

A new
ambition for
STROKE

*A consultation on
a national strategy*



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Foreword

by Alan Johnson MP
Secretary of State for Health



We all know that strokes can have a devastating effect on people's lives – not only for the person who has had a stroke, but also for their families and carers. And we are all working together to see what can be done to reduce the number of strokes and to provide the best possible services when strokes do occur.

This is an exciting time for stroke services. New treatments are emerging and others are on the horizon. There is now a wealth of evidence on models of care that can enable thousands of people who have had a stroke to regain independence and reduce the time they need to spend in hospital.

We know the incredible effect that thrombolysis and care on a stroke unit can have for some stroke patients. Delivering this will, in some areas, mean reorganisation of services to ensure that rapid scanning and the appropriate level of experience are available to deliver it safely.

But this isn't just about medical advances – people also need to be better informed about their condition and supported to lead independent lives in the community.

As many of you will be aware, Professor Roger Boyle, the National Director for Heart Disease and Stroke, has been working hard to develop a comprehensive national stroke strategy. He has liaised closely with representatives from the many organisations and sectors involved in working with people who have had a stroke. Together, they have produced this consultation document, which is the first step in the development of a strategy. I would like to thank all those who have contributed their time, experience and enthusiasm to get us this far.

The aim of this document is to stimulate debate on how we take stroke care forward to meet the opportunities and demands of the 21st century, and I hope that after reading it, you will want to add your voice to the debate.

A handwritten signature in black ink that reads "Alan Johnson". The signature is written in a cursive style with a long horizontal stroke extending from the top of the "A".

Alan Johnson MP
Secretary of State for Health

Introduction

by Professor Roger Boyle National Director for Heart Disease and Stroke



After working for seven years to implement the National Service Framework for Coronary Heart Disease, it has been a great privilege to work with the stroke community, endeavouring to help them make similar progress for their patients.

Despite the considerable gains in advancing stroke units over the last few years, there remains a great deal to be done. Most would agree that stroke prevention and care have not yet received the attention they deserve, and that it is now time to put that right.

As a nation we spend more money than most on stroke services – and a greater percentage of our health budget – yet, overall, we have worse outcomes. Our challenge now must be to improve stroke care at all stages of the clinical pathway so that our patients benefit from all that modern care has to offer. This is a mixture of getting the essential things right all the time in terms of multidisciplinary care and rehabilitation, and making sure that the newer technologies are used appropriately. We know, too, that better care can mean cheaper care, since individuals receiving better care have better outcomes and achieve higher levels of long-term independence.

The challenge that we face is enormous, since it includes the need for better prevention, better awareness, better understanding, better emergency care, better hospital care, better care once people return home, in the short and long term, and better information for individuals with stroke and their families throughout.

My experience of working with the stroke community over the last 18 months suggests that they are fully ready for this challenge, but we need to ensure that they, and those they serve, are fully supported by the wider NHS and social care community in this quest for improvement.

A handwritten signature in black ink that reads "Roger Boyle". The signature is written in a cursive, flowing style.

Roger Boyle
National Director for Heart Disease and Stroke

Purpose and scope of this document

The Department of Health (DH) is developing a strategy for stroke services. This document is consulting on the findings so far.

The stroke strategy

The final strategy is intended to:

- > provide a quality framework against which local services can secure improvements to stroke services, and address health inequalities relating to stroke;
- > provide advice, guidance and support for commissioners, strategic health authorities (SHAs), hospitals, primary care trusts (PCTs) and social care in the planning, development and monitoring of services; and
- > inform the expectations of those affected by stroke and their families, by providing a guide to high-quality health and social care services.

General principles

The final strategy will aim to deliver stroke treatment for everyone which:

- > is based around the needs of individuals and their families;

- > is consistent with the evidence base, where this exists, or national consensus guidelines;
- > is consistent with the relevant National Service Frameworks and the and recommendations of the National Audit Office report *Reducing Brain Damage: Faster access to better stroke care*;
- > is integrated across hospital, community and social care sectors;
- > addresses health inequalities around stroke; and
- > enables local health communities to respond to local needs and circumstances.

Developing the strategy

In March 2006, DH held a conference to launch the development of a stroke strategy and formed six project groups to produce recommendations on the content of the strategy. Each group was led by an independent expert working with a multidisciplinary team of volunteers to produce recommendations in each of the important areas of stroke services and care for the future.

The groups and chairs were:

- > Public awareness and prevention – Professor Charles Wolfe;
- > TIA and minor stroke services – Professor Peter Rothwell;
- > Emergency response – Professor Gary Ford;
- > Hospital stroke care – Dr Tony Rudd;
- > Post-hospital stroke care – Professor Sally Byng; and
- > Workforce – Dr Damian Jenkinson.

A wide range of interested organisations was represented on these project groups, including voluntary organisations and a number of stroke survivors and carers. The work of the project groups was co-ordinated by a steering group chaired by Roger Boyle, National Director for Heart Disease and Stroke. Annex B details the membership of the project groups. The emerging recommendations have also been tested in stakeholder workshops and through two regional listening events.

The consultation document

The consultation document is based on the project groups' discussions with many stakeholders and a thorough review of the evidence. It sets out their views on the challenges currently facing stroke services in England and how these can be met.

The recommendations towards the end of each chapter summarise the project groups' views on the way forward. The whole consultation document is accompanied by a partial Impact Assessment, which provides economic information. A full Impact Assessment will accompany the final strategy.

DH is now inviting all interested stakeholders to comment on the ambition for stroke services outlined in this document and the proposals summarised in the recommendations for how to achieve this ambition. When commenting, stakeholders may wish to consider the feasibility, priorities and affordability of recommendations as well as their clinical effectiveness.

Timetable for consultation

The consultation period began on **9 July 2007** and will end on **12 October 2007**. Details of how to respond are included in Annex A. DH will use the responses to this consultation in the development of the stroke strategy. An easy access version is also available. Both documents can be obtained from the DH website (www.dh.gov.uk/stroke) or by calling Prolog on 08701 555 455 (see back cover for the reference number and further details).



Executive summary

Stroke has a major impact on the nation's health and economy, and on individual lives. Many strokes are preventable and treatable, and post-stroke recovery can be enhanced through specialist rehabilitation and wider support. This document groups the recommendations from the six project groups into four thematic chapters:

- > **Time is brain**, which looks at minimising the damage done by a stroke through prompt action in the early hours and days;
- > **Life after stroke**, which looks at improving rehabilitation and support in the months and years following a stroke;
- > **Working together**, which sets out proposals for improved multidisciplinary working and organising care across clinical networks; and
- > **Everyone's challenge**, which focuses on improving public awareness, choices in treatment and the involvement of stroke survivors in the shaping of services.

The recommendations from the groups appear in shaded boxes throughout this executive summary.

Time is brain

Stroke is a medical emergency. People with acute stroke symptoms need to be transferred by ambulance directly to a receiving hospital that is able to provide 'hyper-acute' stroke care, including 24-hour access to a stroke specialist, an urgent brain scan with expert interpretation, and thrombolytic (clot-busting) treatment. They should then be cared for on a dedicated acute stroke unit. Not everyone will be able to receive thrombolysis but all will benefit from specialist acute stroke care.

A transient ischaemic attack (TIA) is the term used for stroke symptoms that resolve themselves without obvious lasting damage. It is an important warning of a more serious stroke and the time window for effective prevention among high-risk groups is very short. People who experience a TIA need a rapid specialist assessment at a one-stop service.

About 30 per cent of suspected stroke patients will require urgent brain imaging – this means as soon as possible, and within the hour. For these patients a quick decision is needed within a short time window to determine suitability for thrombolysis. Computer Tomography (CT)

scanning is adequate for this. People arriving at hospital more than three hours after their symptoms started will be beyond the time window to be considered for thrombolytic treatment, but will usually benefit from brain imaging within 24 hours. For TIA, carotid imaging is needed at an initial assessment, typically by Doppler ultrasound, to determine whether a patient may benefit from an operation to unblock the arteries in their neck. Ideally this will be complemented by magnetic resonance brain imaging (MRI), which is the most useful form of imaging in TIA and minor stroke.

Recommendations from the project groups

Emergency response

- > Ambulance trusts should manage patients with suspected acute stroke as Category A calls, utilise a pre-hospital assessment tool (for example FAST – the Face Arm Speech Test described on page 66), arrange immediate transfer by ‘blue light’ and pre-notify receiving hospitals providing acute stroke services of admission of suspected acute stroke patients.
- > All patients with suspected acute stroke should be immediately transferred to a hospital providing acute stroke services, with a stroke triage system, able to provide expert clinical assessment and timely imaging, and able to deliver intravenous thrombolysis, throughout the 24-hour period. Minimum requirements at the receiving hospital are an acute stroke unit and 24-hour availability of brain imaging. The opinion of a consultant stroke specialist should be available where required.

- > Patients with suspected acute stroke should receive an immediate structured clinical assessment (for example ROSIER) in A&E or a medical assessment unit to determine likely diagnosis and whether urgent brain imaging is required.
- > All patients with suspected stroke should be scanned as rapidly as possible with skilled radiological and clinical interpretation available. Patients requiring urgent brain imaging (as defined by National Institute for Health and Clinical Excellence guidelines) should be scanned in the next scan slot within usual working hours, and within 60 minutes of an out-of-hours request.
- > All stroke patients should have prompt access to high-quality stroke specialist acute care – ideally they should be admitted to a stroke unit on the day of admission.
- > Specialist neurointensivist care, including interventional neuroradiology/neurosurgery expertise, should be rapidly available, through collaboration and commissioning, to patients with basilar artery occlusion, malignant MCA infarction and posterior fossa haemorrhage.

TIA and minor stroke

- > All patients with suspected TIA who are not already taking regular aspirin should be given 300mg of aspirin immediately.
- > Immediate referral for appropriately urgent specialist assessment and investigation should be considered in all patients presenting with a recent TIA or minor stroke. Urgency should be based on the likely early risk of potentially preventable recurrent stroke (for example ABCD2 system).

- > Local referral protocols should be agreed between primary and secondary care. All patients with minor stroke and all high-risk patients with TIA (for example ABCD2 score ≥ 5) should be assessed and treated within 24 hours.
- > Patients who are assessed as an emergency in the community should be taken by ambulance to an appropriate acute stroke service if their symptoms have not resolved, or if they are otherwise considered to be at high risk of stroke.
- > All other (lower risk) patients with TIA or minor stroke should, as recommended by the Royal College of Physicians and the Public Accounts Committee, be investigated within seven days of the event. Non-urgent referral is only appropriate for very low risk patients, such as those presenting with events several weeks or months previously. Non-referral should only be considered if investigation and treatment are not felt to be in the patient's best interests, e.g. a bed-bound patient with severe dementia.
- > Patients who attend A&E departments, out-of-hours treatment centres or similar providers soon after a TIA or minor stroke must be treated and must not be sent home and simply told to see their GP in due course.
- > Carotid imaging (Doppler ultrasound, MRA or CT) should ideally be performed at initial assessment and should not be delayed for more than 24 hours after first clinical assessment in TIA patients at high risk of stroke (for example ABCD2 score ≥ 5) or in patients with non-cardioembolic carotid-territory minor stroke.

- > Carotid endarterectomy for recently symptomatic severe carotid stenosis should be regarded as an emergency procedure in patients who are neurologically stable, and should ideally be performed within 48 hours of a TIA or minor stroke.
- > MRI, including diffusion-weighted imaging (DWI), gradient echo imaging (GRE) and MRA, should be the standard imaging protocol for TIA and minor stroke, and should be performed within 24 hours when required.
- > In those patients for whom they are clinically indicated, echocardiography and, if needed, 24-hour electrocardiogram (ECG) should be performed within 72 hours of initial assessment and the results acted upon immediately in cases where anticoagulation is required.
- > All patients with TIA or minor stroke should be followed up one month after the event, either in primary or secondary care.

Life after stroke

Stroke unit care delivered by a specialist multidisciplinary team is the single biggest factor that can improve a person's outcomes following a stroke. The strategy aims for everyone who may benefit to be treated within a stroke unit. Intensive rehabilitation, ideally operating across the seven-day week, can also limit disability and improve recovery.

There is also scope to improve the transition from the hospital to the community. Once care in hospital has finished, it can be more difficult to access the support needed. Local areas will want to consider options for improving joint working across health and social care to enable

them to provide the long-term support people need, as well as access to advocacy, care navigation and practical and peer support.

A significant proportion of people who have strokes will die as a result, and good quality palliative care should also be considered.

Recommendations from the project groups

- > Services for people who have had a stroke and their carers should be commissioned to achieve the outcomes set out in *Our health, our care, our say* (detailed on page 27).

Getting home

- > High-quality stroke specialist rehabilitation should be available at all stages of the pathway, including:
 - rehabilitation on stroke units;
 - provision of the appropriate accommodation and equipment for stroke rehabilitation;
 - stroke specialist early supported discharge; and
 - psychological support following stroke.
- > People who have had a stroke and their carers will achieve enhanced health, well-being and quality of life through lifelong access, available immediately after transfer from hospital, to rehabilitation and support from stroke specialist services, delivered by a workforce with the competences and skills required of a community-based stroke service.
- > There should be a seamless transfer of care from hospital to home or care home, involving community-based NHS services, social care, primary care and the voluntary sector.

- > People who have had a stroke and their carers, either living at home or in care homes, should have access to a review from primary care services of their health and social care status and secondary prevention needs to ensure that they achieve improved well-being, choice and control and freedom from discrimination.
- > The review should take place within six weeks of discharge home or to a care home, again before six months, and should be followed by an annual health and social care check, which facilitates a clear pathway back to further specialist review, advice, information, support and rehabilitation where required.

Rehabilitation in the long term

- > People who have had a stroke and their carers will achieve improved emotional well-being and quality of life through a system of regular screening and follow-up for emotional and psychological difficulties, accessible lifelong, with timely access to appropriate social, emotional and psychological support.
- > Quality of life, choice and control and opportunities to make a positive contribution should be enhanced for people who have had a stroke and their carers through enabling access to participate in a wide range of social, leisure, sport, arts, transport and educational activities, adapted to meet the special needs of people who have had a stroke.

Returning to life in the community

- > People who have had a stroke and their carers should have access to vocational rehabilitation services, enabling them to participate in paid, supported or voluntary employment; this must include support for employers and voluntary organisations to adapt working conditions.
- > All people who have had a stroke should have increased choice and control and more opportunities for economic well-being through timely access to all relevant means of financial support.
- > People who have had a severe stroke and will not recover from the illness should have access to high-quality palliative care.

Working together

This new vision for stroke care demands services working together in clinical networks, looking across all aspects of the care pathway. This collaboration will enable some hospitals to develop their hyper-acute services and will ensure that these can be adequately staffed at any time of day or night, while others will continue to provide acute stroke services but may concentrate on specialist rehabilitation. Some parts of the country already have networks and may choose to strengthen these. In other areas, it may be beneficial to broaden the scope of existing cardiac networks that already have considerable expertise in prevention and acute care that can be transferred across to the stroke context.

People who have had a stroke need to be treated by a skilled and competent workforce.

Considerable recent investment in improved stroke research – particularly through the UK Stroke Research Network – is expanding the horizons of stroke care for the future.

Recommendations from the project groups

Networks

- > Clinical networks should be established covering populations of between 500,000 and 2 million, to review and organise delivery to all acute stroke patients of 24-hour specialist care, including thrombolysis, rapid admission to acute stroke units and acute and subsequent rehabilitation.
- > Clinical networks should include all healthcare involved in the provision of acute stroke services, for example ambulance trusts and PCTs.

Workforce

- > All people who have a stroke, or who are at risk of a stroke, should receive care from staff with the skills, competence and experience appropriate to meet their needs. These requirements should apply to all practitioners in all of the different settings relevant to stroke and all stages of the stroke care pathway.
- > There should be core competences for all healthcare staff working with people who have had a stroke, including in non-specialist areas.

- > Commissioners of stroke services should review and revise existing workforce numbers and profiles, or commission new ones, based upon a local population needs assessment and taking account of both DH guidance and that of the Workforce Review Team on stroke services.
- > Commissioners should invest in posts and training to develop the stroke workforce in leadership, managing change and modernising services.
- > There should be investment in teaching and academic posts in stroke to provide teaching for undergraduates and postgraduates, and to address the shortfall in stroke research.
- > The National Occupational Standards for stroke, when completed, should be used to underpin the design and redesign of roles, as a mechanism for ensuring the delivery of high-quality care and services to people who have had a stroke or who are at risk of a stroke. The areas and levels of competences should be consistent with employers' reward systems.
- > SHAs and deaneries should support stroke workforce development. Commissioners should work with deaneries/SHAs to provide authoritative analysis of local workforce needs, to ensure that there are effective supply mechanisms for key workforce groups and to facilitate major innovations in the local multiprofessional workforce.

- > There should be nationally recognised, quality-assured and transferable education and learning programmes in stroke. There should be a national forum for all the relevant professional bodies to agree the content. The programmes should ensure that the relevance of research to practice is emphasised.

Everyone's challenge: raising awareness, informing and involving

Stroke has historically been a poorly understood condition. Although most of us know someone who has been affected by stroke, few of us know what stroke is, how it may be prevented, or what symptoms to watch for. Time is critical – a stroke caught early means a person is more likely to walk away from hospital with few lasting effects. For this to happen, we need to improve public and professional awareness of stroke symptoms.

Many strokes can be prevented through healthier lifestyles and medication to control blood pressure and cholesterol. Stroke shares the same risk factors as other vascular conditions such as heart disease, so broader action to reduce smoking and alcohol and salt consumption, and to improve healthy eating and increase exercise levels is important. More can be done to incorporate stroke into existing prevention programmes and to develop targeted support for the communities most at risk, including African and Caribbean and South Asian people.

Awareness raising and prevention are likely to be more effective where people are fully involved in their health and their care.

This includes improving information provision so that individuals can fully understand their condition and exercise maximum choice over their care. Providing support in the long term, sometimes for years after a stroke, can prevent social isolation and depression and enhance participation.

Recommendations from the project groups

- > There should be investment in local awareness-raising campaigns, and the Government should fund a behaviour change campaign.
- > People at risk of a stroke and patients who have had a stroke should be assessed for and given information about risk factors and lifestyle management issues (exercise, smoking, diet, weight, alcohol), and be advised about possible strategies to modify their lifestyle and risk factors.
- > Risk factors (including hypertension, high cholesterol and diabetes) should be managed according to clinical guidelines and appropriate action taken to reduce overall vascular risk.

- > People who have had strokes at home or in care homes, and their relatives and carers, should have access to information, practical advice, emotional support, advocacy and information throughout the care pathway and lifelong.
- > Patients and their families should have access to independent advocacy, support and information throughout the care pathway and into community living.



Setting the scene



What is a stroke?

A stroke is caused by a disturbance of the blood supply to the brain. There are two main types of stroke:

- > **Ischaemic stroke:** when a clot either narrows or blocks a blood vessel so that blood cannot reach the brain. This reduced blood flow causes brain cells in the area to die from lack of oxygen. This is the most common form of stroke.
- > **Haemorrhagic stroke:** when a blood vessel bursts and blood leaks into the brain, causing damage.

There are also transient ischaemic attacks (TIAs), which are often described as 'mini strokes'. The term TIA is used where the symptoms resolve within 24 hours. A TIA increases the chance of a subsequent stroke.

What is the impact of stroke?

There are approximately 110,000 strokes in England each year, and 20–30 per cent of people who have a stroke die within a month. Stroke is the third largest cause of death in the UK, responsible for 11 per cent of deaths in

England and Wales.¹ Stroke also contributes to the gap in life expectancy between the most deprived areas and the population as a whole.

People from ethnic minorities are at a higher risk of stroke than white people. Incidence rates, adjusted for age and gender, are twice as high in black people as for white people.²

Stroke costs the NHS and the economy about £7 billion a year – £2.8 billion in direct costs to the NHS, £2.4 billion in informal care costs (for example, the costs of home nursing borne by patients' families) and £1.8 billion in income lost to mortality and morbidity, and benefit payments.³

Stroke patients account for over 2.6 million bed days per year. At any one time, one in five acute hospital beds and one in four long-term beds are occupied by stroke patients.⁴

UK outcomes compare poorly internationally, despite our services being among the more expensive, with unnecessarily long hospital stays and high levels of avoidable disability and mortality.⁵ We need to redesign services to ensure that we get the best out of the resources we currently use, and this may mean targeted local investment.

¹ National Audit Office, 2005, *Reducing Brain Damage: Faster access to better stroke care*

² Ibid

³ Ibid

⁴ Ibid

⁵ 2003 data; Leal J, Luengo-Fernández R, Gray A, Petersen S and Rayner M, 2006, Economic burden of cardiovascular diseases in the enlarged European Union, *European Heart Journal*, 27, 1610–19

Stroke can have a devastating and lasting impact on people's lives. Individuals often live with the effects of a stroke for the rest of their lives. A third of people who have a stroke are left with a long-term disability.⁶ The effects can include physical disability, visual problems, loss of cognitive and communication skills (for example, aphasia), depression and other mental health problems.

The policy framework

Stroke services in England have improved significantly over the last decade, as shown by the findings of the Royal College of Physicians' regular Sentinel Audit. There are already many shining examples of excellent care, some of which are highlighted in this consultation document.

The National Service Framework for Older People (2001) included a chapter on stroke and has been influential in driving improvements in care, particularly in the widespread development

of dedicated stroke units. The National Service Framework for Long-Term Conditions (2005) sets out 11 quality requirements for the care of people with long-term neurological conditions. These set out key principles which can valuably be applied to people who have experienced stroke.

However, in 2005, a report by the National Audit Office, *Reducing Brain Damage: Faster access to better stroke care*, highlighted the need for further action to significantly improve outcomes for people who have a stroke, and made specific recommendations for action.

The final strategy will respond to this report in full. DH has taken a number of early actions to encourage improvements in stroke care. In 2006 the Department published *Mending Hearts and Brains*, a report by the National Director for Heart Disease and Stroke, Professor Roger Boyle. This set out the clinical case for change in both heart and stroke services.

DH has produced *Action on Stroke Services: Evaluation Toolkits (ASSET)*, interactive web-

Alan's story

I was aged 42. I had a job, two daughters from a previous marriage and a girlfriend. All was going well when, all of a sudden, I had a stroke.

Like a bolt from the blue. I had no warning.

Just walking and talking one day, flat on my back with a stroke the next.

When it quietened down, I had, along with the stroke disabilities, aphasia, a lifelong communication disability.

Then I couldn't speak for about two and a half years. I still can't speak as well as I did before, get worn out by the constant struggle to put one word in front of another, struggle to put concepts side by side, and so on.

No one says 'there goes a person with aphasia', because it is a hidden disability. It's doubly so because a person with aphasia, nine times out of 10, can't say what it is!

⁶ National Audit Office, 2005, *Reducing Brain Damage: Faster access to better stroke care*, London, NAO

based resources which enable hospitals and commissioners to compare performance in different areas and to analyse the impact of making specific improvements to preventative and acute care.

There have been significant recent developments in the evidence base supporting interventions in prevention and stroke care that have presented increasing opportunities for transforming the lives of people at risk of a stroke or who have had a stroke. There is now a consensus in favour of specialist stroke units, regarding acute stroke as an emergency, rapid access services for people who have had a TIA, immediate access to diagnostic scans and to thrombolysis for patients whose stroke was caused by a clot, and early supported discharge for people with moderate disability as a result of a stroke. There is also a clear desire for more emphasis on prevention and on public awareness. These developments have taken place against a broad health and social care environment where community services are being refocused – built around the needs of the individual, not the service, and promoting independence, well-being and choice. Putting this new evidence into practice requires a reorganisation of the way in which all stroke services are delivered.

The stroke pathway runs from prevention at one end through to support for those who have experienced a stroke and now live with its long-term consequences. The main stages in the pathway correspond to major strands of wider health policy:

> **Prevention** – the main stroke prevention messages are around diet, physical activity, blood pressure, reducing salt consumption

and smoking cessation, key areas in which DH and related agencies, such as the Food Standards Agency, have focused public awareness campaigns.

> **Management of acute stroke and TIA** – the main messages in this area are about ensuring that patients are delivered rapidly into the right sort of hospital environment (ie a stroke unit) and that they have immediate access to the required diagnostic and therapeutic interventions. This is in line with the principles of the strategy for developing urgent care, which emphasises the need for the right care, in the right place, at the right time.

> **Support after stroke** – this is about ensuring an early start to rehabilitation and joined-up services to support those who would benefit back into their own home. This lines up with the vision of integrated and person-centred services outlined in the White Paper *Our health, our care, our say*. Stroke needs to be an important area of concern for those commissioning health and social care, given the amount of NHS resources stroke services consume and the fact that it is the leading cause of adult disability.

> **Palliative care** – the end-of-life care strategy currently under development by DH will offer proposals for appropriate support, which has been largely concentrated on cancer services so far, but we recognise that such services should be available for any terminal condition.

The main thrust of the emerging consensus on how best to support people who have experienced a stroke also resonates with policy initiatives sponsored by other government departments, such as the Life Chances for Disabled People programme and the related

Independent Living Review, and with the Government's overall objective of seeing greater personalisation of public services.

As this consultation document will illustrate, stroke presents two key challenges to commissioners:

- > how to commission to ensure that 'hyper-acute' services, with rapid access to diagnosis and treatment, are in place; and
- > how to manage the joint commissioning necessary to ensure integrated person-centred care to support people after they have had a stroke.

These commissioning challenges have their counterpart for service providers, for whom the challenge is to design and provide services that reflect what the people who use the services are telling us they want and what the evidence base indicates is most effective.



Chapter 1

Time is brain



Stroke is a medical emergency. People with acute stroke symptoms need to be transferred by ambulance directly to a receiving hospital that is able to provide 'hyper-acute' stroke care, including 24-hour access to a stroke specialist, an urgent brain scan with expert interpretation, and thrombolytic (clot-busting) treatment. They should then be cared for on a dedicated acute stroke unit. Not everyone will be able to receive thrombolysis but all will benefit from specialist acute stroke care.

A transient ischaemic attack (TIA) is the term used for stroke symptoms that resolve themselves without obvious lasting damage. It is an important warning of a more serious stroke and the time window for effective prevention among high-risk groups is very short. People who experience a TIA need a rapid specialist assessment at a one-stop service.

About 30 per cent of suspected stroke patients will require urgent brain imaging – this means as soon as possible, and within the hour. For these patients a quick decision is needed within a short time window to determine suitability for thrombolysis. Computer Tomography (CT) scanning is adequate for this. People arriving at hospital more than three hours after their symptoms started will be beyond the time window to be considered for thrombolytic treatment, but will usually benefit from brain imaging within 24 hours. For TIA, carotid imaging is needed at an initial assessment, typically by Doppler ultrasound, to determine whether a patient may benefit from an operation to unblock the arteries in their neck. Ideally this will be complemented by magnetic resonance brain imaging (MRI), which is the most useful form of imaging in TIA and minor stroke.

Aims

1. The NHS to treat people with suspected stroke as a medical emergency in order to maximise the chances of independent living after stroke.
2. The NHS to assess people suffering a TIA or minor stroke rapidly in order to minimise the chances of a full stroke occurring.

The challenge

- Typically, 1.9 million neurons are lost to the brain each minute a stroke goes untreated. There is strong evidence that people with ischaemic stroke who receive treatment with clot-busting drugs (known as thrombolytic therapy or thrombolysis) have better outcomes than those who do not. The development of thrombolysis as a treatment for stroke has, however, been slow in this country with less than 1 per cent of patients receiving it in 2006.
- To deliver a thrombolysis service requires a rapid transfer by the ambulance service to an emergency department, an expert assessment including a brain scan and administration of the thrombolytic drug – all within three hours of the onset of stroke symptoms. Currently 12 per cent of hospitals have protocols in place with ambulance services for the rapid referral of those who have had a stroke and less than 50 per cent of hospitals with acute stroke units have access to brain scanning within three hours of admission to hospital.⁷
- Research has demonstrated that people who have had a stroke have the best outcomes if they are managed in a dedicated stroke unit, particularly in the early (acute) stage of the stroke. Although two-thirds of stroke patients are managed in stroke units at some time during their hospital stay, only 10 per cent of patients are likely to be admitted directly to an acute stroke unit.⁸
- TIA or minor stroke is often the only warning that a stroke is imminent and is an opportunity to take action to prevent further strokes. Research evidence suggests

Peter's story

One morning as Peter, a businessman, got ready for work something happened that changed his life forever.

"I was feeling faint and things weren't very clear in my head. I laid back on the bed for five or ten minutes and it passed."

Two days later Peter, then 61, had the same experience. An MRI scan confirmed that Peter had experienced two TIAs – or 'mini' strokes.

Despite Peter experiencing another four TIAs over a period of six weeks, the neurologist prescribed aspirin and said he probably wouldn't need to see him again.

"It was a very worrying time for my family. No one told us that TIAs could lead to a more serious stroke. We had no idea what was happening or what to expect."

Peter later succumbed to a major stroke. It left him with slurred speech and the inability to move the right side of his body. After three months of treatment at Brighton General Hospital, he was discharged in a wheelchair. Ten years' of physiotherapy later, Peter, a grandfather of three, is now able to walk short distances and has recovered enough movement to dress himself and drive an adapted car.

⁷ Clinical Effectiveness and Evaluation Unit, Royal College of Physicians, 2007, *National Sentinel Stroke Audit 2006*

⁸ Ibid.

that every year around 150,000 people have a suspected TIA or minor stroke,⁹ but currently only 35 per cent of people with TIA are seen and investigated in a neurovascular clinic within seven days.¹⁰

Delivering the ambition

7. Stroke is a treatable condition. A more urgent response to both stroke and TIAs will save lives and reduce long-term disability. Intensive physiological and neurological monitoring in the early phase can halt stroke progression and prevent more brain cells being damaged.
8. If 10 per cent of acute stroke patients were to receive thrombolysis, over 1,000 people per year would regain independence rather than die or become dependent in the long term.
9. A thrombolysis service requires:
 - > a rapid response and 'blue light' transfer by the ambulance service;
 - > a receiving hospital with 24-hour access to a stroke specialist, urgent brain scanning and expertise in interpretation;
 - > treatment with thrombolysis; and
 - > direct admission to an acute stroke unit and sufficient specialist medical and nursing staff to provide 24-hour support.

Getting to the stroke unit

University Hospital Aintree NHS Foundation Trust

A detailed study of services, including capacity and patient needs, was undertaken by the University Hospital Aintree NHS Foundation Trust. The study was carried out because evidence showed that there were delays getting patients to the stroke unit due to a lack of specialist initial assessment, and subsequent referral to the stroke clinical team. The findings were used to outline the desired stroke pathway and identified the need to train specialist nursing, ambulance and A&E staff.

The Trust worked with ambulance services to look at how to ensure a rapid response for stroke patients, and a team of stroke nurse clinicians was brought together to

meet patients in A&E. They were trained to make an initial assessment, followed by more detailed appraisal using agreed stroke guidelines. They were then able to offer rapid access to specialised stroke care, including direct admission to the acute stroke unit and, with the senior medical staff, provision of thrombolysis treatment where appropriate.

This has resulted in a 25 per cent increase in the number of stroke patients directly transferred to the stroke unit and a 70 per cent increase in the number of stroke patients receiving a CT scan within 24 hours; thrombolysis treatment was offered to 3 per cent of the total number of stroke patients admitted.

⁹ Giles MF and Rothwell PM, 2007, Substantial underestimation of the need for outpatient services for TIA and minor stroke in the UK, *Cerebrovasc Dis* 23 (suppl. 2), 17; and Giles MF and Rothwell PM, not yet published, Substantial underestimation of the need for outpatient service for TIA and minor stroke. *Age and Ageing*

¹⁰ Clinical Effectiveness and Evaluation Unit, Royal College of Physicians, 2007, *National Sentinel Stroke Audit 2006*

10. Important first steps include a rapid response to a 999 call, rapid assessment by the ambulance crew and 'blue light' transfer and pre-alert to a receiving hospital able to offer appropriate 24-hour expertise. DH is looking, with ambulance services, at the implications of 999 calls for people with suspected stroke generating a 'Category A' response (within eight minutes). Commissioners will wish to ensure that protocols are in place for the rapid transfer of people with suspected acute stroke to an acute stroke unit.
11. The urgent brain scan is needed to differentiate between those who have had an ischaemic stroke and those who have had a primary intracerebral haemorrhage (PICH) or bleed, as it is not possible to do this by clinical examination alone. Thrombolysis given to a person with PICH would have catastrophic results.
12. Not everyone will be able to receive thrombolysis but they will still benefit from faster entry into acute stroke specialist services.
13. If access to stroke units were to be increased to 75 per cent, this would prevent over 500 deaths per year and result in over 200 more independent survivors.¹¹
14. An acute stroke unit is one that provides high-dependency care including physiological monitoring and rapid treatment of the stroke and associated complications, early rehabilitation and palliative care (see Chapter 2 for more detail on stroke unit care).
15. The majority of stroke patients will require high-dependency care for the first 24 hours of the illness. Effective early management of strokes will reduce the need for intensive care beds. A small proportion of patients will, however, require intensive care during the course of their hospital admission.
16. There are currently insufficient specialist stroke services to be able to provide the level of care identified above for delivering thrombolysis. This could be addressed by the development of 'hyper-acute' centres in a 'hub and spoke' model supported by an increased range of clinicians able to provide specialist acute input, such as acute physicians and specialist nurses. These issues are explored in more detail in Chapter 3.
17. Most hospitals have a stroke unit and the challenge is both to develop some of these to provide hyper-acute services and to bring all units up to the standard of the best. The Royal College of Physicians' Intercollegiate Working Party for Stroke publishes guidelines on good acute stroke care.¹²

Rare conditions

18. There are relatively few indications for neurosurgery in patients who have had a stroke but appropriate intervention in specific cases such as cerebellar haematoma, hydrocephalus and massive peri-infarct oedema, may be life-saving. The care of these patients is increasingly managed by a multidisciplinary team in a neurosciences centre, consisting of a neurologist, neurosurgeon and interventional neuroradiologist. There may be a role for interventional neuroradiology (intra-arterial

¹¹ Clinical Effectiveness and Evaluation Unit, Royal College of Physicians, 2004, *National Sentinel Audit*

¹² Royal College of Physicians, 2004, *National Clinical Guidelines for Stroke*, 2nd edition, prepared by the Intercollegiate Stroke Working Party, London, RCP

thrombolysis/angioplasty) in the management of basilar thrombosis.

19. SHAs can support the co-ordination of the specialist neurointensivist care availability, including interventional neuroradiology/ neurosurgery expertise (see also Chapter 3). Facilities should also be available to investigate and treat unusual causes of stroke.

TIA and minor stroke

20. Of those people with TIA who will go on to have a stroke within three months, over half will do so within the first seven days after their TIA.¹³ The time window for effective stroke prevention is therefore very short. Judging the likely early risk of a recurrent stroke will determine the response to a TIA. This will represent a challenging step change in the handling of TIA cases.
21. Those at highest risk may justify immediate hospital admission. High-risk patients who are felt not to require immediate hospital admission have better outcomes if they are assessed, investigated and treated no longer than 24 hours after referral (including cases presenting on weekends or public holidays). Treating TIAs in this way will not only save lives, but can represent savings in the long term, because of fewer acute strokes and heart attacks. The aim is for a 24-hour service to be available, seven days a week.
22. Lower-risk patients with TIA or minor stroke are best investigated within seven days of the event. Non-urgent referral for TIA is appropriate only for very low-risk patients, such as those presenting with events which occurred several weeks or months previously.
23. Local referral protocols agreed between primary and secondary care will facilitate the timely treatment of people who have had a TIA. An urgent assessment service provided by secondary care that allows same-day access for high-risk cases may best be achieved by allowing open access for GPs, A&E staff and other providers. Appointment-based systems may introduce administrative delays.

Brain imaging

24. A key part of diagnosis for both stroke and TIA is timely access to brain imaging.
25. Around 30 per cent of patients with recent-onset symptoms of stroke will require urgent brain imaging. For these patients, a quick decision is needed within a short time window to determine whether or not the patient has had a haemorrhage. CT scanning will allow decisions about thrombolysis to be made for most patients. It is suggested that these patients be scanned in the next scan slot within usual working hours, and within 60 minutes of a request when out of hours (this mirrors the current NICE guidelines on head injury).
26. Eighty per cent of TIAs are in the carotid territory. Carotid imaging (Doppler ultrasound, magnetic resonance angiography (MRA or CT) should ideally be performed at initial assessment and should not be delayed for more than 24 hours after first clinical assessment in high-risk TIA patients. DH recognises that this represents a challenge and is in discussion with the relevant professional colleges and societies on ways to translate it into reality. We propose to publish a stroke imaging plan

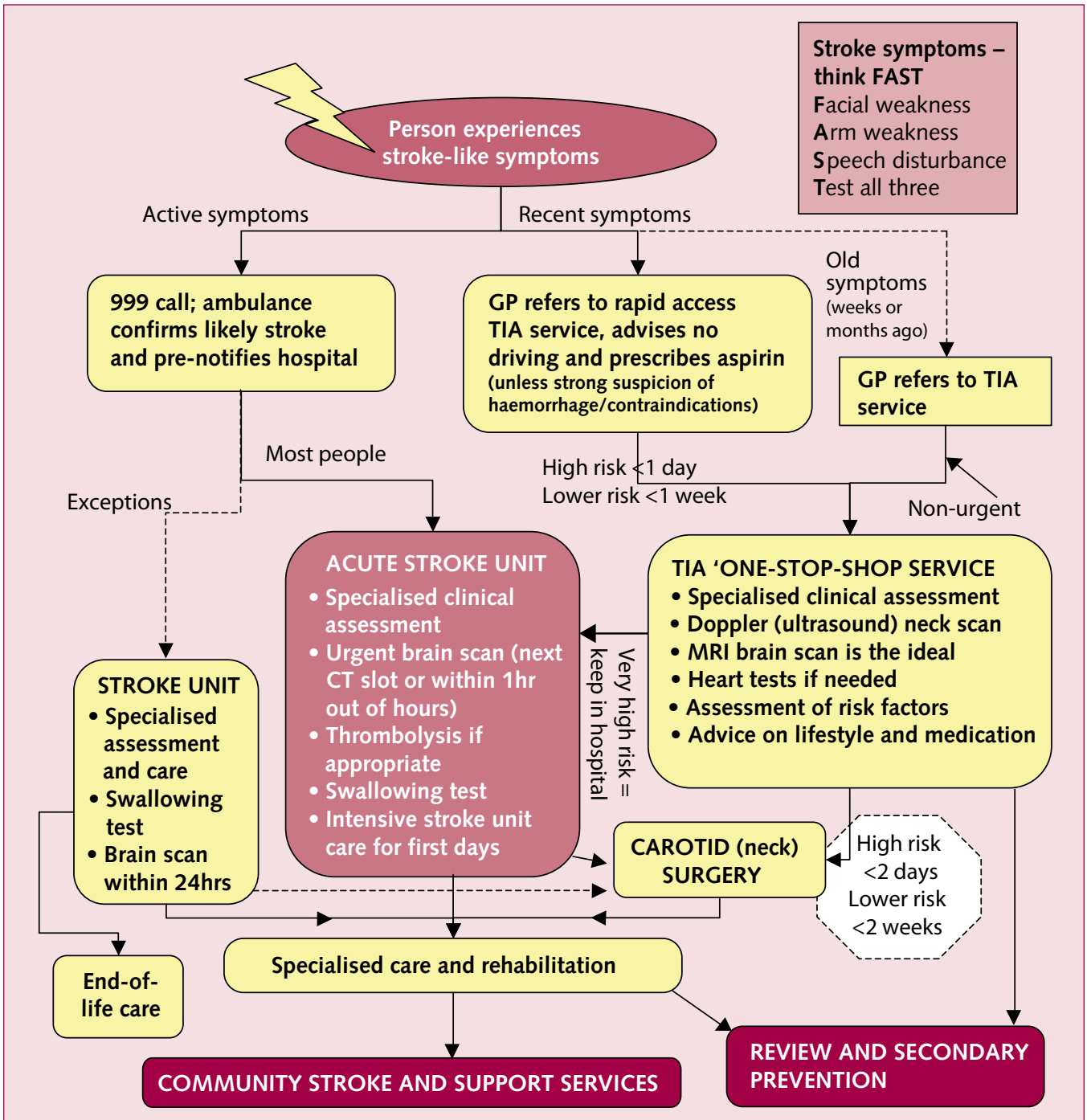
¹³ Coull A, Lovett JK and Rothwell PM, on behalf of the Oxford Vascular Study, 2004, Early risk of stroke after a TIA or minor stroke in a population-based incidence study, *BMJ*, 328, 326–8

in support of the final strategy by the end of 2007.

27. MRI is the most useful form of imaging in TIA and minor stroke. Rapid (within 24 hours of referral) MRI needs to be performed in all patients seen acutely

after a TIA or minor stroke for whom there is uncertainty about the diagnosis, vascular territory or underlying cause. CT scanning is of limited value in patients with TIA.

28. Investing in services to diagnose TIAs and manage the risk of stroke will result in



savings to acute care costs, as more strokes are prevented. Access to emergency scanning and thrombolysis for eligible patients will reduce the number of disabling strokes, and hence reduce the long-term costs of treatment and ongoing support, including rehabilitation and social care. Access to TIA services and thrombolysis could therefore reduce costs at other stages of the NHS pathway, and also reduce the long-term personal care costs that fall on social services.

Evaluating success

29. Given the impact on the NHS and social care services and the scope for improving outcomes, commissioners may want to prioritise stroke services – indeed, we know that many are already doing so. The ASSET guide (available at www.dh.gov.uk/stroke) can help commissioners to identify how to plan for the improvements to stroke services and assess the benefit to their communities.
 30. Commissioners and service providers wishing to assess the quality of their current provision may use the following markers:
 - > local protocol in place between ambulance services and receiving hospitals for a rapid response for stroke patients;
 - > 24-hour access to scans with stroke/neuroradiological specialist advice;
 - > proportion of people who have had a stroke who are receiving a scan within three hours of symptom onset;
 - > proportion of patients spending time in a stroke unit;
- > proportion of patients spending all their time in a stroke unit; and
 - > proportion of people who have had a TIA receiving assessment/treatment within 24/48 hours.

Recommendations from the project groups

Emergency response

- > Ambulance trusts should manage patients with suspected acute stroke as Category A calls, utilise a pre-hospital assessment tool (for example FAST – the Face Arm Speech Test described on page 66), arrange immediate transfer by ‘blue light’ and pre-notify receiving hospitals providing acute stroke services of admission of suspected acute stroke patients.
- > All patients with suspected acute stroke should be immediately transferred to a hospital providing acute stroke services, with a stroke triage system, able to provide expert clinical assessment and timely imaging, and able to deliver thrombolysis, throughout the 24-hour period. Minimum requirements at the receiving hospital are an acute stroke unit and 24-hour availability of brain imaging. The opinion of a consultant stroke specialist should be available where required.
- > Patients with suspected acute stroke should receive an immediate structured clinical assessment (for example ROSIER) in A&E or a medical assessment unit to determine likely diagnosis and whether urgent brain imaging is required.

- > All patients with suspected stroke should be scanned as rapidly as possible with skilled radiological and clinical interpretation available. Patients requiring urgent brain imaging (as defined by NICE guidelines) should be scanned in the next scan slot within usual working hours, and within 60 minutes of an out-of-hours request.
- > All stroke patients should have prompt access to high-quality stroke specialist acute care – ideally they should be admitted to a stroke unit on the day of admission to hospital.
- > Specialist neurointensivist care, including interventional neuroradiology/ neurosurgery expertise, should be rapidly available, through collaboration and commissioning, to patients with basilar artery occlusion, malignant MCA infarction and posterior fossa haemorrhage.

Managing TIA and minor stroke

- > All patients with suspected TIA who are not already taking regular aspirin should be given 300mg of aspirin immediately.
- > Immediate referral for appropriately urgent specialist assessment and investigation should be considered in all patients presenting with a recent TIA or minor stroke. Urgency should be based on the likely early risk of potentially preventable recurrent stroke (for example ABCD2 system).
- > Local referral protocols should be agreed between primary and secondary care. All patients with minor stroke and all high-risk patients with TIA (for example ABCD2 score ≥ 5) should be assessed and treated within 24 hours.
- > Patients who are assessed as an emergency in the community should be taken by ambulance to an appropriate acute stroke service if their symptoms have not resolved, or if they are otherwise considered to be at high risk of stroke.
- > All other (lower risk) patients with TIA or minor stroke should, as recommended by the Royal College of Physicians and the Public Accounts Committee, be investigated within seven days of the event. Non-urgent referral is only appropriate for very low risk patients, such as those presenting with events several weeks or months previously. Non-referral should only be considered if investigation and treatment are not felt to be in the patient's best interests, e.g. a bed-bound patient with severe dementia,
- > Patients who attend A&E departments, out-of-hours treatment centres or similar providers soon after a TIA or minor stroke must be treated and must not be sent home and simply told to see their GP in due course.
- > Carotid imaging (Doppler ultrasound, MRA or CT) should ideally be performed at initial assessment and should not be delayed for more than 24 hours after first clinical assessment in TIA patients at high risk of stroke (for example ABCD2 score ≥ 5) or in patients with non-cardioembolic carotid-territory minor stroke.
- > Carotid endarterectomy for recently symptomatic severe carotid stenosis should be regarded as an emergency procedure in patients who are neurologically stable, and should ideally

be performed within 48 hours of a TIA or minor stroke.

- > MRI, including diffusion-weighted imaging (DWI), gradient echo imaging (GRE) and MRA, should be the standard imaging protocol for TIA and minor stroke, and should be performed within 24 hours when required.
- > In those patients for whom they are clinically indicated, echocardiography and, if needed, 24-hour electrocardiogram (ECG) should be performed within 72 hours of initial assessment and the results acted upon immediately in cases where anticoagulation is required.
- > All patients with TIA or minor stroke should be followed up one month after the event, either in primary or secondary care.

Consultation questions

1. Are the recommendations from the project groups the right ones?
2. Will the recommendations deliver improved services for people who experience TIA?
3. Will the recommendations help to ensure that stroke is treated quickly and effectively?
4. Are these the right recommendations to feed into an imaging strategy for TIA and stroke?
5. Will this approach support continuing improvements to stroke unit care?
6. Do the recommendations adequately address the need for close working across first contact services, ambulance services and hospitals?
7. Is there anything that has been missed?

To respond to these questions, download a response form from www.dh.gov.uk/stroke

**Suspect a stroke?
Act FAST. Call 999.**

F **Facial weakness**
Can the person smile? Has their mouth or eye drooped?

A **Arm weakness**
Can the person raise both arms?

S **Speech problems**
Can the person speak clearly and understand what you say?

T **Test these symptoms**

Stroke is a medical emergency.
By calling 999 early treatment can help prevent or reduce long-term damage.
Stroke help line 24/7 020 1000 www.stroke.org.uk

STROKE UNIT
HOSPITAL



Chapter 2

Life after stroke



Stroke unit care delivered by a specialist multidisciplinary team is the single biggest factor that can improve a person's outcomes following a stroke. The strategy aims for everyone who may benefit to be **treated within a stroke unit**. Intensive rehabilitation, ideally operating across the seven-day week, can also limit disability and improve recovery.

There is also scope to improve the transition from the hospital to the community. Once care in hospital has

finished, it can be more difficult to access the support needed. Local areas will want to consider options for **improving joint working** across health and social care to enable them to provide the long-term support people need, as well as access to advocacy, care navigation and practical and peer support.

A significant proportion of people who have strokes will die as a result, and good quality palliative care should also be considered.

Aims

1. Ensuring the correct type and levels of support for people who have experienced a stroke and for their family and carers is the second key area of challenge for commissioners and providers. For those who have had a stroke, their relatives and carers, the aim is to achieve a good quality of life and to be supported to live independently. The support needs of people who have experienced a stroke are similar to those of many others living with long-term

conditions, and the quality requirements from the National Service Framework (NSF) for Long-term Conditions and the NSF for Older People are of considerable relevance. These are set out in Annex C.

The challenges

2. We need to enable people living with stroke to achieve a good quality of life by delivering services and opportunities that

Ken's story

Ken had his stroke in May 2001 while watching the FA Cup final between Arsenal and Liverpool. Ken previously worked as a salesman selling equipment to schools.

"I remember waking up in hospital and nobody wanted to tell me that my club Arsenal had lost because Liverpool scored later in the match."

Ken was in hospital for five weeks and at first could not walk or talk at all. He had to learn to walk again and, with the help of friends, family and professionals, he has regained much of his speech. From the outset he was keen to get back to some form of work or volunteering.

Ken became involved with Connect, the disability communication network, and as a result of his experience after stroke now helps train others who are involved in the care of people like him. He helps to train healthcare professionals such as speech and language therapists and has been involved in training staff working in galleries and museums, as well as volunteers, who are looking to improve their knowledge of how to deal with people with a communication disability such as aphasia.

As someone who is now helping to deliver training, Ken is taking a proactive role in improving services for those who have suffered a stroke – a role he greatly enjoys.

achieve the outcomes set out in *Our health, our care, our say*:

- > improved health and emotional well-being;
 - > improved quality of life;
 - > making a positive contribution;
 - > choice and control;
 - > freedom from discrimination;
 - > economic well-being; and
 - > personal dignity.
3. People who have had a stroke and their carers value continuity, being kept informed, being included and having a clear, consistent point of contact. Well co-ordinated, partnership working between
- health and social care services is of central importance, but it needs to be flexible enough to bring in other services where appropriate.
4. Many people experience emotional difficulties after a stroke. These can affect long-term outcomes, such as poorer functional status, reduced cognitive performance, greater physical disability, poorer language functioning and even mortality.¹⁴ Stroke can also result in mental health problems; many people suffer from depression, and there is also a link to dementia. Carers may have difficulty coping and may also be vulnerable to depression.¹⁵ Services often fail to match the need for support.¹⁶ Returning to old activities and roles may be difficult.

¹⁴ Robinson RG, 2006, Cognitive, behavioural and emotional disorders following vascular brain injury, *The Clinical Neuropsychiatry of Stroke*, 2nd edition, New York, Cambridge University Press

¹⁵ Grant JS, Glandon GL, Elliot TR, Giger JN and Weaver M, 2004, Caregiver problems and feelings experienced by family caregivers of stroke survivors the first month after discharge, *International Journal of Rehabilitation Research*, 27, 105–111

¹⁶ Logan P, Gladman J et al., 2001, The use of transport by stroke patients, *British Journal of Occupational Therapy* 64(5), 261–4

People who have had a stroke, especially those with communication and cognitive difficulties, may not feel able, or lack sufficient support, to try out new activities or attempt the resumption of old activities. This can lead to loss of confidence, depression and feelings of helplessness, with the result that they can become socially isolated and housebound.¹⁷

5. People who have had a stroke and their carers need to receive good quality, appropriate, tailored and flexible rehabilitation; this will affect their long-term recovery and reduce long-term disability. At present only around half of individuals receive sufficient rehabilitation to meet their needs in the first six months following discharge from hospital, falling to around a fifth in the following six months.¹⁸ This includes people who are living in or moving to care homes.
6. Co-ordination between health and social care services, particularly at the point of leaving hospital, remains difficult. Too often people do not get social care packages arranged in a timely fashion, resulting in prolonged hospital stays, unnecessary placement in care homes and increased stress and loss of confidence for both the person who has had the stroke and their carer. Carers also often lack the support they feel they need in order to continue in their role.¹⁹
7. Three-quarters of younger survivors want to return to work.²⁰ We know that work is good for physical and mental health.²¹

The workplace allows people both economic independence and valuable social relationships. Many workplaces could offer simple reasonable adjustments to enable people who have had a stroke to return to work.

8. Vocational rehabilitation services for people who have had a stroke in the UK are poorly defined and provision is patchy. There is still a perception that stroke is an older person's disease and therefore there is little emphasis on supporting people who have had a stroke to return to work.
9. Although a great deal has been done to make public transport more accessible, and the situation continues to improve, the picture across the country is patchy and a lack of accessible transport remains a barrier to participation for some people. Stroke causes a range of difficulties that can mean people give up driving, so people who have had a stroke and their carers may be more reliant on public transport or locally available transport schemes. However, using public transport can pose its own problems for people who have had a stroke, particularly those with communication and cognitive difficulties. For those wishing to return to driving, mobility centres across the country can provide an assessment of ability to drive or advice on adaptations required to enable someone to return to driving if they have a physical impairment as a result of a stroke.²² Advice is also available for a person who has had

¹⁷ Alaszewski H, Alaszewski A, Potter J, Penhale B and Jennings B, 2003, *Life after stroke: Reconstructing everyday life*, Canterbury, Centre for Health Services Research, University of Kent

¹⁸ Department of Health, 2005, *Long-term (Neurological) Conditions National Service Framework*, London, DH

¹⁹ Ibid.

²⁰ The Stroke Association and Different Strokes, 2006, *Getting back to work*

²¹ Waddell G and Burton KA, 2006, *Is work good for your health and well-being?*, London, The Stationery Office

²² For more information see www.mobility-centres.org.uk

a stroke or a carer on modifications to aid access to the vehicle. There are limited services across the country, so people may have to travel some distance to access these services.

10. In England, currently about a third of people who have strokes will die as a result; many of these people will not do so immediately, but within three months of the stroke.²³ However, people who have had a stroke have, until very recently, not always been considered eligible or appropriate for active palliative or end-of-life care. Indeed, people who have had a stroke and are not seen as having a good prognosis may have rehabilitation services either withdrawn or never offered. Only rarely are these services substituted by active palliative or end-of-life care.

What would good post-stroke services and support look like?

11. Commissioners, when looking at the needs of their local communities, should commission services for people who have had a stroke and their carers to achieve the outcomes set out in *Our health, our care, our say*:
- > improved health and emotional well-being;
 - > improved quality of life;
 - > making a positive contribution;
 - > choice and control;
 - > freedom from discrimination;
 - > economic well-being; and

Delivering the ambition

Support to leave hospital

North Tyneside facilitated discharge team

A facilitated discharge team was developed to provide a smooth, organised and early discharge from hospital with intensive support and domiciliary rehabilitation. The team includes a full-time co-ordinator, a senior physiotherapist, a senior occupational therapist, an occupational therapist technical instructor, a speech and language therapist, a social worker and a number of generic support workers covering a range of hours to provide a flexible service.

The work of this team has proved that early facilitated discharge after a stroke is effective.

There has been no evidence of any negative effects on patients following a reduced length of stay in hospital. The team also promotes understanding of individual professional roles, experience and communication, leading to improved inter-agency working.

Initially it was intended to pilot supported discharge with specific referral criteria in one locality (North Shields), but the demand for services was so great that it was developed across North Tyneside within six months.

"... the best part of his care was the support worker on the facilitated discharge team."

²³ National Audit Office, 2005, *Reducing Brain Damage: Faster access to better stroke care*

Components of multifaceted stroke specialist rehabilitation

Support is available for:

- > mobility and movement;
- > communication;
- > everyday care activities, for example dressing, washing, meal preparation;
- > depression and distress;
- > swallowing;
- > nutrition;
- > cognitive difficulties;
- > vision and visual perceptual difficulties;
- > continence;
- > sex;
- > personal dignity.

12. Commissioners may want to consider engaging a wide range of provision that can meet the needs of the local population, and look to develop services to meet those needs, which may mean involving the third sector. Services should also be appropriate for all ages – a quarter of people who have a stroke are under 65.

13. Rehabilitation after stroke works. Specialist co-ordinated rehabilitation started early after the stroke and provided with sufficient intensity, reduces mortality and morbidity. Early rehabilitation is effective when provided in specialist stroke units, or as part of properly supported early discharge and then provided longer term in the community, according to need.²⁴

Commissioners can support a balance for early rehabilitation between a stroke unit and early supported discharge. Payment by Results can offer an incentive to commissioners to understand the benefits of improving care for people living with stroke. Specific work has been done to identify how the tariff can be unbundled to support rehabilitation in a non-acute setting, but DH

recognises that further work will need to be done.

14. As set out in the NSF for Older People, rehabilitation on a stroke unit should be supported by a multidisciplinary team, with a range of allied health professionals. The environment will, ideally, have been designed or adapted for stroke patients. The Cochrane review of stroke unit trials showed not only that rehabilitation stroke units benefit all patients irrespective of age and severity of stroke, but that those who had had more severe strokes gained most.²⁵ Other settings, such as generic intermediate care beds, may not be as effective in improving outcomes for individuals but may be appropriate in some settings, for example in more rural areas where people may benefit from being closer to home.

Getting home

15. Health and social care services should work together to ensure that there is a plan for individuals leaving hospital. Where health and social care services work together to facilitate a smooth transition home, it can

²⁴ Langhorne P et al., 2005, Early supported discharge services for stroke patients: A meta-analysis of individual patients' data, *Lancet*, 365(9458)

²⁵ Stroke Unit Trialists' Collaboration, 2001, *Organised inpatient (stroke unit) care for stroke*

help people recover more quickly, reduce the pressure on the individual and their family and prevent unnecessary readmissions to hospital or care homes. Involving social workers in the multidisciplinary team at an early stage is an effective way to achieve this. The challenge is to ensure that individuals feel reassured when they leave hospital that they know what arrangements for ongoing care, support and rehabilitation have been made and how to access information and advice, as well as who will be taking forward the next stage of their rehabilitation and support. This may mean that emergency packages of care are put in place while a full assessment is completed, and information is made accessible for people with communication and cognitive difficulties.

16. A good assessment process for someone who has just had a stroke will involve a person-centred assessment of the individual's needs, where possible joining health and social care assessments and signposting to other services, such as housing or transport. Family members or friends who may be taking on a caring role are entitled to an assessment of their needs in their own right. It will be important to bear in mind that those who have had a stroke may need additional communication support to be able to participate in the assessment.
17. Local areas will already be using the Single Assessment Process (SAP) to support this – ensuring that individuals are placed at the heart of the assessment and care planning,

and that these processes are timely and in proportion to individuals' needs.

18. Providing the right environment can be the key to helping people return home; small adaptations or equipment provided quickly can mean that the individual is able to return home safely, and can prevent delayed discharges. Although some equipment may have been obtained to facilitate the transfer home, this may need to be reassessed to check for long-term needs.
19. Early supported discharge for up to 50 per cent of patients to a stroke specialist and multidisciplinary team (which includes social care) in the community, but with a similar level of intensity of care as a stroke unit, can lower overall costs and reduce long-term mortality and institutionalisation rates.²⁶ There would be considerable gains for both the health economy and people who have had a stroke if this model of care were routinely available. However, the focus should be on those patients who will benefit most; premature discharge to inadequate community facilities is likely to increase individuals' long-term dependency and therefore reduce the more immediate savings from a shorter length of stay.

Rehabilitation in the long term

20. Recovery can continue for many years after an individual has had a stroke, so it is important to consider how to provide access to community-based services over the long term.²⁷ The impact of a stroke lasts a lifetime, which means that services will need to be available for the whole of an individual's life. Services in the community can help people build on the improvements

²⁶ Department of Health, 2005, *Long-term (Neurological) Conditions National Service Framework*, London, DH

²⁷ van der Gaag A, Smith L, Mowles C, Davis S, Moss B and Laing S, 2004, Therapy and support services for people with stroke and aphasia and their relatives: A six month follow-up study, *Clinical Rehabilitation*, 19(4) June 2005, 372–80(9)

that they have made while in hospital or during early supported discharge, in a setting where they feel more comfortable and relaxed. There is evidence that co-ordinated community stroke teams prevent people from deteriorating once they are home, and that targeted interventions can help with specific problems such as communication, dressing, leisure and transport.²⁸ An example of this is that people on the higher rate mobility component of the Disability Living Allowance have the option to exchange this benefit for a car or powered wheelchair through the Motability scheme.

21. Rehabilitation – support to regain well-being – does not just have to be provided by rehabilitation professionals. It can also be provided by, for example, a wide range of community-based opportunities offered by statutory and voluntary agencies, such as exercise classes, communication support groups, access to further education, and arts and leisure organisations, or through self-management activities and self-help groups.
22. Many people living with long-term disabilities have, in recent years, developed methods to participate in managing their own conditions, or to participate in peer-support activities. The Expert Patient Programme provides training for people to develop the skills they need to take effective control of their lives. There is scope to expand the range of 'self-management' activities available for people who have had a stroke. Careful planning of the underpinning support systems required to enable them to participate needs to be undertaken, especially to enable the inclusion of people with communication and cognitive difficulties. An Expert Carers Programme is also being developed and is expected to come on stream during 2008.
23. Some people who have had a stroke will be assessed as being eligible for social care support from the local council. For this group, the option of direct payments will be available. Direct payments can be a valuable tool in allowing individuals to take control of meeting their own needs for social care. Individual budgets are also currently being piloted. The aim is to enable people to design their own support with the knowledge of what finance is available, and to manage the funding to provide that support.
24. People who struggle to adjust to the longer-term effects of a stroke need access to a wide range of services. These can range from access to good peer support or local counselling services through to referral to psychiatric and psychological services. Providers should consider how they will support access to these services for people with communication and cognitive difficulties. Screening should identify those who can benefit from access to a broad range of mental health and psychological services.
25. People who have had a stroke and their carers, either living at home or in a care home, should have access to a review by primary care services of their health and social care status and secondary prevention needs to ensure that they achieve improved well-being, choice and control, and freedom

²⁸ Walker MF, Leonardi-Bee J et al., 2004, An individual patient meta-analysis of randomised controlled trials of community occupational therapy for stroke patients, *Stroke*, 35(9), 2226–32

from discrimination. Best practice indicates that this review should take place within six weeks of discharge home or to a care home and again before six months after discharge home or to a care home, and should be followed by an annual health and social care check, which facilitates a clear pathway back to further specialist review, advice, information, support and rehabilitation where required.

26. Following *Our health, our care, our say*, everyone with a long-term condition should be offered a care plan by 2010, and all PCTs and local authorities will need to have established joint health and social care managed networks and/or teams to support those with long-term conditions. Given the numbers of people who have had a stroke and have long-term needs (stroke is the biggest single cause of adult disability) providers would be advised to look at stroke as a key area in delivering this commitment.
27. In addition, people tell us that they need to know how to seek further support when they need it. Tools for self-assessment are being developed to provide individuals with the ability to self-refer, either back into traditional services or to other places that can meet their needs.
28. DH is currently consulting on a review of the Government's national strategy for carers – *Caring about carers* – published in 1999.²⁹ This review will consider ways in which commissioners and providers can further support those acting in a caring role.

Returning to life in the community

29. People who have had a stroke, and their carers, want to be able to return to the many and varied roles they had before the stroke and to be involved in their local communities again.³⁰ Long-term assistance, review and rehabilitation to overcome physical, psychological and attitudinal barriers and to engage and participate in community activities are essential if people are to lead autonomous lives. To maximise emotional recovery, people need information and advice about local opportunities and resources, including clubs, hobbies, leisure, education and sports facilities. Studies looking at leisure activities for people who have had a stroke found that there were numerous clubs, societies, specialist pieces of equipment and written information, but that people needed someone to get them started or help them return after a break due to a stroke.³¹ Therapists have been successful in this role but a wider range of local support organisations, including from the community and voluntary sectors, could be used with success, as could peer support. Local services may also need to adapt to meet the specific needs of people who have experienced a stroke. Organisations and groups providing opportunities and activities that people who have had a stroke may wish to participate in do not necessarily know how to adapt those opportunities to make them accessible to people with difficulties in mobility, communication, cognition or confidence following a stroke. These organisations and groups may need

²⁹ Department of Health, 1999, *Caring about carers: A national strategy for carers*, London, DH

³⁰ Parker CJ, Gladman JR et al., 1997, The role of leisure in stroke rehabilitation, *Disability and Rehabilitation*, 19(1), 1–5

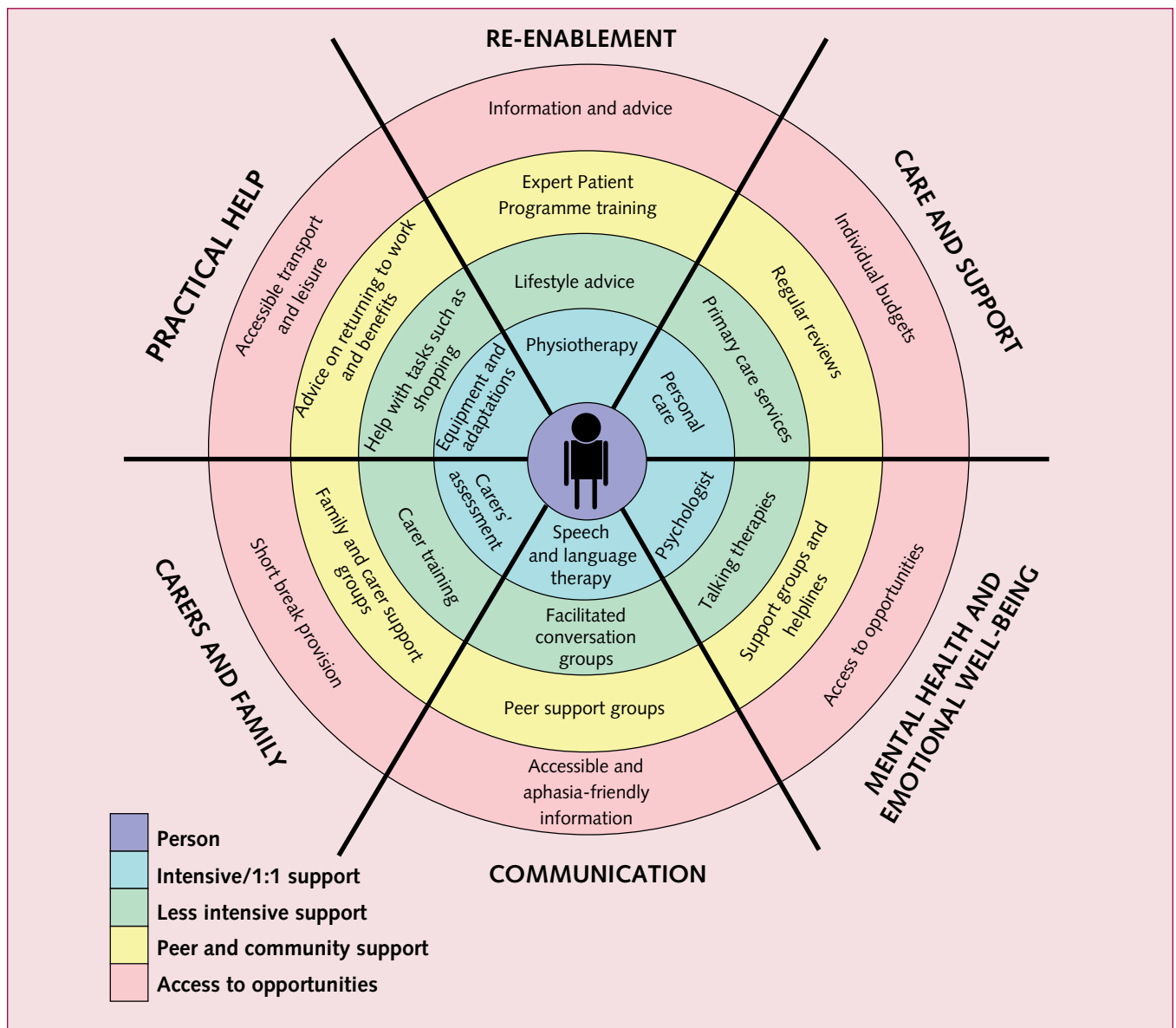
³¹ Drummond AE and Walker MF, 1995, A randomised controlled trial of leisure rehabilitation after stroke, *Clinical Rehabilitation*, 9, 283–90

more awareness and understanding of stroke and its impacts. This is essential if people are to maintain activities once stroke specialist assistance has ceased. Stroke specialists are well placed to provide occasional advice and training to a wide range of community providers to enable them to make their activities and opportunities more accessible and to enhance participation.

Return to work

- 30. The pathway back to paid or supported employment and voluntary work for people of any age who have had a stroke, and their carers, will also include access to government schemes for return to work, access to vocational rehabilitation, and support for employers and voluntary organisations to adapt working conditions,

The range of support someone may need after a stroke



especially for people with communication and cognitive difficulties. There is evidence that this can be achieved by offering vocational rehabilitation to people after a stroke, and this may need to begin when they are in hospital.³² The workplace is one of the best forms of rehabilitation.³³ Many people who have had a stroke will not be ready to return to work in the short term, but may be able to do so in the longer term and so can benefit from arrangements that give access to rehabilitation and support for return to work weeks, months or years post-stroke, as appropriate for the individual.

Links to other Department of Health and wider government initiatives

31. The Department for Work and Pensions (DWP) is aware of the requirement to provide better information about eligibility for other benefits to new customers claiming Employment Support Allowance and is currently working on the business design and IT to make sure that this is addressed. In addition, 'information prescription' pilots are currently under way and are designed to give people receiving a diagnosis of illness from a doctor more information about benefit entitlement, and demonstrate how local partnerships can be effective in supporting individuals. DWP, with DH, is looking at how to improve employers' awareness of the benefits of employing people who are on Incapacity Benefit, overturn employers' negative preconceptions about people with disabilities and improve employment outcomes for people in receipt of the benefit. The accessibility of this information to people with communication and cognitive difficulties will be important, as will acknowledgement of the needs of people with these difficulties even in the absence of physical difficulties.
32. Caring responsibilities can sometimes stop people from working due to anxiety, depression and worry over needing to work flexibly. From 6 April 2007 the legal right to request flexible working has been extended to include employees who undertake a caring role.
33. The Commissioning Framework for Health and Well-being will support commissioners to improve their practice and base it on the needs of individuals and their local community, with a focus on reducing health inequalities and promoting equality.
34. DH will shortly be launching a consultation on increasing choice beyond elective care. The consultation document will set out a minimum standard of choice that should be available to everyone with a long-term condition, including stroke survivors. This includes the option to agree a care plan. Commissioners must ensure that there is a range of services available locally for people to choose from when agreeing their care plan. The consultation will seek views on how commissioners can meet this challenge.
35. Local authorities need to look at accessibility planning and how they meet the needs of those who have had a stroke through their local transport plans process. Introduced in 2006, this process aims to ensure that local

³² Jordan L, Bryan K et al., 2006, *Work after stroke: Stroke survivors' perspectives*, Harrogate: UK Stroke Forum Conference

³³ Waddell G and Burton KA, 2006, *Is work good for your health and well-being?* London, The Stationery Office

authorities take a clearer and more systematic approach to identifying and tackling the transport barriers that people face, particularly in accessing jobs and key services. Physical access will be important, but local authorities should consider the wider needs of those who have communication and cognitive difficulties.

36. The Supporting People Programme (SPP) and the Disabled Facilities Grant (DFG) are two key opportunities for local authorities to provide housing-related support for people who have had a stroke. Communities and Local Government is looking at improvements to DFG delivery to make the grant more responsive to the needs of individuals. The SPP helps vulnerable people, including those with disabilities because of a stroke, to live independently. In the case of people who have had a stroke, SPP money can be used to contribute towards costs, such as the employment of a home improvement agency to oversee all aspects of having homes adapted so that people who have had a stroke can continue to live there; or it can contribute towards a warden service in a sheltered housing scheme, which would give some people who have experienced a stroke the confidence to continue to live independently and reduce the likelihood of them moving into residential care.

End-of-life care

37. People who have had strokes and are not likely to recover will achieve personal dignity and improved quality of life through receiving active end-of-life care from a workforce with appropriate skills and

experience, whether they are in hospital, at home or in a care home. Judging when someone who has had a stroke is more appropriate for palliative and end-of-life care rather than active rehabilitation and providing such care when communication is difficult are considerable challenges and require skilled decision making and interaction from an experienced workforce. DH is developing a new strategy for end-of-life care, which will inform commissioners and providers about how to care for people at this stage of their lives.

Recommendations from the project groups

- > Services for people who have had a stroke and their carers should be commissioned to achieve the outcomes set out in *Our health, our care, our say* (detailed on page 27).

Getting home

- > High-quality stroke specialist rehabilitation should be available at all stages of the pathway, including:
 - rehabilitation on stroke units;
 - provision of the appropriate; accommodation and equipment for stroke rehabilitation;
 - stroke specialist early supported discharge; and
 - psychological support following stroke.
- > People who have had a stroke and their carers will achieve enhanced health, well-being and quality of life through lifelong access, available immediately after transfer from hospital, to rehabilitation

and support from stroke specialist services, delivered by a workforce with the competences and skills required of a community-based stroke service.

- > There should be a seamless transfer of care from hospital to home or care home, involving community-based NHS services, social care, primary care and the voluntary sector.
- > People who have had a stroke and their carers, either living at home or in care homes, should have access to a review from primary care services of their health and social care status and secondary prevention needs to ensure that they achieve improved well-being, choice and control and freedom from discrimination.
- > The review should take place within six weeks of discharge home or to a care home, again before six months, and should be followed by an annual health and social care check, which facilitates a clear pathway back to further specialist review, advice, information, support and rehabilitation where required.

Rehabilitation in the long term

- > People who have had a stroke and their carers would achieve improved emotional well-being and quality of life through a system of regular screening and follow-up for emotional and psychological difficulties, accessible life long, with timely access to appropriate social, emotional and psychological support.
- > Quality of life, choice and control and opportunities to make a positive contribution should be enhanced for people who have had a stroke and

their carers through enabling access to participate in a wide range of social, leisure, sport, arts, transport and educational activities, adapted to meet the special needs of people who have had a stroke.

Returning to life in the community

- > People who have had a stroke and their carers should have access to vocational rehabilitation services, enabling them to participate in paid, supported or voluntary employment; this must include support for employers and voluntary organisations to adapt working conditions.
- > All people who have had a stroke should have increased choice and control and more opportunities for economic well-being through timely access to all relevant means of financial support.
- > People who have had a severe stroke and will not recover from the illness should have access to high-quality palliative care.

Consultation questions

1. Are the recommendations from the project groups the right ones?
2. Will the recommendations help improve transitions from hospital to home?
3. Do the recommendations adequately address the needs of carers?
4. Do the recommendations adequately address the needs of younger stroke survivors, who may face additional challenges?
5. How can services best improve access to psychological support?
6. Is there more that can be done to improve joint working across services?
7. Is there anything that has been missed?

To respond to these questions, download a response form from www.dh.gov.uk/stroke



Chapter 3

Working together



This new vision for stroke care demands services working together in **clinical networks**, looking across all aspects of the care pathway. This collaboration will enable some hospitals to develop their hyper-acute services and will ensure that these can be adequately staffed at any time of day or night, while others will continue to provide acute stroke services but may concentrate on specialist rehabilitation. Some parts of the country already have networks and may choose to strengthen these. In other areas, it may be beneficial to broaden the scope of existing cardiac

networks that already have considerable expertise in prevention and acute care that can be transferred across to the stroke context.

People who have had a stroke need to be treated by a **skilled and competent workforce**.

Considerable recent investment in improved **stroke research** – particularly through the UK Stroke Research Network – is expanding the horizons of stroke care for the future.

Aims

1. To have structures in place which ensure a focus on quality of services and continuous service improvement.
2. To develop a workforce that will ensure that all people who have had a stroke, or who are at risk of a stroke, receive care from staff with the appropriate level of competences (knowledge and skills), and experience.

The challenge

3. Although high-quality care and services for people who have had a stroke or who are at risk of a stroke need to be delivered by staff with specialist stroke knowledge, there are no formal mechanisms to achieve this. The challenge is to ensure capability, capacity and collaborative working both within stroke teams and across providers and commissioners so that there is an overall

Jasvinder's story

Jasvinder, now 46, was just 31 years old, with a promising career as deputy head of a Yorkshire primary school, when he experienced a major stroke. As a keen climber and runner, he had negotiated his fair share of challenges, but none compared with the emotional hurdles associated with stroke. On top of a stroke, an operation left him with epilepsy and aphasia – a language disorder resulting in loss of speech and the ability to communicate.

"The neurologist said I would never walk and talk again. I was distraught. I felt as though I was in a prison cell."

Despite daily speech and physiotherapy sessions, Jasvinder was still in a wheelchair and unable to talk when he was discharged six weeks later. The therapies continued, but progress was painfully slow. Understanding Jasvinder's need to come to terms with what had happened, his speech therapist, Sally, arranged for him to see a clinical psychologist, who readmitted him to hospital.

"At first I got very upset and my epilepsy worsened, but then, as I started to get everything out of my system, I began to physically recover more quickly. Everything started to come back."

Now Jasvinder is able to talk, walk and even run as he always did. He worked as a teacher's assistant in Bradford before moving to Sheffield three years ago, where he now gives talks to local and national groups of stroke survivors.

"We pay a lot of attention to mending the mechanics of our bodies, but a lot of healing takes place in the mind. I was lucky to have good support from the NHS, especially from Sally – my speech therapist – who recognised that by taking the time to treat patients as individuals, you can better help them to overcome the emotional and psychological barriers to physical recovery."

focus on delivery of high-quality stroke care and services.

Capability

4. Staff working in stroke have variable levels of knowledge and skills. Basic information is provided in all medical, nursing and allied health professional education, but specialist knowledge has developed ad hoc in practice, and through attendance at one-off courses. There is no nationally standardised stroke-specific training, nor are there

competence requirements for any professional group. Medical stroke sub-specialty training has been recently established (2004) to deliver stroke physicians, but this is not yet mandatory and will not be applied retrospectively. National Occupational Standards and Skills for Health competence frameworks for stroke are, however, being developed.

Capacity

5. Existing staffing numbers and skill-mix profiles are insufficient to deliver the required input in stroke care pathways. As stroke medicine is becoming an increasingly interventionist field, the demand for stroke physicians is increasing. A survey conducted by DH and the Royal College of Physicians of 92 stroke units suggested that, for hospital care, only 25 per cent of units had adequate staff numbers for nursing and therapy. Often even these staffing numbers include higher than recommended quotas of unqualified staff. High proportions of patients are dependent, with complex care and rehabilitation needs. Nearly two-thirds need help with at least one basic activity, and half of these are totally dependent. Even so, not all patients requiring therapy receive it, with 75 per cent getting less than an hour and therapy input being limited to daytime hours and weekdays. By contrast, nursing input is delivered over 24 hours each day. However, despite the assessment, monitoring and dependency demands of these patients, 75 per cent get fewer than four hours' nursing input each 24 hours. For community care, availability is much more difficult to gauge. However, it is clear that there are few established community stroke specialist teams, and little specialist co-ordination of services.³⁴

Collaborative working

6. Changes need to be made to existing ways of working in stroke teams. We recognise that it will be a challenge, as staffing levels can make it difficult to find time for frequent

team meetings to reflect on individual patient care or team working. However, these meetings present an opportunity to ensure effective communication, appreciation of professional expertise, shared responsibility, empowerment and support.

7. Eight stroke research networks have been formed, covering 70 per cent of the population of England, but there are few wider networks across providers which might take an overview and consider how to address shortfalls in provision.

Delivering the ambition

Networks

8. Clinical networks for stroke have real potential to improve the way in which services are planned and delivered for both patients and staff. Health and social care members may agree to work together or share information, functions and resources so as to offer services or improve their efficiency and quality of service. Organisations join networks because they can do what they need to do more effectively together than if they operate alone.
9. Increasingly, it is becoming impracticable for organisations to offer care pathways which are safe, of high clinical quality and responsive to patients without being part of well-defined networks. Networks make the most effective use possible of scarce resource and expertise. For example, the average district general hospital will not have consultants with a full range of

³⁴ Department of Health/Royal College of Physicians, 2007, *Survey of Stroke Unit Staffing and Patient Dependency*

How a network can work

North West Stroke Task Force

The Stroke Task Force has, over the last seven years, developed into an active group of stroke enthusiasts who have supported substantial stroke service developments across the North West Region. Milestones for the achievement of key aspects were laid out nationally, and the Task Force publicised these across the region. Further funding was provided by the Regional Development Fund, and later the Strategic Health Authorities (SHAs), which allowed the Task Force to take a more hands-on and active role in stroke service development.

Advice and support (at an individual, group, trust and SHA level) are provided to health and social care, to inform the commissioning and development of stroke services. Mechanisms to monitor service provision (service surveys and review visits) have encouraged the development of quality services, based on current evidence. The active involvement and participation

of all key stakeholders has been ensured by bringing together (through meetings and conferences) organisations and groups in the North West to share information and experiences, discussing matters of common interest, identifying unmet needs, and learning about best practice from other service provision locally and nationally.

The Task Force aims to establish a culture of continuous improvement in service provision through active research and education and workforce development by: drawing attention to emerging issues; disseminating evidence-based standards for stroke management to PCTs, acute trusts and SHAs; increasing the profile of stroke prevention and management across primary and acute care, social services and the voluntary sector; and working in areas with poorly developed stroke services to facilitate service modernisation.

expertise in all the sub-disciplines, and it would be wasteful for all hospitals to invest in hi-tech facilities that would be used only for a small number of patients.

10. As outlined in *Mending Hearts and Brains*, in stroke services it will not be possible to deploy the necessary specialist staff to be in every hospital to enable the fast response to stroke.³⁵ The development of clinical networks for stroke, serving a population of between 500,000 and 2 million and organised in a 'hub and spoke' service

model, is one solution. A hyper-acute stroke unit (hub) would have an on-site 24-hour acute stroke team, with 24-hour radiology access, including advanced imaging. Stroke patients receiving hyper-acute care could be transferred to a 'spoke' acute stroke unit within 48 hours. Each network would need to agree access to neurointensivist care for certain conditions (see Chapter 1).

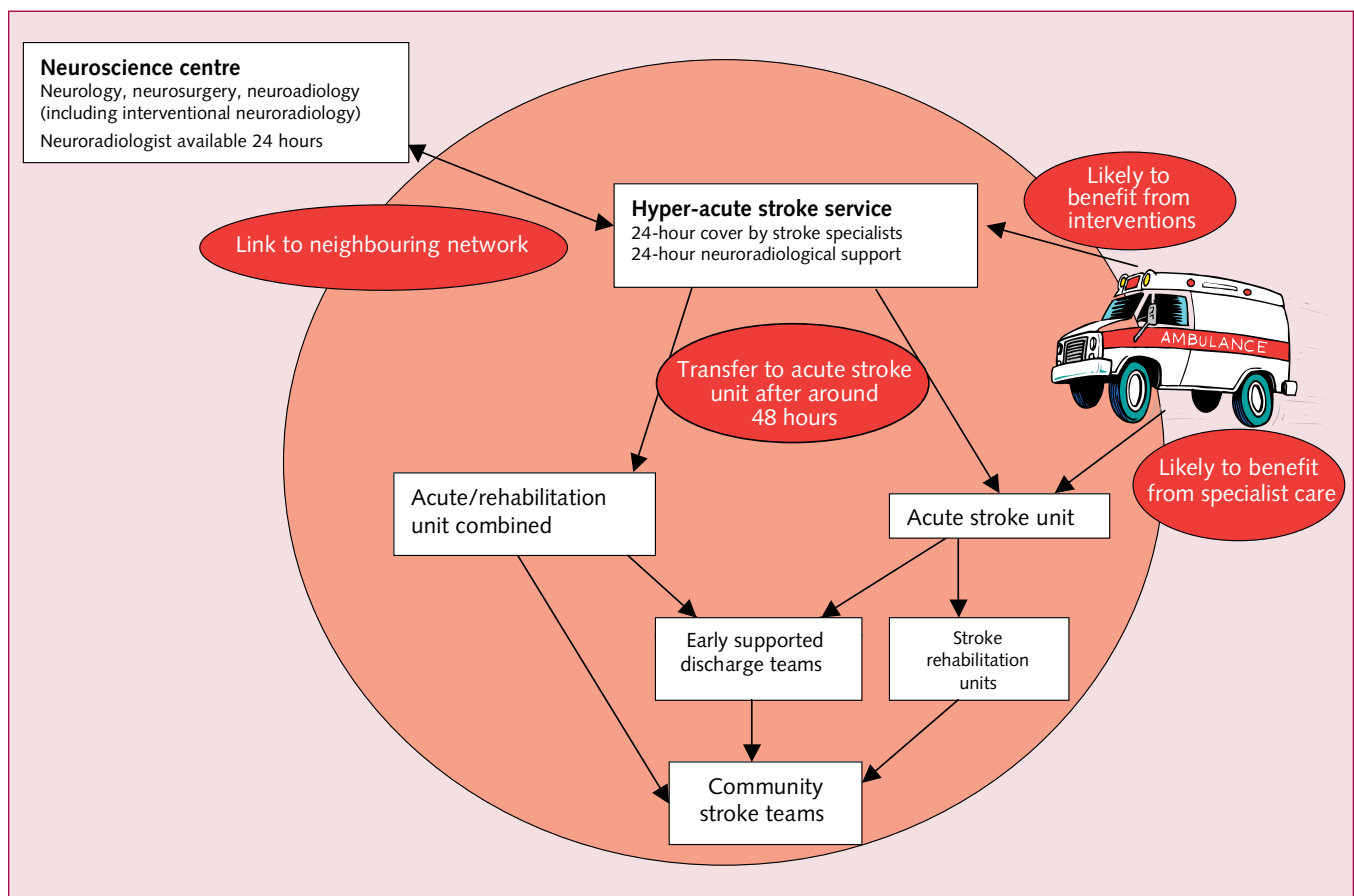
11. 'Virtual networks', where patients are seen, assessed and imaged at local hospitals with appropriate teleradiology and telemedicine

³⁵ Department of Health, 2006, *Mending Hearts and Brains*, London, DH

support, are also a possibility. Selected complex cases would transfer to a hyper-acute centre in this model.

12. Networks are also of huge benefit to patients. If well managed, they make a reality of the patient pathway. Rather than a series of disconnected episodes of care from apparently disjointed services, the patient can experience seamless, co-ordinated care across primary, secondary and tertiary NHS care and also into social care and the voluntary sector. This is particularly important in planning discharge from hospital and post-hospital support in the community.
13. Commissioning networks can also be beneficial. Not every PCT can be expected to have staff with the relevant expertise to commission stroke services for their resident population, and it is complex for providers to work with multiple commissioners. Collective commissioning groups with one PCT taking a lead on stroke is a possible way forward.
14. Experience in other services, such as those for coronary heart disease and cancer, has demonstrated that networks are of great value to the organisations which comprise them. Networks can develop solutions to local problems as well as learn from each other about more common issues.

An example of a network model



They are potentially a powerful force to bring services up to a consistently high quality.

15. Cardiac networks have expertise in service improvement techniques and experience in delivering an emergency response, which may be helpful in supporting stroke services. The prevention challenge is common to both conditions. It may be beneficial to broaden the scope of existing cardiac networks to cover both heart disease and stroke. Views are invited on the desirability and logistics of this option.

Workforce

16. High-quality care and services for people who have had a stroke or who are at risk of a stroke, are delivered by inter-professional and inter-agency teams who are competent in their own roles and have stroke expertise, understand the roles of others and their key activities, and are able to support the activities of other staff when required.

An identified person needs to be responsible for leading service delivery and development, including development of staff, as well as for developing mechanisms for, and an ethos of, shared responsibility.

17. In order to build such teams, service providers may need to consider new and more flexible roles, to ensure professional development opportunities and to support their staff with the availability of evidence, standards and guidelines, and protected learning time. This will involve competence-based training for the extension of roles, the development of generic skills (IT, research) and consideration of competences for non-specialist staff. This includes linking grading to the NHS Knowledge and Skills Framework and to the Stroke Specialist Competence Framework. Design and redesign of roles will need to be underpinned with National Occupational Standards.

Clinical educator for stroke

Bradford Teaching Hospitals NHS Foundation Trust

The Trust has joined forces with its local social services department and appointed a clinical educator for stroke to deliver education and training to a range of staff across the whole pathway of care. A senior nurse from the hospital's stroke unit delivers stroke-awareness education in the social services training centre, and candidates are identified by the social services team. Training programmes explain the causes of stroke and various

aspects of its management and rehabilitation from admission to discharge from hospital.

This has seen healthcare assistants, therapy assistants, staff from day care centres, mobility centres and senior care home assistants learn more about stroke. A number of nurses from acute wards have also been trained as stroke key workers. Future sessions will include staff from private nursing and care homes.

18. There is a need for nationally recognised, quality-assured and transferable training and education programmes for stroke, linked to professional roles and career pathways, which could be addressed by a national training forum for all relevant professional bodies. In addition, there will need to be a detailed review of the stroke workforce, and the development of workforce plans will ensure that there are sufficient numbers of suitably qualified or skilled staff in stroke services to enable the NHS to deliver high-quality services equitably across England.
 19. Social care services for people who have suffered a stroke are likely to be delivered by non-specialist staff, and the focus needs to be on access to high-quality information and access to training to help social care staff deal more effectively with stroke.
 20. SHAs will need to work together with PCTs, deaneries, higher education and provider organisations to facilitate the introduction of major workforce innovations and encourage the development of deaneries with a multiprofessional focus.
 21. As well as investing in medical training posts for stroke and teaching and academic posts to provide learning opportunities for undergraduates and postgraduates, SHAs will want to consider all relevant stroke service settings: independent, voluntary sector, hospital, home and community.
 22. Commissioners can ensure effective leadership, which is the best way to deliver change in the improvement of stroke service, with engagement on stroke services at board level. Leaders will need to ensure that they consider service development roles.
- ### Research and audit
23. Improvement in the capacity and capability of NHS stroke research, and the integration of research with service delivery, will enhance the care of people who have had a stroke and their carers.
 24. DH has provided £20 million over five years to support the UK Stroke Research Network (www.uksrn.ac.uk), which is part of the UK Clinical Research Network. The Stroke Research Network will provide a world-class health service infrastructure to support clinical stroke research and remove barriers to its conduct. The primary aim of the Network is to facilitate the conduct of randomised prospective trials and other well-designed studies of stroke, including those for prevention, diagnosis and treatment.
 25. The Royal College of Physicians' *National Sentinel Stroke Audit* has been carried out in two-yearly cycles since 1998. This enables providers to benchmark the quality of their services and assess progress on delivery against national guidelines and standards.
 26. DH has produced toolkits for providers (ASSET) and for commissioners (ASSET 2) which facilitate the use of the audit data and data from other sources to assist in identifying shortfalls in service provision and future service priorities.
- ### Evaluating success
27. Commissioners undertaking a local needs assessment will need to look at existing staffing, consider projections for staffing

numbers, and review and revise workforce numbers, with the long-term view of ensuring a stroke-skilled workforce.

28. SHAs will wish to monitor equity across their area, ensure effective supply mechanisms and quality assurance mechanisms for learning.
29. For commissioners wishing to assess the quality of current provision, the following markers may be informative:
 - > numbers of different types and skill mix of staff on acute and rehabilitation units, in early supported discharge teams;
 - > job descriptions that are linked to the Knowledge and Skills Framework and National Occupational Standards;
 - > numbers of specialist trained staff;
 - > length of stay;
 - > hospital mortality; and
 - > numbers of early readmissions.

Recommendations from the project groups

Networks

- > Clinical networks should be established, covering populations of between 500,000 and 2 million, to review and organise delivery to all acute stroke patients of 24-hour specialist care, including thrombolysis, rapid admission to acute stroke units and acute and subsequent rehabilitation.
- > Clinical networks should include all healthcare involved in the provision of acute stroke services, for example ambulance trusts and PCTs.

Workforce

- > All people who have had a stroke, or who are at risk of a stroke, should receive care from staff with the skills, competence and experience appropriate to meet their needs. These requirements should apply to all practitioners in all of the different settings relevant to stroke and at all stages of the stroke care pathway.
- > There should be core competences for all healthcare staff working with people who have had a stroke, including in non-specialist areas (for example, those created by the Scottish Health Board).
- > Commissioners of stroke services should review and revise existing workforce numbers and profiles, or commission new ones, based upon a local population needs assessment and taking account of both DH guidance and that of the Workforce Review Team.
- > Commissioners should invest in posts and training to develop the stroke workforce in leadership, managing change and modernising services.
- > There should be investment in teaching and academic posts in stroke to provide teaching for undergraduates and postgraduates, and to address the shortfall in stroke research.
- > The National Occupational Standards for stroke, when completed, should be used to underpin the design and redesign of roles, as a mechanism for ensuring the delivery of high-quality care and services to people who have had a stroke or who are at risk of a stroke. The areas and levels of competences should be consistent with employers' reward systems.

- > SHAs and deaneries should support stroke workforce development. Commissioners should work with deaneries/SHAs to provide authoritative analysis of local workforce needs, to ensure that there are effective supply mechanisms for key workforce groups and to facilitate major innovations in the local multiprofessional workforce.
- > There should be nationally recognised, quality-assured and transferable education and learning programmes in stroke. There should be a national forum for all the relevant professional bodies to agree the content. The programmes should ensure that the relevance of research to practice is emphasised.

Consultation questions

1. Are the recommendations from the project groups the right ones?
2. Will clinical networks drive the changes needed?
3. What are the benefits and concerns about expanding the cardiac network infrastructure?
4. Will the recommendations support more effective local workforce planning for stroke?
5. Are there any key gaps in research activity which need to be addressed to support the implementation of this strategy?
6. Is there anything that has been missed?

To respond to these questions, download a response form from www.dh.gov.uk/stroke



Chapter 4

Everyone's challenge: raising awareness, informing and involving



Stroke has historically been a poorly understood condition. Although most of us know someone who has been affected by stroke, few of us know what stroke is, how it may be prevented, or what the symptoms are to watch for. Time is critical – a stroke caught early means a person is more likely to walk away from hospital with few lasting effects. For this to happen, we need to **improve public and professional awareness of stroke symptoms**. DH is working in partnership with the voluntary sector on awareness-raising activity, such as the Stroke Association's 'FAST' campaign.

Many strokes can be **prevented** through healthier lifestyles and medication to control blood pressure and cholesterol. Stroke shares the same risk factors as other vascular conditions such as heart disease, so broader action to reduce smoking and

alcohol and salt consumption, and to improve healthy eating and increase exercise levels is important. More can be done to incorporate stroke into existing prevention programmes and to develop targeted support for those disadvantaged groups and communities most at risk, including African and Caribbean and South Asian people.

Awareness raising and prevention are likely to be more effective where people are fully **involved** in their health and their care. This includes **improving information provision** so that individuals can fully understand their condition and exercise maximum choice over their care. Providing support in the long term, sometimes for years after a stroke, can prevent social isolation and depression and enhance participation.

Aim

1. To improve public and professional awareness of the risk factors and symptoms of a stroke, and what action to take, and ensuring people who experience a stroke and their carers are involved in decisions about their treatment and in the designing of services

The challenge

2. Lack of awareness of stroke is a significant problem. People do not know what a stroke is, what the symptoms are, or that it is a treatable disease that warrants the same response as a heart attack. Nor do they know what their own risk of having a stroke is, or how to reduce that risk. Knowledge about stroke is also low among health and social care professionals.

3. **Symptoms** will depend upon the part of the brain that has been affected, and the extent of the damage. They will vary from person to person. Symptoms come on suddenly, and can include:

- > weakness or numbness down one side of the body – ranging in severity from weakness in the hand to complete paralysis of one side of the body;
- > weakness and drooping of the face, which can cause drooling;
- > problems speaking and understanding what people are saying;
- > problems with balance and co-ordination; and
- > difficulty swallowing.

Janet's story

Back in July 1994 and at 35 years of age, Janet was a healthy, busy mum running a household with three young children. She also worked as a financial adviser. Out of the blue she experienced a severe brain haemorrhage and was unconscious for eight days.

She spent a few weeks in the neurological unit of a large northern city hospital and was then transferred back to her local hospital where she began the long process of relearning and rehabilitation. Janet had aphasia and experienced problems with the ability to understand language and was also unable to speak very well. Her vision was also

distorted – half the field of vision for each eye had been lost.

Two years after her stroke, Janet joined an aphasia self-help group, run by Speakability. Support from the group enabled Janet to take a leading role in Speakability as the co-ordinator of the charity's Speakers' Panel, which empowers people with aphasia to present their story to members of the public and health professionals in a series of workshops. She continues to work as a group support worker in the north of England, offering help and encouragement to existing self-help groups, and is working hard to develop new self-help groups in the region.

Recognising a stroke or TIA

The Stroke Association recommends using the Face Arm Speech Test (FAST) to help you recognise the symptoms of a stroke or TIA in other people.

Face – can the person smile, or has their mouth or eye drooped?

Arm – can the person raise both arms?

Speech – can the person speak clearly and understand what you say?

Test – for one, two or all three of the above signs.

4. The National Audit Office report highlighted that the failure to recognise stroke symptoms as a medical emergency – including by NHS Direct and GPs – was one of the reasons why urgent medical treatment for stroke could be delayed.³⁶ In a MORI poll commissioned by the Stroke Association, only half of people asked could correctly identify what a stroke is, with only 40 per cent correctly naming three stroke symptoms.³⁷ Sixty per cent said they would contact their GP or NHS Direct, and only a third of respondents said they would call an ambulance or go to hospital.³⁸ A quarter did not even believe that any specialised treatment or care could make a difference.³⁹
5. This is not just an issue for members of the public, but also for healthcare professionals. Nearly one in five GPs said they do not refer

around a fifth of cases of a TIA or stroke.⁴⁰ Just over half of GPs said they would refer someone with a suspected stroke immediately.

6. There are groups who are at higher risk of having a stroke. People who live in disadvantaged areas have a higher rate of stroke, as well as heart disease and other related diseases. People of African or Caribbean ethnicity are at higher risk of having a stroke. Incidence rates, adjusted for age and gender, are twice as high in black people as for white people.⁴¹
7. A recent national survey of stroke patients revealed that while 89 per cent are satisfied with the care they received, almost half are dissatisfied with the information they received and 52 per cent wished they had been more involved in their care. Carers too are often dissatisfied with the amount of information they are given.⁴²

Delivering the ambition

8. Members of the public, and healthcare staff, need to be able to recognise and identify the main symptoms of stroke and know it must be treated as an emergency. A fast response to stroke reduces the risk of death and disability. However, this cannot be done without recognition of the symptoms of stroke and an urgent response. To initiate an emergency response to a suspected stroke, it is crucial that staff who have contact with the public (GP receptionists, NHS Direct call handlers, ambulance control call handlers

³⁶ National Audit Office, 2005, *Reducing Brain Damage: Faster access to better stroke care*

³⁷ MORI poll, 2005, commissioned by the Stroke Association

³⁸ National Audit Office, 2005, *Reducing Brain Damage: Faster access to better stroke care*

³⁹ MORI poll, 2005, commissioned by the Stroke Association

⁴⁰ National Audit Office, 2005, *Reducing Brain Damage: Faster access to better stroke care*

⁴¹ Ibid.

⁴² Healthcare Commission, 2006, *Survey of patients 2006. Caring for people after they have had a stroke: A follow-up survey of patients*

and hospital triage staff) are able to recognise the symptoms of stroke or TIA, even when they cannot see the individual.

9. Commissioners also have a role to play in raising both public and professional awareness of stroke – and in doing so to ensure that people receive the right care. Part of building a good stroke service means including stroke awareness as part of the training of staff (see Chapter 3 for further information). Initially the focus may be on frontline staff. Many voluntary organisations already support this process at a local level, providing information such as leaflets advising on stroke prevention, supporting those who have had a stroke and their carers.
10. Promoting healthy living is very important to help prevent stroke, particularly in disadvantaged areas and groups. Healthy lifestyles and management of specific risk factors reduce the risk of an initial stroke and the risk of a subsequent stroke. Some 20,000 strokes could be avoided through preventive work on high blood pressure, irregular heartbeats, smoking cessation, and through wider statin use.⁴³ Preventing strokes can not only reduce the associated suffering, morbidity and mortality, it may also lead to NHS savings, as each stroke costs approximately £15,000 to treat, excluding informal care costs.⁴⁴ For those who have already had a stroke or TIA, this is even more important. This means assessing individuals for their risk factors, giving them information, and advising them about possible strategies to modify their lifestyle and how these can reduce their risk.
11. Primary care services are at the forefront of activity to encourage people to change their lifestyle in order to reduce the risk of ill-health, including stroke, as GPs manage risk factors according to national guidelines.⁴⁵ It is important that primary care professionals update and maintain their knowledge of these guidelines and implement them in their practice, specifically targeting higher-risk groups. The Quality and Outcomes Framework (part of a GP's contract) includes a number of quality indicators relating to measurement of risk associated with vascular disease, for example a section devoted to recording diagnosis and ongoing management of high blood pressure.
12. *ASSET 2 and Improving Stroke Services: a guide for commissioners* can assist commissioners when they are assessing how best to organise services, by showing how many lives could be saved through improved prevention measures.⁴⁶ For example, commissioners can look to ensure a smoke-free environment is promoted, not just Stop Smoking Services and other interventions aimed solely at smokers who have decided to quit. Work in the Spearhead areas (the fifth of areas with the worst health and deprivation indicators

⁴³ Department of Health, 2006, *ASSET 2 – Action on Stroke Services: an Evaluation Toolkit for commissioners*, London, DH

⁴⁴ National Audit Office, 2005, *Reducing Brain Damage: Faster access to better stroke care*

⁴⁵ Royal College of Physicians, *National Clinical Guidelines for Stroke*, 2nd edition. Prepared by the Intercollegiate Stroke Working Party, London, RCP, 2004. British Cardiac Society, British Hypertension Society, Diabetes UK, HEART UK, Primary Care Cardiovascular Society, and the Stroke Association, 2005, Joint British Societies' Guidelines on Prevention of Cardiovascular Disease in Clinical Practice, *Heart*, 91

⁴⁶ Department of Health, 2006, *Improving Stroke Services: A guide for commissioners*, London, DH

Key worker system

Mendip PCT

The role of named key worker was established when the Kearnton Stroke Unit at Shepton Mallet Hospital was opened in 2004. The key worker role for a person who has had a stroke may be assigned to speech and language therapy, physiotherapy, occupational therapy or the stroke co-ordinator, and it operates in conjunction with a named nurse for each person.

The main aim of the key worker role is to provide information and support for the person who has had a stroke and their family throughout their journey with stroke. As well as providing the main point of contact and communication for people with stroke and

their families, the key worker is also responsible for arranging all family meetings, leading discharge planning and communicating with other relevant agencies. The stroke co-ordinator leads a weekly multidisciplinary team meeting both on the stroke unit and in the community to update, supervise, share, exchange ideas and facilitate goal setting.

Once the person who has suffered the stroke is stable, and has been transferred back home, they remain on the case load of the stroke co-ordinator for life. This has helped to ensure that since the stroke unit has been opened, there have been no complaints.

in England) has proved that such targeted work can achieve positive results.

13. Directors of Public Health will have a role in supporting the prevention message, particularly in deprived areas and among disadvantaged groups, and will also incorporate stroke into existing healthy lifestyle or information programmes.
14. Individuals who have had a stroke, and their family and carers, want to be kept informed, be included and have a clear, consistent point of contact for as long as they live with the effects of a stroke, which for many people will be the rest of their lives. A stroke may require considerable changes in daily life. People benefit from consistent support in accessing information and in knowing how to access a full range

of services from the NHS, social care and others. They also ask for more support in navigating the health and social care systems. Service providers often work closely with the voluntary sector which has traditionally undertaken this information and navigation role in some areas. The Brain and Spine Foundation has developed an Information Access Toolkit that professionals and stroke survivors and their families can access.⁴⁷

15. The information needs of people who have had a stroke and their carers are diverse and change over time. Quality information and education, provided at the right time and in an accessible format, can improve opportunities for choice and levels of independence.⁴⁸ It can also enhance morale, confidence and well-being. Good

⁴⁷ Available from www.brainandspine.org.uk/information/information_access_toolkit/index.html

⁴⁸ Department of Health, 2004, *Better information, better choices, better health: Putting information at the centre of health*, London, DH



information will be flexible enough to meet the different requirements of different people, for example those with aphasia or other communication problems, or in other 'hard to-reach' groups. A significant proportion of people have aphasia as a result of a stroke, which means they find it difficult to speak, read, write or understand what people are saying, especially if rushed or under pressure.

16. Commissioners who want to deliver a good service (including a fast response when a stroke happens) will be ensuring that people who have had a stroke and their families are informed and empowered to take control of their care and support, particularly from

disadvantaged and hard-to-reach groups. Involving people who have had a stroke and their carers in the development of services can help drive improvement and tackle problems; for example, consulting them about the relevance, suitability and completeness of services and resources to meet their individual needs will improve the quality of information. Regular audits involving people who have had a stroke and their carers, including people with communication and cognitive difficulties, should improve the effectiveness of information provision.

17. As set out in *Our health, our care, our say*, people's voices need to be heard at a local

level where spending decisions are taken, and it will be important to include those who have had a stroke in these discussions. Some people may have specific support needs (such as those with aphasia) which need to be met to enable them to do so. Commissioners should also take into account the needs of deprived areas and disadvantaged groups in their planning.

Evaluating success

18. Commissioners and service providers who have decided to make stroke a priority or wish to assess the quality of their current provision may use the following markers:

- > proportion of patients who seek medical attention within two hours of the onset of stroke symptoms;
- > number of patients with a suspected acute stroke seen within the recommended time window; and
- > proportion of patients with stroke or other cardiovascular disease who have blood pressure, glucose or cholesterol, or smoking controlled within the recommended range.

Services have in place systems to:

- > support people who have experienced stroke, and their carers, to have a voice in the development, delivery and quality of stroke services; and
- > provide prompt, sensitive information in a variety of formats accessible to all those who have experienced a stroke, and their carers, with clear routes to accessing such information for life.

Recommendations from the project groups

- > There should be investment in local awareness-raising campaigns, and the Government should fund a behaviour change campaign.
- > People at risk of a stroke and patients who have had a stroke should be assessed for and given information about risk factors and lifestyle management issues (exercise, smoking, diet, weight, alcohol), and be advised about possible strategies to modify their lifestyle and risk factors.
- > Risk factors (including hypertension, high cholesterol and diabetes) should be managed according to clinical guidelines and appropriate action taken to reduce overall vascular risk.
- > People who have had strokes at home or in care homes, and their relatives and carers, should have access to information, practical advice, emotional support, advocacy and information throughout the care pathway and for life.
- > Patients and their families should have access to independent advocacy, support and information throughout the care pathway and into community living.

Consultation questions

1. Are the recommendations from the project groups the right ones?
2. Will the recommendations improve public awareness?
3. Will the recommendations improve professional awareness?
4. Is this the right approach to improve information and advice for people at risk of a stroke or who have experienced a stroke?
5. What more could be done to support primary care in recognising and reducing people's risk of stroke?
6. Is there anything that has been missed?

To respond to these questions, download a response form from www.dh.gov.uk/stroke



Annex A

Responding to the consultation

This consultation seeks views on the recommendations developed by the stroke strategy project groups, as set out in this document. Consultation questions are included in each chapter, and a response form can be downloaded from www.dh.gov.uk/stroke or obtained by writing to us at the address below. An easy-read version is also available.

How to respond

The consultation period began on **9 July 2007** and will run until **12 October 2007**. Please ensure that your response reaches us by that date. If you would like further copies of this consultation document, it can be found at www.dh.gov.uk/consultations, or you can contact stroke@dh.gsi.gov.uk

Please send consultation responses by email to:
stroke@dh.gsi.gov.uk

Or by post to:

The Stroke Team
c/o Pasha Mondal
Department of Health
Room 403
Wellington House
133–155 Waterloo Road
London SE1 8UG

DH will use the responses to this consultation in the development of the stroke strategy. The strategy will put forward a vision for the delivery of health and social care services for those at risk of or who have had a stroke.

When responding, please state whether you are responding as an individual or representing the views of an organisation. If responding on behalf of a larger organisation, please make it clear who the organisation represents and, where applicable, how the views of members were assembled.

Information provided in response to this consultation, including personal information, may be published or disclosed in accordance with the access to information regimes (these are primarily the Freedom of Information Act 2000, the Data Protection Act 1998 and the Environmental Information Regulations 2004).

If you want the information that you provide to be treated as confidential, please be aware that, under the Freedom of Information Act, there is a statutory Code of Practice with which public authorities must comply and which deals, among other things, with obligations of confidence. In view of this, it would be helpful if you could explain to us why you regard the information you have provided as confidential. If we receive a request for disclosure of the information we will take full account of your

explanation, but we cannot give an assurance that confidentiality can be maintained in all circumstances. An automatic confidentiality disclaimer generated by your IT system will not, of itself, be regarded as binding on DH.

DH will process your personal data in accordance with the Data Protection Act and, in the majority of circumstances, this will mean that your personal data will not be disclosed to third parties.

What will happen next

A summary of responses, including the next steps, will be published by **7 December 2007** and will be available at www.dh.gov.uk/stroke; paper copies will be available on request.

Impact Assessments

A partial Impact Assessment and a partial Equality Impact Assessment are available at www.dh.gov.uk/stroke

Comments or complaints (but not responses to the consultation itself) should be directed to:

Consultation Co-ordinator
Department of Health
Skipton House
80 London Road
London SE1 6LH

Email: Mb-dh-consultations-coordinator@dh.gsi.gov.uk

The consultation criteria

The consultation is being conducted in line with the Code of Practice on Consultation. The criteria are listed below; a full version of the criteria can be found at www.cabinetoffice.gov.uk/regulation/Consultation/Code.htm

The Cabinet Office Code of Practice criteria are as follows:

1. Consult widely throughout the process, allowing a minimum of 12 weeks for written consultation at least once during the development of the policy.
2. Be clear about what your proposals are, who may be affected, what questions are being asked and the timescale for responses.
3. Ensure that your consultation is clear, concise and widely accessible.
4. Give feedback regarding the responses received and how the consultation process influenced the policy.
5. Monitor your department's effectiveness at consultation, including through the use of a designated Consultation Co-ordinator.
6. Ensure your consultation follows better regulation best practice, including carrying out an Impact Assessment if appropriate.

Annex B

List of stakeholders consulted

The Department of Health would like to thank those who gave up their time to contribute to the development of this document, including:

Steering group members

Professor Roger Boyle (Chair) (National Director for Heart Disease and Stroke), Professor Charles Wolfe (Guy's and St Thomas' NHS Foundation Trust), Professor Gary Ford (Royal Victoria Infirmary, Newcastle upon Tyne) Dr Tony Rudd (Guy's and St Thomas' NHS Foundation Trust), Professor Sally Byng (Connect), Dr Damian Jenkinson (The Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust), Professor Peter Rothwell (Radcliffe Infirmary, Oxford), Mark Cooke (Ambulance Service Association), Jon Barrick (Stroke Association), Dr Jane Williams (Portsmouth Hospital), Stephanie Ticehurst (Coffham Hospital, Bristol), Dr Ian Kneebone (University of Surrey), Ian Basnett (Tower Hamlets PCT and the London Borough of Tower Hamlets), Dee Carlin (Lewisham PCT), Mike Ripley (Different Strokes), Dr Susan Whittle, (Connect), Basia Grzybowska (Connect), Robert Baillie (Stroke Association), Phil Collis (Stroke Project), Melanie Pitt (HM Treasury),

Elaine Yardley (Association of Directors of Adult Social Services), Professor Caroline Watkins (University of Central Lancashire).

Project group members

Public awareness and prevention project group

Professor Charles Wolfe (Guy's and St Thomas' NHS Foundation Trust), Joe Korner (Stroke Association), Dr David Colin-Thome (Department of Health), Professor John Potter (University of East Anglia), Hanif Bobat (Manchester Race and Health Forum), Professor Lalit Kalra (King's College London), Sarah Ransome (Blood Pressure Association), James Brandon (Food Standards Agency), Dr Sarah Jarvis (Richford Gate Medical Practice), Amanda Jones (Sheffield Teaching Hospital Foundation Trust), Dr Jonathan Mant (University of Birmingham), Dr Alan Maryon-Davis (Southwark PCT), Margaret Leid (Cheshire and Merseyside Cardiac Network), Wendy Proctor (Central Office of Information), Charlie Snow (Delaney Lund Knox Warren), Nick Joliffe (Stroke Association), Susie Honour (Stroke Association), Jane Stokes (Connect).

Post-hospital stroke care project group

Professor Sally Byng (Connect), Isatu Mason (Tower Hamlets PCT and Barts and The London NHS Trust), Emma Turner (Royal Free Hospital), Fiona Kelly (Royal Free Hospital), Professor John Young (St Luke's Hospital), Amy Fraser and Claire Wheeler (Camden Carers' Centre), Dr Tim Ayers (East Devon PCT), Hannah Need (St John's Therapy Centre), Jane Reed (Solihull PCT), Elaine Roberts (Stroke Association), Heather Webber (Stroke Association), Professor Ann Ashburn (University of Southampton), Dr Ian Kneebone (University of Surrey), Jasvinder Khosa (Stroke Association), Carole Headley Barton (Connect), Cathy Ingram (Lambeth PCT), Matthew Winn (Southwark PCT), Philippa Shreeve (Care Services Improvement Partnership), Leila Paxton (St John's Therapy Centre), Claire Moser (Royal College of Speech and Language Therapists).

Hospital stroke care project group

Dr Tony Rudd (Guy's and St Thomas' NHS Foundation Trust), Annie Laverty (Alnwick Infirmary), Stephanie Ticehurst (Coffham Hospital, Bristol), Peter Allen (Different Strokes), Tom Penman (Connect), June O'Connell (King Edward VII Hospital), Jon Barrick (Stroke Association), Rekha Elaswarapu (Healthcare Commission) Dr Sheldon Stone (Royal Free and University College Medical School), Dr John Bamford (Leeds General Infirmary), Dr Jane Williams (Portsmouth Hospital), Jayne Spink (National Institute for Health and Clinical Excellence), Binnie Grant (Chelsea and Westminster Hospital).

TIA and minor stroke services project group

Professor Peter Rothwell (Radcliffe Infirmary, Oxford), Peter Lamont (Bristol Royal Infirmary), Professor Averil Mansfield (Stroke Association), Dr Mo Hammady (St Mary's Hospital), Clare Gordon (The Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust), Christina Meacham (Different Strokes), Dr Robin Davidson (St Augustine's, Medical Practice, Bristol), Adrian South (Dorset Ambulance NHS Trust), Avril Macdonald (Royal Hampshire County Hospital), Dr Michael Pelly (Imperial College School of Medicine), Joe Jarosz (King's College Hospital, London), Peter Allen (Different Strokes), Phil Collis (Stroke Project), Peter Humphrey (Walton Centre for Neurology and Neurosurgery), Dr Angus Kennedy (Chelsea and Westminster Hospital).

Workforce project group

Dr Damian Jenkinson (The Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust), Sue Kellie (British Dietetic Association), Professor Martin Brown (University College London), Dr Chris Burton (University of Central Lancashire), Dr Jane Williams (Portsmouth Hospital), Professor Caroline Watkins (University of Central Lancashire), Kamini Gadhok (Royal College of Speech and Language Therapists), Monica Fletcher (Education for Health), Sarah Bazin (Heart of England NHS Foundation Trust), Carron Sintler (University Hospital Birmingham NHS Foundation Trust), Mick Ward (Leeds City Council), Professor Bill Burr (Yorkshire Deanery), Fleur Kitsell (Severn and Wessex Deanery), Dr Joanne Knight (Stroke Association), Vicky Osgood, (Workforce Review Team), Kiran Cheema (Workforce Review

Team), Professor Alan Crockard (Modernising Medical Careers), Rav Jayram (Skills for Health), Julia Scott (College of Occupational Therapists), Wendy Brooks (Epsom and St Helier NHS Trust), Kathryn Hudson (Department of Health), Robert Baillie (Stroke Association), Dr Pip Logan (Queens Medical Centre, Nottingham).

Emergency Response Project Group

Professor Gary Ford (Royal Victoria Infirmary), Carol Wilby (Department of Health), Mark Cooke (Ambulance Service Association) Professor George Alberti (Department of Health), Dr George Kassianos (Ringmead Practice, Bracknell), Basia Grzybowska (Connect), Professor Caroline Watkins (University of Central Lancashire), Dr Susan Whittle (Connect), Enid Povey (NHS Direct), Phil White (Western General Hospital, Edinburgh), Professor Alastair Buchan (Radcliffe Infirmary, Oxford), Richard Evans (Society and College of Radiographers), Kate Garas (Society and College of Radiographers), Derek Whitehead (Stockport Metropolitan Borough Council), Katherine Henderson (Guy's and St Thomas' NHS Foundation Trust), Sue Nyfield (Joseph Levy Charitable Foundation/Stroke Association).

Case studies were provided by: Connect, Speakability, University Hospital Aintree NHS Foundation Trust, Somerset PCT, Northumbria Healthcare NHS Foundation Trust, Bradford Hospitals Teaching NHS Foundation Trust.

Wider stakeholders

The following stakeholder organisations will also be invited to respond to the consultation. Please contact the Stroke Team with the names of any other stakeholder groups not on the list that you feel might be able to contribute, via the address given in Annex A.

Afiya Trust
Age Concern
Ambulance Service Association
Association of British Neurologists
Association of Directors of Adult Social Services
Association of Directors of Social Services
Association of Professional Music Therapists
Birmingham and the Black Country Cardiac Network
Blood Pressure Association
British and Irish Orthoptic Society
British Association of Art Therapists
British Association of Dramatherapists
British Association of Prosthetists and Orthotists
British Association of Social Workers
British Association of Stroke Physicians
British Cardiovascular Society
British Dietetic Association
British Geriatric Society
British Heart Foundation
British Hypertension Society
British Pharmacological Society
British Psychological Society
British Society of Medical Rehabilitation
Cardiovascular Research Funders Forum
Chartered Society of Physiotherapy
College of Health
College of Occupational Therapists
Commission for Social Care Inspection
Connect
Connecting for Health

Deaneries
Diabetes UK
Different Strokes
Disability Rights Commission
English Community Care Association
Faculty of Public Health
FATIMA Women's Network
Food Standards Agency
Health and Social Care Advisory Service
Healthcare Commission
Heart Improvement Programme
Help the Aged
Improvement and Development Agency
Intercollegiate Working Party on Stroke
Joint Royal Colleges Ambulance Liaison Committee
Local Government Association
Manchester Race and Health Forum
National Audit Office
National Care Association
National Care Forum
National Collaborating Centre for Chronic Conditions
National Employment and Health Innovations Network
National Institute for Health and Clinical Excellence
NHS Confederation
NHS Direct
NHS Institute for Innovation and Improvement
North West Stroke Taskforce
Office for Disability Issues
Patients' Forum for the London Ambulance Service
Postgraduate Medical Education and Training Board
Registered Nursing Home Association
Relatives and Residents Association
Renal Patients
Royal College of General Practitioners
Royal College of Nursing
Royal College of Physicians
Royal College of Psychiatrists
Royal College of Radiologists
Royal College of Speech and Language Therapists
Royal Pharmaceutical Society
Skills for Health
Skills for Care
Social Care Institute for Excellence
Society and College of Radiographers
Society for Vascular Technologists
Society of Chiropractors and Podiatrists
South Yorkshire Stroke Network
Speakability
Stroke Association
Stroke Modernisation Initiative
Stroke Nurses Forum
Stroke Research Network
The Stroke Project
Vascular Society
Workforce Review Team

Annex C

Key resources

National Service Framework for Older People

The *National Service Framework for Older People*, published in 2001, included a standard that aimed to reduce the incidence of stroke in the population and ensure that those who have had a stroke have prompt access to integrated stroke care services. This has driven forward improvements in stroke care. For example, most trusts that care for people who have had a stroke now have a stroke unit – a rarity just ten years ago. However, there remain issues about capacity and responsiveness, and this is one of the drivers for the development of a stroke strategy.

www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4003066

National Service Framework for Long-Term Conditions

The *National Service Framework for Long-Term Conditions*, published in 2005, aims to promote quality of life and independence for people with long-term neurological conditions by ensuring they receive co-ordinated care and support that is planned around their needs and choices. The NSF does not address individual neurological conditions separately as there are so many elements of service provision that are common to different conditions. It will clearly be important for commissioners to take into account the quality requirements of the NSF when planning services for stroke survivors who have long-term support and care needs. References are made throughout this strategy, highlighting where the quality requirements in the *NSF for Long-Term Conditions* are relevant.

www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4105361

National Clinical Guidelines for Stroke

The *National Clinical Guidelines for Stroke* were developed by the Intercollegiate Stroke Working Party, co-ordinated by the Clinical Effectiveness and Evaluation Unit of the Royal College of Physicians (2002). The aims of the guidelines are to provide explicit recommendations for practising clinicians, managers, patients and carers about the management of stroke and transient ischaemic attack (TIA), covering the whole care pathway from the acute event to longer-term management in the community based on best available evidence. The second edition was published in September 2004; a supplement on early recognition was produced in 2006; and it is expected that a third edition of the full guidelines will be published in 2008.

www.rcplondon.ac.uk/pubs/books/stroke/

Royal College of Physicians Sentinel Audit

The CEEU conducted the first round of the National Sentinel Stroke Audit in 1998 and four further rounds in 1999–2002, 2004 and 2006. The objective of the Sentinel Audit is to assess the quality of care for people who have had a stroke and to help trusts use audit as a means of quality improvement. The audit is based on evidence-based standards for the organisation of services and process of care agreed by the representatives of the colleges and professional organisations of the disciplines involved in the management of stroke. This has been an important driver for improvement, as services are able to judge their standards against the performance and standards of others.

www.rcplondon.ac.uk/college/ceeu/ceeu_stroke_home.htm

Reducing Brain Damage: Faster access to better stroke care

The National Audit Office published *Reducing Brain Damage: Faster access to better stroke care* in November 2005, recommending further improvements in preventing strokes in the first place, and treating and managing people with strokes. The National Audit Office will review their findings within the lifetime of the current Parliament.

www.nao.org.uk/pn/05-06/0506452.htm

Mending Hearts and Brains

The report *Mending Hearts and Brains* by Professor Boyle, National Director for Heart Disease and Stroke, published in December 2006, made the clinical case for reconfiguration in terms of delivering better urgent care for heart attack and 'brain attack'. This stressed the need for heart attack and stroke services to be delivered by personnel with an appropriate level of experience and training in settings with sophisticated diagnostic and monitoring facilities on a 24-hours-a-day, seven-days-a-week, immediate-access basis.

www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_063282

Improving Stroke Services: A guide for commissioners

Improving Stroke Services: A guide for commissioners, published in December 2006, was designed to help commissioners assess their local need, review how well services are meeting it currently, and identify where to invest in the future. It provided advice on good practice to commissioners which highlights key issues to consider, and summarised supporting resources. It focused on ways to apply the DH commissioning framework to stroke services, highlighting emerging themes from the national strategy in order to support services in planning ahead for implementation.

www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_063260

Action on Stroke Services: An evaluation toolkit (ASSET) for providers and commissioners

Action on Stroke Services: An evaluation toolkit (ASSET) for providers was created to help healthcare organisations improve and transform stroke services for patients. It enables trusts to benchmark their performance against the rest of England. It also demonstrates the impact for the particular trust of several key improvements to TIA clinics and acute stroke care in terms of better patient outcomes and reduced lengths of stay. ASSET for commissioners builds on this and shows PCTs and GPs, by using their own statistics, how better care – including improved

prevention activities – will save money in the long run, reduce hospital bed days, reduce disability and save lives.

www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4134498

Delivering Quality and Value. Focus on: Acute stroke

Delivering Quality and Value. Focus on: Acute stroke aims to help local health communities and organisations improve the quality and value of care for acute stroke patients. This document is part of a series produced by the Delivering Quality and Value team at the NHS Institute for Innovation and Improvement as part of the high-volume Healthcare Resource Groups programme.

www.institute.nhs.uk

Ischaemic stroke (acute) – alteplase

The National Institute for Health and Clinical Excellence has now published guidelines on the treatment of acute ischaemic stroke.

www.guidance.nice.org.uk/TA122

Annex D

Glossary

ABCD2 system – The ABCD2 score is calculated using the patient's age (A); blood pressure (B); clinical features (C); and duration of TIA symptoms (D). Scores are between 0 and 7 points. **A**ge (60 years or over, 1 point); **B**lood pressure at presentation (140/90 mmHg, 1 point); **C**linical features (unilateral weakness, 2 points; speech disturbance without weakness, 1 point); **D**uration of symptoms (60 minutes, 2 points; 10–59 minutes, 1 point). Low risk = 0–3; moderate risk = 4–5; high risk = 6–7.

Action on Stroke Services: An evaluation toolkit (ASSET) – Excel spreadsheet intended to assist commissioners modernise stroke services. It shows primary care trusts and GPs, by using their own statistics, how better care will save money in the long run, reduce hospital bed days and save lives.

Acute care – Care for a disease or illness with rapid onset, severe symptoms and brief duration

Allied health professionals – Allied health professionals (arts therapists, chiropodist/podiatrists, dietitians, occupational therapists, operating department practitioners, orthoptists, physiotherapists, prosthetists and orthotists, psychologists, psychotherapists,

radiographers and speech and language therapists) are part of a healthcare team with a range of different skills, each bringing their particular expertise to caring for the patient. Allied health professionals have their own caseloads of patients and are key members of a skilled multidisciplinary team

Aphasia – Partial or total loss of the ability to articulate ideas or comprehend spoken or written language, resulting from damage to the brain

British Hypertension Society – The British Hypertension Society provides a medical and scientific research forum to enable sharing of cutting edge research in order to understand the origin of high blood pressure and improve its treatment

Clinical Effectiveness and Evaluation Unit (CEEU) – The main aim of the CEEU, which is based at the Royal College of Physicians, is to improve the quality of care delivered to patients in the NHS. The CEEU does not undertake basic clinical research but concentrates on ways of ensuring that best practice and evidence-based approaches to care are widely disseminated and used for the benefit of patients

Commissioners – Primary care trusts have the responsibility of commissioning the right services for their patients and providing links with GPs and local authorities

Commissioning – The full set of activities that local authorities and primary care trusts undertake to make sure that services funded by them, on behalf of the public, are used to meet the needs of the individual fairly, safely, efficiently and effectively

Direct payments – Payments given to individuals so that they can organise and pay for the social care services they need, rather than using the services offered by their local authority

Directors of Public Health – A chief officer post in the NHS responsible for public health, Directors of Public Health monitor the health status of the community, identify health needs, develop programmes to reduce risk and screen for early disease, control communicable disease and promote health

Disabled Facilities Grants (DFGs) – Grants issued by councils to contribute towards the cost of providing adaptations and facilities (such as level-access showers and stair lifts) to enable disabled people to continue to remain independent in their own homes

Expert Carer's Programme – To support carers and those they care for, the Department of Health has announced the creation of the Expert Carer's Programme. The programme will provide training to carers enabling them to care for themselves and those they care for more effectively. The Department is presently consulting with national carers' charities as to the exact nature of the programme's content,

but it will reflect the diversity of roles and experiences of carers

Expert Patient Programme (EPP) – The EPP is an NHS programme designed to spread good self-care and self-management skills to a wide range of people with long-term conditions. Using trained non-medical leaders as educators, it equips people with arthritis and other long-term conditions with the skills to manage their own conditions

FAST – The Face Arm Speech Test, which helps people recognise the symptoms of a stroke or TIA in others

Individual budgets – Individual budgets bring together a variety of income streams from different agencies to provide a sum for an individual, who will have control over the way it is spent to meet their care needs

Joint British Societies – A group composed of the following associations: British Cardiovascular Society, British Hypertension Society, Diabetes UK, Heart UK, Primary Care Cardiovascular Society and Stroke Association. Its aims are to promote a consistent, multi-disciplinary approach to the management of people with established atherosclerotic cardiovascular disease and those at high risk of developing symptomatic atherosclerosis

Local Area Agreements (LAAs) – An LAA is a three-year agreement that sets out the priorities for a local area in certain policy fields as agreed between central government, represented by the Government Office for the Region, and a local area, represented by the local authority and Local Strategic Partnership and other partners at local level. The agreement is made up of outcomes, indicators and targets aimed

at delivering a better quality of life for people through improving performance on a range of national and local priorities

Local Delivery Plan (LDP) – A plan that every primary care trust prepares and agrees with its strategic health authority on how to invest its funds to meet its local and national targets, and improve services. It allows primary care trusts to plan and budget for delivery of services over a three-year period

Local Strategic Partnerships (LSPs) – LSPs bring together representatives of all the different sectors (public, private, voluntary and community) and thematic partnerships. They have responsibility for developing and delivering the sustainable community strategy and Local Area Agreement

National Audit Office – The National Audit Office scrutinises public spending on behalf of Parliament. It is totally independent of government. It audits the accounts of all central government departments and agencies, as well as a wide range of other public bodies, and reports to Parliament on the economy, efficiency and effectiveness with which they have used public resources.

National Institute for Health and Clinical Excellence (NICE) – The independent organisation responsible for providing national guidance on the promotion of good health and the prevention and treatment of ill-health

NHS Connecting for Health – An agency of the Department of Health that delivers new, integrated IT systems and services to help modernise the NHS and ensure that care is centred around the patient

NHS Direct – NHS Direct provides 24-hour access to health information and clinical advice, via telephone (0845 46 47 in England), and its website (NHS Direct Online, www.nhsdirect.nhs.uk) and interactive digital TV service (NHS Direct Interactive). A printed NHS Direct Healthcare Guide is also available

Our health, our care, our say – The *Our health, our care, our say* White Paper sets out a vision to provide people with good quality social care and NHS services in the communities where they live. NHS services are halfway through a 10-year plan to become more responsive to patient needs and prevent ill-health by the promotion of healthy lifestyles. Social care services are also changing to give service users more independence, choice and control

Palliative care – Palliative care is the active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments

Payment by Results (PbR) – A scheme that sets fixed prices (a tariff) for clinical procedures and activity in the NHS whereby all trusts are paid the same for equivalent work. See also 'Tariff unbundling'

Practice Based Commissioning (PBC) – PBC gives GPs direct responsibility for managing the funds that the primary care trust has to pay for hospital and other care for the GP practice population

Primary intracerebral haemorrhage – Bleeding in the brain caused by the rupture of a blood vessel within the head

Quality and Outcomes Framework (QOF) – Part of the contract primary care trusts have with GPs. It is nationally negotiated and rewards best practice and improving quality

Rehabilitation – Combined and co-ordinated use of medical, social, educational and vocational measures for training or retraining the individual to their highest level of functional ability

ROSIER – Recognition of Stroke in the Emergency Room scale

Royal College of Physicians – The Royal College provides extensive information about the practice of medicine and aims to improve communications in the field

Skills for Care – Skills for Care is responsible for the strategic development of the adult social care workforce in England. It supports employers in improving standards of care through training and development, workforce planning and workforce intelligence. Alongside the new Children's Workforce Development Council, it is the English component of Skills for Care and Development, the UK-wide Sector Skills Council for social care, children and young people

Skills for Health – Skills for Health is the Sector Skills Council for the health sector in the UK, covering all roles and functions within the NHS and the independent sector. It helps the sector develop solutions that deliver a skilled and flexible workforce to improve health and healthcare

Spearhead group – The fifth of areas with the worst health and deprivation indicators compared with the rest of England. The Spearhead group list was refreshed in 2006 to take account of the new primary care trust boundaries. It covers 70 Spearhead group local authorities (which remain unchanged) and the 62 primary care trusts that map to them

Supporting People programme – A grant programme providing local housing-related support to services to help vulnerable people move into or stay independently in their homes

Tariff unbundling – Current tariffs include several stages of a procedure, for example the follow-up outpatient appointments after an operation itself. Unbundling breaks the tariff down to cover these constituent parts

Third sector – Includes the full range of non-public, non-private organisations which are non-governmental and 'value driven'; that is, motivated by the desire to further social, environmental or cultural objectives rather than to make a profit



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