact Chris Rennison, Stroke Association Business Manager 01482 830440 e-mail crennison@stroke.org.uk)

- Current work/information of interest

Two of the National Directors Ian Philp, National Director, Older People and David Colin-Thome, National Primary Care Director are currently visiting all Strategic Health Authority areas. This is a joint tour, to encourage amongst other things the development of primary care services for older people.
National Service Frameworks: a practical aid to implementation in primary care

National Service Frameworks: a practical aid to implementation in primary care has been produced as a resource for all those in primary care, whether based in general practice, the community or in Primary Care Trusts, involved in implementing National Service Frameworks (NSFs).

The pack was launched in August 2002, and is designed to highlight opportunities where common processes, systems and ways of working can be applied to a number of NSFs. It aims to bring together key elements of the NSF agenda, outlines what support is available for implementation and illustrates approaches that others have found helpful.

Copies of the pack have been distributed to all general practices in England, and it is also available on the NatPaCT web site at www.natpact.nhs.uk
INVOLVING USERS AND CARERS

Through listening to users and carers we can have a better understanding of their experiences. This can be an effective method of making sure that services meet needs and one which professionals generally find a valuable learning experience. However, one of the problems highlighted by people who have experienced strokes is the need for continued long-term care, once a person has completed the ‘acute’ pathway (although it’s worth noting that many people who have experienced a stroke will view the first three years after the stroke as the ‘acute’ phase).

This is different from the perspective of most stroke service providers and planners. People have expressed a sense of loss or abandonment, after therapy services have completed their rehabilitation package. Therefore there is a need for long-term programmes centred on the support offered to families and patients, in particular the long-term help they receive for changing lifestyle, identity, skills and relationships.

Examples

A group of stroke survivors and carers in Hull and East Yorkshire have formed a self-advocacy group known as “Strokewatch”. The group has actively campaigned for better local stroke services and two years ago succeeded in persuading the Health Authority to fund a specialised stroke unit. The group continues to monitor the quality of services through its membership and through feedback forms given to all patients. Members of the group were recently invited to form a user involvement subgroup of the district stroke strategy committee. A member talks to student nurses 4 times a year in Hull and occasionally in York.

Strokewatch has its own quarterly newsletter “The Stroke Survivor”. Its Stroke Survival Handbook addresses recovery from stroke from the patient and carer’s point of view. (Contact details can be found in Appendix A)

The voluntary organisation Connect employs a person with aphasia following stroke as its ‘Working Together Co-ordinator’ in order to ensure that the voices of service users with aphasia are represented throughout the organisation. In developing its work in the South West of England it formed a planning group of people with aphasia meeting monthly to plan the proposed services and organised a series of consultation events with people with aphasia and family members. Connect provides training courses for service providers to support them in including people with communication disabilities in consultation processes. (More information can be found on www.ukconnect.org)
In Walsall canvassing service users and carers’ views to inform the decision-making process of stroke delivery has been the cornerstone of the Integrated Stroke Service. Users and Carers have been asked retrospectively their opinion of services received during their stroke journey, via Focus Groups and questionnaires.

Service users suggested a lack of social support following the rehabilitation phase of their journey, and, whilst there was access to traditional Day Centres, they felt the provision was not appropriate to their needs, particularly for younger stroke survivors. In response the stroke service agreed partnership working arrangements with the LEA and Voluntary Sector to create four Maintenance Centres throughout the Borough.

One of the centres provides culturally appropriate activities for the Black and Asian stroke population, whilst another specialises in computer and art skills, utilised predominately by the younger stroke patients. A major achievement within the group has been the production of a newsletter, notice boards and construction of a web site to provide on line contact between one another. In addition, there is a named nurse who visits monthly to offer advice and support, with a ‘revolving door’ approach back into active rehabilitation if required. All support staff within the centres receive basic training in stroke awareness, transfer and handling skills.

Recently, retrospective surveys have been replaced by prospective interviews, with each service user offered an entry and exit interview at each stage of their stroke journey. (Contact details can be found in Appendix B)

- Current work/information of interest

Patients' Forums

Patients' Forums were announced in the NHS Plan as a method of giving patients and carers:

- a genuine opportunity to voice their views on services provided by the NHS

- an opportunity for them to influence the service provision and strategic planning of the NHS

Membership will be by volunteers and each Forum will have between 12 and 20 members. They will be supported by staff from the Commission for Patient and Public Involvement in Health.

Every PCT and Trust in England will have a Patients' Forum. Their role will be to:
monitor and review the operation of NHS services through inspection and observation

collect the view of patients and carers and inform the Trust/PCT of these views

provide information to patients and carers about local service provision

provide Independent Complaints Advocacy Services (ICAS) to assist individuals to take forward a concern or make a complaint about their NHS care and treatment. (This is a role for PCT’s Patients’ Forums only)

An essential role for Patients’ Forums will be for them to seek the views of the public and whether NHS services meet their particular needs. Patients’ Forums will go out to all the diverse groups of their local community to gather this information.

If the Forum feels that the Trust/PCT is not properly responding to patient issues, or if they have concerns about service provisions not being addressed they may take these issues to the local Overview and Scrutiny Committee, Strategic Health Authority, Commission for Patient and Public Involvement in Health.

The launch of Patients’ Forums depends on early development of the Commission of Patient and Public Involvement in Health, as they will conduct the recruitment and selection exercise. It is likely that we will see PCT Patients’ Forums coming in by June/July 2003 and Trust Patients’ forums by October. Regulations and Guidance will be available by early next year.

Rosemary Robinson is the policy lead and can be contacted on Rosemary.Robinson@doh.gsi.gov.uk

Better Government for Older People Programme

Better Government for Older People is about integration, joined-up government and making a difference by listening and working together. The Better Government for Older People programme pilots project's which bring together local agencies and older people in new ways to improve services and give older people a bigger say in their local community.

There are many materials published by the Better Government for Older People and a useful website: www.bettergovernmentforolderpeople.gov.uk
LONG TERM SOCIAL AND PSYCHOLOGICAL EFFECTS OF STROKE

Living with the effects of a stroke usually involves major adaptation of both lifestyle and identity the person who has had the stroke and those with whom they live. While many stroke services provide excellent acute and immediate rehabilitation services, it is a challenge for the NHS and social care to recognise the often complex and long-term problems associated with stroke. Long-term support to meet individual users’ and carers’ needs is, however, key to maintaining mental and physical health, supporting engagement with life again, reducing use of health and social care resources, and ensuring the best possible quality of life. The views from users and carers involved in various, care pathway-mapping events have made it clear that the long-term focus of care needs much greater attention and promotion.

This involves addressing a broad range of access issues e.g. support in adapting lifestyle, effective emotional support, life long learning opportunities, work - paid and unpaid, accessible information, breaks for carers, community transport, community safety. These could broadly be described as ‘access to life after stroke’ services. This needs to be emphasised in working with local strategic partnerships, in order to secure increased investment in low-level community support/prevention services, which enable older people to live independently and promote social inclusion.

People living with stroke have highlighted the need for community services to be developed in parallel with specialist acute services and the development of outreach teams. Much of this type of work at present is carried out by the voluntary sector, in partnership with health and social care, but for a limited time and with very limited resources. If, however, people living with stroke are to be able to have a good quality of life, services to meet long-term needs are required. It is not clear why this work should have been left to the voluntary sector and not paid due attention by statutory services, especially when people living with stroke emphasise its importance to them.

Example

In Bournemouth, after discharge, patients are followed up as outpatients in the Day Hospital or in the Follow-up Clinic. Outreach physiotherapy and occupational therapy can be provided and all patients are visited at home by a Family Support Worker after discharge. There is a successful support forum for patients and carers that meets monthly. The group devises the monthly agenda, which may include speakers and they have been involved in many of the stroke service development plans. (Contact details can be found in Appendix B)
• Current work/information of interest

The Stroke Association

The Stroke Association is a national charity providing support to people who have had a stroke, their family and carers. The following are only two examples of a wide range of support The Stroke Association provides. To find more out about The Stroke Association and the work they do please contact them directly. (Appendix C).

The Stroke Association Family Support Service

Commissioned by the NHS and Social Services, this offers a visiting service which provides emotional support in the early days after the stroke and over the time when the patient goes home. This is an expanding service. If there is one in your area the organiser will lend a sympathetic ear to your problems, suggest practical solutions, and point you towards all the help you are entitled to. Details can be found through contacting The Stroke Association (Appendix C).

The Stroke Association Dysphasia Support Service

This is also commissioned by the NHS and Social Services and aims to help people who have lost the ability to speak or understand speech because of stroke. The service, which has almost 3,000 specially-trained volunteers and staff who work to improve communication skills in people who have lost their ability to speak, read or write after a stroke, operates in a number of ways including home visits, group meetings, social events and carers’ groups. The Stroke Association produces a range of publications about stroke for both the public and professionals and operates a national Information Service (0845 30 33 100) and a local Information Service from its 16 regional offices across England and Wales. The service is operated by trained staff who can answer questions, and also offer information on a wide variety of topics concerning stroke. For more information about this service in your local area please contact The Stroke Association (Appendix C).

Connect

Connect is an innovative voluntary sector organisation promoting practical, creative and lasting ways of living with communication disability after stroke. Connect provides services which offer people the chance to learn new ways of living with stroke and communication disability, to think about the future and to access new life opportunities. People living with stroke and communication disability also provide their experiences and expertise to offer mutual support and practical ideas. Counsellors provide an opportunity for people with stroke and communication disability and their relatives to cope with the emotional issues they are experiencing. Connect is a London-based charity, providing services at its centre in London, and growing services across the South West of England. It also runs an extensive programme of training courses for
service providers from across the UK and overseas to enable other service providers to offer services addressing access to life and long-term support, for both people with stroke and communication disability and relatives and carers.

Connect also provides a demonstration of authentic ‘user involvement’, for example employing people with communication disabilities on its staff, having trustees with communication disabilities and delivering services collaboratively. Connect has created an environment where people are valued, where they are able to develop personally. Connect was commended in the Department of Health’s Health and Social care awards in 2001 for improving the lives of people with disabilities. More information is available from www.ukconnect.org.
RESEARCH AND DEVELOPMENT

The NSF Task Group responsible for drafting the Stroke Standard was fortunate in having the first version of the National Clinical Guidelines for Stroke available to inform their work. This is a synthesis of stroke research used to formulate specific good practice guidelines encompassing prevention, acute care, rehabilitation and longer-term care. Many research gaps remain, however, particularly for specific rehabilitation techniques and for longer-term care and support. The National Clinical Guidelines for Stroke are constantly modified and updated in response to new research findings. Practitioners would therefore find it helpful to develop a routine of regularly reviewing the website (www.rcplondon.ac.uk) to update their clinical practice. Engagement in research and development also seems to foster a climate of service improvement.

The Chartered Society of Physiotherapy recently undertook a research priorities exercise which has identified the questions most urgently requiring research in physiotherapy for stroke.


Example

In Bournemouth, there is a nurse research post in the stroke unit. This researcher is involved in various projects, which help determine how to improve stroke care and outcomes. (Contact details can be found in Appendix B)

In the Wirral, the stroke service takes part in a number of different research projects, and is as a result at the forefront of developments. (Contact details can be found in Appendix B)

Current work/information of interest

Government-Funded Research & Development (R&D) Relevant to the Development of Stroke Services

Research to underpin the NSF for Older People is a priority for the Department of Health and the NHS. A number of projects relevant, both directly and indirectly, to the development of stroke services are funded through national programmes as well as the Medical Research Council. The cumulative effect of all of these studies is to improve the delivery of stroke services. Information about the major funders in stroke research and some examples of current research are outlined below:
Service Delivery & Organisation programme (www.sdo.lshtm.ac.uk)
A scoping report commissioned by the SDO recommended that longitudinal studies of patients’ experiences of continuity of care were vital because too little is known about this issue. It also argued that the contribution that continuity of care makes to health outcomes must be determined. As a result, a programme of research was commissioned and at the beginning of 2002 two studies focusing on continuity of care in stroke services were funded.

The first of these will examine the relationships between different organisations and professional groups involved in the delivery of stroke care as well as looking at care trajectories in stroke as experienced and perceived by patients, carers and health care professionals. The second project will develop a measure of continuity of care and then assess the effects of continuity of care in stroke on physical function, mood and quality of life.

Policy Research Programme (www.doh.gov.uk/research/rd2/prpindex.htm)
The PRP advertised for proposals to support implementation of the NSF for Older People in Spring 2002. Stroke was one of the areas highlighted in the brief and research is due to be commissioned at the end of 2002. The PRP is also funding several projects that will have implications for the development of stroke services. The British Regional Heart Study is the most nationally representative prospective investigation into the causes of ischaemic heart disease, hypertension and stroke in middle-aged men. The Women’s Heart and Health Study is examining reasons for sex differences, geographic and social class variation in cardiovascular disease risk factors, morbidity, mortality and health care utilisation. Another study is seeking to explain inequalities in health and health care after stroke. It will develop a beacon to monitor stroke inequalities in a multi-ethnic urban population and then explain inequalities from the perspective of patients, professional and statutory organisations (NHS, Local Authorities).

Health Technology Assessment programme (www.ncchta.org/)
The HTA have funded projects on stroke costing over £2.5 million that include work on prevention, treatment and rehabilitation.

New and Emerging Applications of Technology Programme (www.neatprogramme.org.uk/index.asp)
A call for proposals in national priority areas, including stroke, has recently been advertised through this programme. The deadline is November 2002.

Medical Research Council (www.mrc.ac.uk)
The MRC, mainly funded through the Government’s Office of Science & Technology (OST), is a major funder of stroke research including work on screening, treatment and prevention.

Funders’ Forums
The Department of Health has been involved in setting up the Funders’ Forum for Research on Ageing and Older People and the Cardiovascular Research Funders’ Forum. These bring together the major funders in these two areas including the Department of Health, the research councils, the Wellcome
Foundation and key research charities (including The Stroke Association). Their aim is to identify areas that would benefit from joint working approaches and to exchange information about research priorities and gaps in research. Research into stroke services is of interest to both these groups.

Other sources of funding

The Stroke Association (wedwards@stroke.org.uk)
The Stroke Association puts £2 million into stroke research each year, this is a regular commitment. The funds go into a range of research projects, treatments and services. A two year "Home Therapy Project", provided occupational therapy to people in their own home. This is about to be published, funded by The Stroke Association. For more information please contact Wendy Edwards at The Stroke Association (details in Appendix A).

Other sources of information
Details of current and completed R&D projects funded by, or of interest to the NHS are available from the National Research Register www.doh.gov.uk/research/nrr.htm and the DH Research Findings electronic Register (ReFeR: www.doh.gov.uk/research/rd3/information/findings.htm), as well as from the individual websites.

Calls for proposals from these different government research bodies are advertised at either www.doh.gov.uk/research/callsforproposals.htm or on their individual websites (see above). RDInfo (www.rdinfo.org.uk/) provides UK researchers with direct access to all health related research funding opportunities including those in the area of stroke. It is funded by the Department of Health and contains information on over 1,000 funding bodies including government, charitable and voluntary organisations.
EFFECTIVE USE OF INFORMATION TECHNOLOGY

The Internet is increasingly providing a medium for people living with stroke to share experiences and personal stories. These can be important ways of representing experiences.

The development of stroke registers is still in its very early stages but this is important for the future prevention and management of stroke. In setting up stroke registers, it is important to recognise the need to collect data that will be compatible with IT initiatives in the acute sector, primary care and social services, thus ensuring data can be accessed, utilised and aggregated effectively. There also must be compatibility between IT systems to allow information to be shared. This in turn will help ensure that stroke care can be monitored and progressed. More general information can be found in the Information Strategy for Older People at http://www.doh.gov.uk/ipu/strategy/nsf/4.htm

Example

Connect is developing personal websites with people living with aphasia as part of a project funded by the Economic and Social Research Council and the Medical Research Council. These websites are a means of people addressing issues about their changed identity following stroke and aphasia. The project is also designing a website that is accessible to people with communication disabilities. (Contact details can be found in Appendix A)

- Current work/information of interest

The Department of Health Information Policy Unit (IPU) has commissioned the NHS Information Authority to develop a standard specification for practice-based registers for stroke to enable patients with stroke to be identified accurately and facilitate call and recall of patients for review and secondary prevention. The background to this project and draft specification is set out in an appendix to the Information Strategy for Older People, to be found on the DoH website at http://www.doh.gov.uk/ipu/strategy/nsf/4.htm

It is also published together with details of practice-based registers for CHD and Diabetes on the NHSIA website at http://www.nhsia.nhs.uk/phsmi/datasets/pages/pbrs.asp. The revised specification for practice-based registers for Stroke is projected to be published, together with associated term and code sets for Primary Care, in autumn 2002. For further information contact Eleanor Bell Eleanor.bell@nhsia.nhs.uk or Lyn Hillier lyn.hillier@messa.scheshire-ha.nwest.nhs.uk
The NHS Information Authority is developing national data standards to support NSF implementation in relation to stroke, with particular regard to the intercollegiate clinical guidelines. The approach to dataset development will include consideration of ‘existing solutions’, with the intention of producing a draft subset of data based on key clinical indicators by spring 2003 and a more comprehensive, approved dataset by spring 2005. For further information or if you can help please contact Penny Bray, Project Manager, Information Products Delivery Team, NHS Information Authority penny.bray@nhsia.nhs.uk.'
CLINICAL GOVERNANCE

Clinical governance is an essential part of improving or maintaining service quality. (Clinical governance: quality in the new NHS, 1999). Reflective practice is the key to successful clinical governance but this ideally requires systematically collected information combined with group learning to influence care delivery improvements. The National Sentinel Audit for Stroke, now in its third round, has proved very useful and over 90% of acute trusts are now participating. The Audit benchmarks a local stroke service against the national data. Many stroke services will undertake additional audits to supplement this national audit, often as a prelude to service developments. Involvement of patients and carers living with stroke, although difficult, can be especially rewarding to ensure services are firmly based on the user perspective.

National good practice stroke guidelines, for example, the National Clinical Guidelines for Stroke referred to earlier, usually require re-interpretation in the local context. Although this can be time consuming work, if done in an inclusive way it has the additional advantage of promoting stroke service team working and encourages local ownership of the adapted guidelines that greatly facilitates their uptake into clinical practice. Including service users in this process could also be very valuable. Local guidelines should focus on common issues, particularly those that cut across organisational boundaries. Examples include secondary prevention, continence management, swallowing management, assessment processes, discharge arrangements and longer-term care.

Example

**Stroke Northumbria** set up four subgroups to address their clinical governance strategy, to ensure that local and national guidelines were met. Each subgroup has its own objectives and feeds back to the main strategy and management groups. (Contact details can be found in Appendix B)

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- **Current Work/information of interest**

Clinical Governance programme

The Clinical Governance Development Programme provides delegate teams with the opportunity to stand back and take a fresh look at the way in which their organisations deliver patient care.

The CG Development Programme supports delegate teams as they explore the use of the RAID Model (Review, Agree, Implement, Demonstrate) model to facilitate the implementation of Clinical Governance. The underlying principle of the programme is that engagement of people has to precede development of structures and solutions. It encourages shared learning to
equip and empower front-line healthcare professionals to lead and achieve real improvements in the delivery and outcomes of clinical care in their localities.

For information about other aspects of the CGST programme contact Harpal Ghattoraya, Programme Administrator on 0116 2952025 or e-mail harpal.ghattoraya@ncgst.nhs.uk
EFFECTIVE MANAGEMENT OF CHANGE

A district wide stroke service does not necessarily develop quickly or easily. There are many separate and complex elements to introduce. To turn a vision into a successful service needs a strategy but that strategy need not be implemented overnight. Incremental changes can be very successful – as new funding or new possibilities come along. Setting targets that are achievable is important; building a service brick by brick can be far more effective than setting unrealistic goals that may fail.

One advantage of the care pathway approach to stroke planning is that it does appear to facilitate a widely shared sense of ownership by the strategic group. This allows sustained attention and creates a process of incremental, year on year, service development. Certainly in the stroke beacon sites, there was a strong sense of “what we are doing new this year” and “what we are proposing for next year”. Looking backwards, an obvious stroke service development track was apparent. However, an important finding has been that the universally useful first step in developing a district-wide stroke service is to establish a dynamic stroke rehabilitation unit. It is clear that this quickly raises the district-wide profile of stroke and acts as a visible structure around which other stroke services can evolve. There are obvious parallels here with the coronary care unit, which has similarly acted as the pivotal service around which coronary heart disease management has developed. Moreover, there are many examples where the stroke rehabilitation unit has, after one or two years of operation, given opportunities for key staff (notably therapists and nurses) to develop enhanced specialist skills which can then be utilised as the stroke service evolves (e.g. the role of stroke co-ordinators)

Example

In NorthEast Devon, the strategy was devised by a steering group of all key members. Parts of the strategy have been implemented, as the scope to do so has become available. (Contact details can be found in Appendix B)

- Current work/information of interest

The Service Improvement Team, NHS Modernisation Agency

The Service Improvement Team in the Modernisation Agency is able to offer support with:
- Change management facilitation
- Advice on project management arrangements etc
- Leadership development (in conjunction with the Leadership Centre) for project teams
- Spread of good practice, including events
- Advice on spread, adoption and sustainability of strategies
• Links to existing programmes of work, to learn from existing development work across the care pathway e.g. Emergency Access both at national and local level to increase connectivity
• Support with developing whole systems.

The team can be contacted through:

Nicki McNaney
Project Manager Information Pilot Programme (ROWBI) / Clinical Development Manager
NHS Modernisation Agency

Mobile  0778 651 5114
Fax  01952 222180
Email  Nicki.McNaney@npat.nhs.uk
CONCLUSION

The development of better services and improved standards in stroke care requires the right balance between national standards, provided by the national service framework, and local control. This review aims to support that process but local action is required to:

- Review existing and proposed services in the light of the success factors and evidence presented in this review
- Ensure that stroke care services are co-ordinated and fully integrated with the full range of other services
- Establish effective ways of learning from good practice and supporting professional development.
# APPENDICES

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# APPENDIX A

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<td><a href="mailto:strokesurvivors@hotmail.com">strokesurvivors@hotmail.com</a>, <a href="http://www.strokesurvivors.co.uk">www.strokesurvivors.co.uk</a></td>
</tr>
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<td><a href="mailto:Norma.Tindle@nothumbria-healthcare.nhs.uk">Norma.Tindle@nothumbria-healthcare.nhs.uk</a></td>
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<td>Professor of Stroke &amp; Older People's Care &amp; North West Regional Stroke Task Force Co-ordinator Department of Nursing University of Central Lancashire Preston</td>
<td><a href="mailto:Clwatkins@uclan.ac.uk">Clwatkins@uclan.ac.uk</a></td>
</tr>
</tbody>
</table>

National Service Framework for Older People November - What make a good stroke service and how do we get there? November 2002
<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
<th>Organization</th>
<th>Address</th>
<th>Email</th>
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<tbody>
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<td><a href="mailto:Swinter@lambeth.gov.uk">Swinter@lambeth.gov.uk</a></td>
</tr>
<tr>
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<td><a href="mailto:John.young@bradfordhospitals.nhs.uk">John.young@bradfordhospitals.nhs.uk</a></td>
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APPENDIX B

Previous Beacons Sites

The beacon scheme is currently being reviewed. During this review process stroke beacons are being suspended. Therefore previous dissemination activity will not be taking place. In the spirit of promoting and supporting practice, contact details have been provided should more information about specific services be required. All text following was provided by the beacon sites.

STROKE NORTHUMBRIA

Stroke Northumbria aims to provide services based upon the standards outlined in the RCP National Clinical Guidelines for Stroke. It provides consistent, organised and integrated acute and rehabilitative stroke services to a large and complex geographical area. Service users and professionals are carefully guided through the stroke journey by a multidisciplinary, evidence-based pathway of care.

The service comprises a range of facilities including rapid access TIA clinics, to support diagnosis and secondary stroke prevention issues. Supported early transfer from hospital into the community has been facilitated through community rehabilitation and facilitated discharge teams. A strong emphasis is placed on education and support for all. The development of specialist education courses for staff promotes a knowledgeable and committed workforce. A professional care guide to inform and support staff has been developed, and a user version is currently being written. Patients and carers are more informed through established education programmes, and the development of the website has enabled us to share practice with others.

Research has demonstrated that organised stroke care reduces death and dependency. Stroke Northumbria started as a result of a review of stroke services, following the merger of several acute and community trusts. Access to organised stroke care was inconsistent, and in some areas not available at all. A review process was established with the objective of providing high quality and consistent care to all stroke patients in Northumbria, by professionals with specialist knowledge of stroke.

Effective management of the service has been ensured by involving service users and staff from all levels in the review process. (primary and secondary care, health authority, social services, and voluntary agencies). The establishment of a Stroke Executive Group, Stroke Steering Group and Unidisciplinary Professional Groups have ensured that all members have an equal say in the development of the service. Regular audit of the multidisciplinary pathway ensures that care is consistent across the Trust. The appointment of a Stroke Practice Development Facilitator has fostered an environment where continuous professional development is encouraged and
consequently staff are working across professional boundaries thus providing a more effective and efficient model of care.

As a result of the review process, there is now increased equity of stroke care across the Trust. Every patient can be admitted to a dedicated stroke bed, resulting in timely assessments and interventions by a co-ordinated multidisciplinary team. Care is focused around patient and carer needs with a strong emphasis on goal setting, and facilitated by weekly multidisciplinary team meetings. Strong and effective partnerships have been developed with service users, voluntary and statutory agencies and Universities. The establishment of the ENB 923 course in stroke care and the Foundation course in stroke care has provided the service with highly trained staff, with some lecturers being ex patients and carers, who are keen to share experiences with professionals. The introduction of the website and care guide has ensured that a much wider audience is reached, in order to share our experience of service provision.

The impact of organising stroke services has been assessed in a number of ways:

- Consultation with service users, CHC, and local HIMP
- Stakeholder events and roadshows
- Feedback from local stroke clubs
- Involvement of primary care teams in steering groups has generated a sense of partnership and sharing information
- Education programmes have enabled knowledge to be shared with staff out with the Trust
- Staff presentations at various meetings of voluntary groups
- Service users kept informed via education programmes, both in the design and implementation, and in development of the care guide

The review process has been complete for some time now. The structure of Stroke Northumbria has been maintained through the Executive, Steering and Unidisciplinary groups. However, a more structured approach was needed to ensure that ongoing objectives to meet local and national guidelines were met.

Four subgroups now work to address our Clinical Governance strategy. Each has their own objectives and feedback to the main groups:

Continuing professional development group is striving to maintain and improve education and training for staff also working on establishing work based competencies for all grades of staff working in stroke care. Quality and consistency group is working to maintain pathway compliance and quality of care across the Trust through audit supported by the stroke register. Community Pathway group currently drafting a patient held record of stroke care within the Community setting. Information and support group is developing systems for improving information and long term support for patients and carers.
KEY SUCCESS FACTORS:

Structure for development of services
Leadership
Development of challenging new roles
Committed and enthusiastic workforce
Working with service users
Multidisciplinary pathway
Education and training for all

Contact Details

Norma Tindle
Norma.Tindle@northumbria-healthcare.nhs.uk
EAST DEVON PRIMARY CARE TRUST

A dispersed but comprehensive, equitable, evidence-based stroke service, implemented across a rural community through integration of primary care, acute trust, community trust, social services, private and voluntary sector organisations.

A multi-disciplinary group representing health, social and voluntary organisations who have redesigned services for stroke patients and their carers in North & East Devon Health Authority, with the objective of reducing institutionalisation and handicap from stroke whilst keeping the service sensitive to local needs. A pathway for stroke care across organisational boundaries, based on evidence of good practice, has been produced. The model of stroke care allows delivery of consistent best practice for patients both at home and in hospital, either in local community hospitals or in the central acute stroke unit. Providing stroke rehabilitation in community hospitals and in the home reflects the rural environment and the local health-care culture. The reconfigured stroke service is being phased in across the Health Authority based on initial work in East Devon Primary Care Trust. A project manager, provided through collaboration with GlaxoWellcome UK, leads the strategic work using a new service agreement. A stroke co-ordinator to facilitate changes in clinical practice within the community hospitals is key to the uniform provision of the components of organised stroke care that confers the benefit. A rapid access clinic ensuring equity of diagnostic access for patients not admitted to the central stroke unit and a reconfigured dysphasia service are also illustrative of the service benefits for patients.

Contact Details

East Devon Primary Care Trust
Honiton Hospital
Marlpits Road
Honiton
Devon
EX14 2DE

Tel: 01404 540535
Fax: 01404 540550

Contact:
Stroke lead 01404 540535
ROYAL BOURNEMOUTH

A comprehensive and integrated high-quality service, meeting the medical and rehabilitative needs of stroke patients. Patients suffering transient ischaemic attack or stroke with minor disability are assessed rapidly and equitably, receiving appropriate advice on modification of lifestyle and vascular risk factors. Patients suffering acute stroke are managed at the Acute Stroke Unit at the Royal Bournemouth Hospital. According to evidence-based written protocols, all patients undergo CT brain scanning the majority of scans are performed within 48 hours and 10% within three hours of admission. All patients are clerked using a standardised pro-forma, into multi-disciplinary notes approved by the Royal College of Physicians. All patients are seen by the Research Registrar in the Acute Stroke Unit and the Stroke Liaison Nurse. Patients needing a prolonged period of rehabilitation are transferred to the Stroke Rehabilitation Unit at Christchurch Hospital, reopened in November 1999 following a £500,000 rebuild and providing a modern, well-lit and spacious rehabilitation environment for patients. Patients may be approached at any phase of their admission for their consent to enter trials in stroke, both multi-centre pharmaceutical and local studies, measuring cerebral blood flow using transcranial Doppler and radio-labelled Xenon. After discharge, patients are followed up in outpatients in the Day Hospital or in the Gastrostomy Follow-up Clinic. Outreach physiotherapy and occupational therapy can be provided and all patients are visited at home by a Family Support Worker after discharge.

Contact Details

Royal Bournemouth & Christchurch Hospitals NHS Trust
Stroke Unit - Christchurch Hospital
Fairmile Road
Christchurch
Dorset
BH23 2JX
01202 705412
01202 705391

Contact: Ms. Denise Shave 01202 705412
ORGANISED STROKE CARE IN WALSSALL CONSISTS OF A TEAM APPROACH TO PROVIDE EQUITABLE STROKE MANAGEMENT FROM ONSET TO LIFELONG FOLLOW-UP. EVIDENCE EXISTS TO SUPPORT THE NEED FOR ORGANISED STROKE SERVICES IN REDUCING MORBIDITY, INSTITUTIONALISATION AND DEPENDENCY (STROKE UNIT TRIALLISTS' COLLABORATION, 1997). THE WALSALL STROKE SERVICE SPANS BOTH COMMUNITY AND HOSPITAL TRUSTS IN ACHIEVING THESE OBJECTIVES. A CLINICAL CARE PATHWAY WAS DESIGNED TO GUIDE CLINICIANS AND PATIENTS THROUGH ANY STROKE EPISODE, WHETHER INTERVENTION TAKES PLACE IN HOSPITAL OR IN THE COMMUNITY. IN ADDITION, IT IS A VALUABLE TOOL FOR PROVIDING CONSISTENT INFORMATION THROUGHOUT THE CONTINUUM FOR PATIENTS AND CARERS. HOWEVER, AS HEALTH PROFESSIONALS, THERE IS A TENDENCY TO 'PRESCRIBE' WHAT IS BELIEVED TO BE BEST PRACTICE FOR PATIENTS, WITHOUT ALWAYS CONSULTING THEM, THEREBY BECOMING RESOURCE-LED INSTEAD OF NEEDS-LED. TO ENABLE CONTINUED DEVELOPMENT OF A HIGH QUALITY SERVICE, EFFORTS MUST BE MADE TO ENSURE THAT THE PATIENTS ACCESSING SERVICES ARE ENCOURAGED TO BE INVOLVED IN DECISION-MAKING ABOUT THEIR OWN CARE, AND TO PLAY A GREATER PART IN THE FUTURE DEVELOPMENT OF HEALTH SERVICES. WALSALL STROKE PATIENTS WERE RETROSPECTIVELY ASKED THEIR OPINIONS OF THE SERVICE THEY HAD RECEIVED. THE RESULTS OF THE SURVEY GENERATED ADDITIONAL PATHWAYS SPECIFIC TO COMMUNITY SERVICE PROVISION. THE DEFICITS IDENTIFIED INCLUDED: LACK OF CHOICE - SUPPORT AND MANAGEMENT FOR NEWLY DIAGNOSED STROKE PATIENTS WHO DO NOT GET ADMITTED TO HOSPITAL - POOR MANAGEMENT OF TRANSIENT CEREBRAL ISCHAEMIC ATTACK (TCIA) BY GENERAL PRACTITIONERS - LACK OF APPROPRIATE SOCIAL INTERVENTION FOLLOWING A REHABILITATION PROGRAMME.

CONTACT DETAILS

Walsall Community Health (NHS) Trust & Walsall Hospitals (NHS) Trust
Dartmouth House Rehabilitation Unit
Ryecroft Place – Ryecroft
Walsall
West Midlands
WS3 1SW
01922 858000
01922 858085
Mrs. Margaret Craddock craddockm@cht.walsallch-tr.wmids.nhs.uk
01922 775095
Research has proven that organised stroke care saves lives. The Wirral Stroke Service uses an inter-disciplinary care pathway to ensure that simple effective treatments are put into practice to benefit patients. Introduction of the Wirral Stroke Service Care Pathway has achieved the following:
- assessment and treatment delivered by stroke specialists - all Wirral Acute Stroke Unit patients have a bedside swallowing assessment (Wirral 100%, national average 55%) - earlier CT brain scanning (Wirral 90%, national average 50%)
- increased use of simple effective treatments, e.g. aspirin, all appropriate patients now receive aspirin in Wirral (national average 85%)
- more information is given to patients at a more appropriate time, i.e. early in their stay (Wirral 100%, national average 50%)
- hidden stroke problems are found (especially perceptual and cognitive) - reduced Stroke Rehabilitation Unit length of stay from 61 days to 39 days - low incontinence rates on discharge (Wirral 21%, national average 40%)
- Wirral patients continue to improve with treatment following hospital discharge as measured by their Barthel ADL (activities of daily living) scores. These excellent results were confirmed in the 1998 Royal College of Physicians National Sentinel Audit for Stroke with further improvements evident in the re-audit in 1999.

Contact Details

Wirral Hospitals NHS Trust
Dept of Medicine for the Elderly & Rehabilitation
Clatterbridge Hospital - Clatterbridge Road
Wirral
Merseyside
CH63 4JY
0151 334 4000
0151 482 7691
Contact:

Dr. James Barrett james.barrett@ccmail.wirralh-tr.nwest.nhs.uk
0151 482 7734
SHEFFIELD-
(This was not a beacon site but has been recognised as a good practice example.)

Background

Within Sheffield stroke patients have been cared for on more than one site with stroke rehabilitation units established in the south of the city at the Royal Hallamshire hospital (RHH) and the north of the city at the Northern General Hospital (NGH). The services have evolved quite differently with different resource availability; some of the differences included specialist stroke nurses at the RHH and higher levels of therapy staff.

Due to the closure of the RHH accident and emergency department about 6 years ago, the majority of stroke patients were admitted to the NGH. This led to an unequal distribution of stroke patients, and due to the lack of specialist stroke nurses, insufficient stroke unit beds and low therapy levels, patients were often admitted to non-stroke wards and received limited specialist assessment and treatment. The two acute hospitals have recently merged to form one trust and significant collaboration between the two hospital sites has taken place to address these issues.

Recent Developments

In 1999, Sheffield Health Authority carried out a review of the stroke service and found from a city wide perspective there were significant gaps in the service including: -

- Fragmentation and lack of co-ordination
- Inequality of resources
- Problems with access to specialist services
- Lack of consistency and standardisation of approach
- Lack of therapy and specialist nursing particularly in the north
- Lack of longer-term support
- Lack of a clinical lead.

This led to a Strategic Stroke Stakeholders Group convening and a set of specific objectives being formulated to address the gaps

Some of the developments over the past 2 years: -

- Appointment of a lead clinician with a city-wide remit
- Recruitment of stroke nurse consultant with a city wide remit
- Development of clinical management team
- Initiation of a single point of access to stroke services which has 4 integrated functions:-
  - Development of a stroke data-base
• Expert advice and information
• Arranging hospital admission to the nearest stroke unit instead of A&E department
• Rapid Stroke Assessment Clinic

• Initiation of a city-wide stroke care pathway
• Development of a collaborative integrated stroke care record
• Increased therapy and specialist nursing posts at the north stroke unit and also its expansion and integration (now with 16 acute beds and 40 rehabilitation beds)
• Initiation of nurse led stroke follow up clinics
• Initiation of a 6 month review process by district nurses.
• Clinical Governance strategy for stroke
• Initiation of a stroke course

The stroke service has made significant improvements and developments particularly over the past 2 years. There are now 84 dedicated stroke beds in the city as well as a comprehensive community based rehabilitation service, which can provide a complete alternative to hospital based treatment. There are now 6 stroke nurse co-ordinators between the 2 hospitals who along with the stroke nurse consultant, are key in ensuring the care pathway operates well to ensure the stroke patient’s journey is as seamless as possible and of the highest quality. Approximately 1200 patients have accessed the rapid stroke assessment clinics.

The increase in therapy and specialist stroke nurse provision in the north of the city has ensured that patients are being assessed as soon as they are admitted to hospital and this has significantly reduced the numbers of stroke patients on outlying wards. The nurses have taken extra training to assess and manage dysphagia. The initiation of nurse led follow up clinics and district nurse reviews has meant that patients and their cares are being systematically reviewed in the longer-term phase.

The setting up of monthly strategic, operational and site stroke meetings has ensured good channels of communication between the various health professionals and agencies involved along the pathway.

For more information about the service in Sheffield please contact Amanda Jones, Nurse Consultant Amanda.Jones@sth.nhs.uk
APPENDIX C

Suggested reading material

The following is a list of documents and publications that support the development of stroke services with contact details attached.

- The older people’s champions tool kit is also a good general source of information. This is now available on the Older Peoples NSF Website www.doh.gov.uk/nsf/olderpopel.htm
- The Chartered Society of Physiotherapy, and two clinical interest groups, AGILE and ACPIN, in collaboration with the Royal College of Physicians, has published a physiotherapy-specific version of the National Clinical Guidelines for Stroke, as a means for aiding clinicians with implementation of the guidelines. Please contact CSP on www.csp.org.uk
- The Stroke Association publishes a series of very useful documents available from their Northampton Resource Centre - 01604 231000.
- Stroke - good practice resource pack (for those working in secondary health care)
- Stroke - good practice in primary care
- Stroke - good practice in social care

All these documents also provide information about other useful reading material resources and guides.
The NHS Leadership Centre

The NHS Leadership Centre was created as part of the Modernisation Agency to support NHS staff to achieve sustainable service improvement. The NHS Plan describes the purpose of the Leadership Centre as being to:

“promote leadership development closely tied to the Modernisation Agency’s work to deliver improved patient services. It will benefit all staff by widening access to work based development programmes, delivered on line as well as face to face. It will provide tailored support for clinicians and managers with leadership potential at different stages in their careers and for those already in leadership roles. Its target group will include people who run service departments, clinical services and community based networks who want to stay in the front line as well as those who seek to progress into executive roles. Chair and non-executive development will form part of its remit. It will be open to social care organisations.” (NHS Plan)

The NHS Plan provided an ambitious blueprint for service modernisation across the NHS and identified the essential role of effective leadership in supporting the delivery of this change.

Leadership is vital to successful modernisation across all services.

Challenges for leaders at all levels of the organisation, both clinical, and non-clinical are defined by the size and pace of change and the need to work in partnership, across boundaries. For leaders working in older people’s services these demands increase in complexity as a result of the range of agencies and key stakeholders who need to be engaged in that agenda.

The NHS, in common with all other areas of the public sector is undergoing a massive programme of change, underpinned by four key principles:

- set clear standards nationally
- devolve responsibility to front line staff
- ensure flexibility
- allow for choice and contestability

These principles represent a considerable challenge to leaders.

Leaders are usually associated with vision but more importantly with being able to communicate that vision. A good leader should both show the way and inspire and motivate others to follow it.

The establishment of clear national standards for health services articulated in the National Service Frameworks have delineated overt standards of care and subsequently expectations, for a variety of populations and clinical conditions. It requires effective and articulate leadership to translate those standards into the working practices of staff and to make them meaningful for service users.
Devolving responsibility to front line staff to a degree which allows them to respond creatively requires a considerable degree of courage. Leadership, which sets the parameters, gives “permission” to do things differently and supports risk taking to the degree that staff feel able to innovate without fear of reprisal can liberate skill and knowledge within the organisation. An important factor here is also the changing relationship between the service user and the service provider: effective leaders can do much to act as a role model for this new relationship and to enable staff to respond to more informed service users, by modelling the values that underpin this way of working.

The foundation for service modernisation across the NHS therefore is built on these values of public sector reform and can be considered in the light of three guiding principles:

- seeing through the service user’s eyes - putting people who use services at the centre of everything the NHS does
- reshaping services - helping staff teams to find local solutions within a national framework
- developing leaders at every level to champion and support progress.

Working in collaboration with the Older People’s National Director and the older people’s Care Group Workforce Team, the NHS Leadership Centre is able to offer a focus on the development of local leadership capacity and capability properly integrated with the tools and techniques of service improvement and the sharing and spreading of good practice.

Specific groups working in older people’s services will be targeted for individual and team leadership development programmes.

Within older peoples services three target groups for leadership development have been defined as follows:

- Exemplars (specialist practitioners, nurse consultants)
- Older Peoples Champions:
- Health and Social Care practitioners.

Exemplar programmes would be a combination of access to generic Leadership Centre programmes and some specifically designed programmes looking at a range of issues including network leadership and whole systems leadership skills.

Following the Champions conference in March of this year this group has been identified as a first priority for leadership development, with initially a particular focus on clinical Champions. Regional facilitated events will be taking place later in the year to help Champions identify the key features of their leadership role, how this can best be discharged and the skills needed to do this. Champions’ development will be supported through the use of the
Champions’ toolkit and website. Support will also be offered through facilitated workshops and more local action learning sets, as well as support to establish Champions’ networks in local areas.

In addition, individuals will be helped to identify their personal learning needs and how these can best be supported.

Implementation of programmes for health and social care practitioners would be ongoing linked to education and generic programmes and integrated with the evolving competencies framework.

A recent study by the Audit commission examined a number of good practice sites providing services to older people. All pilot sites studied emphasised the importance of leadership at a senior level, but also the need for middle managers and team leaders to mirror those behaviours and values and cascade consistent messages and approaches. Their research has identified a number of leadership competencies that have been evident in successful whole systems approaches to care. These include such skills as being able to work with complexity, manage the political situation, risk sharing and taking joint responsibility for delivery. In addition leaders who model and act as champions for partnership behaviour and who can develop a whole systems culture, valuing staff who also work in this way were demonstrably more effective.

Identifying these competencies provides valuable information in developing our programmes for leaders in older people’s services.

There is a need to ensure that leadership development is an integral part of service changes not an “add-on” and that we develop people who can lead across agencies and across boundaries i.e. whole systems leadership.

Leadership cannot be developed in a vacuum and, as we expand the programme, we need to consider not only a variety of approaches to learning and mechanisms for delivery, but also how we continue to spread the learning from this programme to other clinical areas.

The challenge will be continually to refresh and expand the learning of both existing and aspiring leaders to enable them to meet the demands of a service agenda that strives continuously to improve the patient experience.

Not everyone will be a leader but everyone should understand what it’s about and why it is important.

Details of the leadership programme can be found on www.modern.nhs.uk
APPENDIX D

Organisations and Website Addresses

Age Concern
www.ageconcern.org.uk/

Age Concern England
Astral House
1268 London Road
London
SW16 4ER
Tel: 020 8765 7200

Association of Chartered Physiotherapists in Neurology
www.acpin.net/

Chartered Physiotherapists Working With Older People
www.agile-uk.org/

Chartered Society of Physiotherapy
www.csp.org.uk

Cochrane Stroke Group
www.dcn.ed.ac.uk/csrg/

Different Strokes
www.differentstrokes.co.uk
Head Office
162, High Street
Watford
Hertfordshire
WD1 2EG

Help the Aged
www.helptheaged.org.uk/
Head Office:
207-221 Pentonville Road
London
N1 9UZ
Tel: 020 7278 1114
Fax: 020 7278 1116

The Stroke Association
www.stroke.org.uk