



# HASCAS

**Health and Social Care Advisory  
Service (HASCAS)**

**STANDARDS FRAMEWORK FOR  
THE QUALITY OF LIFE AFTER  
STROKE PROJECT**

**A DEPARTMENT OF HEALTH FUNDED  
NATIONAL PROJECT**

June 2006



Making a positive difference



## Health and Social Care Advisory Service (HASCAS)

### STANDARDS FRAMEWORK FOR THE QUALITY OF LIFE AFTER STROKE PROJECT

#### A DEPARTMENT OF HEALTH FUNDED NATIONAL PROJECT

#### **Briefing paper**

This briefing paper presents the standards and emerging themes from the project on Quality of Life after Stroke funded by the Department of Health. The project benchmarked the quality of life experienced by people after a stroke, and has been conducted on nine sites across England, including urban and rural areas. This briefing paper both describes the content of the standards framework, and also outlines, for each standard, the themes and recommendations that have been provisionally identified as emerging from the project.

This standards framework has been prepared to focus on the care of people after a stroke, with an emphasis on practical, social and emotional well being of the individual and their carers for three years following their stroke. The individual standards cover:

- Assessment, treatment and care during the acute care episode immediately after the stroke
- The transition from acute care to rehabilitation and medium and long-term care
- Continuing medium and long-term care in the community, including involvement with carers and from other agencies

The standards are:

1. Local comprehensive strategies
2. Management and organisation of the relevant services
3. Information and communication
4. Staffing and resources
5. Primary prevention and health promotion
6. Initial assessment & investigations for stroke and transient ischaemic attacks (TIA)
7. TIA management
8. Immediate stroke management
9. Secondary prevention
10. Rehabilitation
11. Medium term care (up to six months)
12. Longer-term care
13. Support for informal carers
14. Support for paid carers
15. Clinical and service outcomes

**1. Local comprehensive strategies exist for the provision of co-ordinated and evidence-based stroke care within primary and specialist health care and social care services (including specialist stroke teams for acute and rehabilitation), in hospital, residential, ambulance services and community settings.**

1.1 There is a local comprehensive strategy for the overall co-ordination of stroke care within primary and specialist health care and social care services (including specialist stroke teams for acute and rehabilitation), in hospital, residential and ambulance services, and in community settings.

1.2 Local strategies exist for the provision of evidence-based stroke care within each element of the overall service (including any specialist stroke teams for acute and rehabilitation), in hospital, residential, ambulance services and in community settings.

1.3 There is a strategy to develop the ability of local organisations to change and to be a continuing learning organisation.

1.4 Users and carers are involved in planning local services.

1.5 Users and carers are treated with dignity and respect, and their views are taken into account.

1.6 The needs of members of ethnic minorities are taken into account, in all aspects of service planning and service delivery.

1.7 Stroke pathways identify the role of carers.

1.8 There is a strategy for recruitment and retention of staff, including contingency planning for staff shortfalls.

**The emerging themes:**

- Local overarching, multi-disciplinary, multi-agency strategies specific to Stroke Services are under developed, these should be developed to include the needs of people from black and minority ethnic groups, service users and carers in all aspects of the stroke pathway.
- Clearly defined stroke care pathways need to be developed.
- Audits of staff recruitment and retention across the entire stroke pathway and exit interviews for leavers should be routinely offered.
- Partnership work should be undertaken with all healthcare organisations to ensure the involvement of service users and carers in planning services and that participants are representative of the local population.
- Regular audits should be undertaken to assess the views of users and carers in relation to their inpatient experiences and treatment by staff and that outcomes are publicised and used to inform all staff development programmes.

## **2. Management and organisation of the relevant services**

2.1 There is a clear management structure which is known to the managers of each element of the service.

2.2 Arrangements are in place for regular effective liaison and co-ordination across all agencies and elements of the service.

2.3 Written patient referral (inclusion and exclusion) criteria exist, both early in the episode and during the care journey, and including criteria for younger adults.

2.4 Stroke services are organised so that users are treated by a specialist team (see Appendix A) for their acute care and rehabilitation.

2.5 There is evidence of written care pathways.

2.6 An appropriate range of evidence based interventions (see Appendix B) are available for the users.

2.7 Staff are aware of current relevant clinical practice guidelines and other practice protocols.

2.8 Clinical and social care are available 24 hours a day, seven days a week (including bank holidays, Christmas period).

### **The emerging themes:**

- The stroke pathway documentation and accompanying audit tool should be developed to accurately reflect the patient and carers journey throughout the whole pathway.
- There needs to be a multi-agency approach that includes the voluntary sector, to promote and operationalise the stroke pathway through practice protocols.
- A multi-agency communication mapping exercise should be undertaken to support the development and implementation of stroke pathway and to identify methods in which strategic plans can be more effectively communicated at all levels, including ground level / operational staff.
- Operational project groups should be developed within each department with communication feedback loops to the strategic planning forums in order to agree operational detail and to encourage commitment to implement policy.
- A competency based training model should be developed and then used to identify and deliver multi-disciplinary specialist stroke related training.
- Social Services should prioritise the designation of linked social workers to wards, and specifically stroke wards in order to more effectively contribute to multi-disciplinary meetings and decision making particularly in relation to discharge planning.
- Processes should be established by Social Services to ensure improved provision of information to service users and carers about Carers Assessments and Direct Payments before discharge from hospital.
- Priority should be given to increasing the Dietetic and Speech and Language resources, to more effectively manage demand and provide improved service to stroke survivors.

### **3. Information and communication**

3.1 Information about local services is available to users and carers in a range of formats appropriate to their needs and impairments.

3.2 Up to date and accurate information on relevant health and social care related issues is available to users and carers, to cover all stages of the care process.

3.3 Users and carers experience effective communication that is sensitive to their individual needs (e.g. awareness of confusion and aphasia problems).

3.4 Where there is a likelihood of a severe ongoing disability or limitation, information is discussed with carers with the prior consent of the service user where obtainable.'

3.5 Users can ask to meet with any member of staff concerned with their care, and are supported in asking questions about their care.

3.6 Effective communication networks exist between all service providers.

3.7 Written information is available in the main languages of the area served by the health and social care community.

3.8 Translators are available in all the minority languages of the area served by the health and social care community.

3.9 Users are encouraged to consent to the sharing of information with their families and carers.

3.10 Members of staff demonstrate positive attitudes when communicating with users, families and carers.

#### **The emerging themes:**

- The post of stroke coordinator should be developed to provide a conduit for information and communication across the entire stroke pathway.
- The Single Assessment Process documentation should be prioritised for implementation across the whole stroke pathway.
- Information should be more readily available to service users and carers in publicly accessible areas of the hospitals including information relating to the formats in which information can be made available.
- Interpreters should be more widely used and staff should be made aware that it is not appropriate to use carers, friends and family for this purpose because of service user confidentiality and conflicting views.
- Each ward should have a named individual responsible for co-ordinating discharge plans, as well as a visibility on the ward of their name and contact details.
- A multi-disciplinary discharge information pack should be developed for service users. This should include contact details and eligibility criteria for all relevant services and information legal rights of carers to a social care assessment and how to request this. The information pack should be personally discussed with the service user and or carer prior to discharge.
- Specific information about stroke and medication should be developed for patients and carers.



#### **4. Staffing and resources**

4.1 There are sufficient numbers of staff who are knowledgeable and well trained assessed both by range of professions and skill-mix.

4.2 There is provision for ongoing training of staff which is stroke specific.

4.3 The approach to care is active multi disciplinary team working.

4.4 There is evidence of good human resources practice, including appraisal (at least once a year) leading to professional development plans.

4.5 There is a regular review procedure to ensure there are sufficient places and resources to respond to local needs.

4.6 There are sufficient numbers of staff at night.

#### **The emerging themes:**

- Continuing personal and professional development opportunities for permanent night staff should be reviewed.
- Staffing levels at night should be reviewed
- Short term practice based project work should be commissioned from local universities to fill the knowledge and skills deficits identified by the nursing teams.
- Nursing staff should be trained to undertake therapy tasks in the absence of therapy staff in order to promote independence and more effectively utilise resources.
- Social Services need to increase the availability and range of flexible institutional care placements and community based support services such as intermediate care.
- The availability of psychological services to service users and carers needs to be increased. In many areas this is a major shortfall and alternative models of delivery should be considered such as using counsellors, CPNs and psychology support for ward staff to increase their awareness of the psychological needs of service users and carers.
- A leadership package should be developed for overseas nurses that include a clinical supervisor.
- The views and ideas of therapy staff should be shared with the whole multi-disciplinary team in order to develop a more integrated approach and shared learning between disciplines.

## **5. Primary prevention and health promotion**

5.1 Early risk identification screening is available and implemented.

5.2 Up to date and accurate information is available for the population at risk.

### **The emerging themes:**

- The TIA and stroke pathways should be regularly discussed at GP training forums.
- Referrals to the TIA clinics should be audited and outcomes fed back through the GPs training forums to increase awareness and understanding of the condition and service.
- The uptake of primary prevention of stroke services should be monitored by black and minority ethnic groups and action plans developed to address any shortfall in uptake.

## **6. Initial assessment & investigations for stroke and TIA**

6.1 Initial assessment & investigations for stroke and TIA are carried out rapidly.

6.2 A standard procedure exists and is followed for initial assessment

6.3 For older users, assessment conforms with the locally agreed Single Assessment Process (SAP).

6.4 Brain imaging is undertaken as soon as possible (within 3 hours of stroke) where local thrombolytic therapy is available.

### **The emerging themes:**

- CT scanning should be available twenty-four hour basis to reflect the philosophy that stroke is an acute and critical condition.
- The criteria for referral for Carotid Doppler tests should be audited to identify how to reduce the waiting time.
- The Single Assessment Process (SAP) needs to be fully implemented within Health and Social Care.

## **7. TIA management**

7.1 Users with TIA, and those with a stroke who have made a good immediate recovery, are assessed and investigated in a specialist service as soon as possible within seven days of the incident

7.2 Users likely to have a diagnosis of TIA are prescribed aspirin or alternative anti-platelet medication immediately.

7.3 Users with more than one TIA in a week are investigated in hospital immediately.

### **The emerging themes:**

- All referrals to the TIA clinic should be audited with the outcomes being fed back through the GPs training forum to increase awareness of the condition and service (This audit must include those people who are seen in the general elderly care clinic).
- The TIA and the stroke pathway should be regularly discussed at the GP training forums.

## **8. Immediate stroke management**

8.1 Users emotional needs are assessed alongside their medical and care assessment.

8.2 Users social needs are assessed alongside their medical and care assessment.

8.3 There is evidence that needs assessment guides the care planning processes.

8.4 An appropriate range of evidence based interventions are available for the user and are applied.

8.5 Users should undergo as much rehabilitative therapy appropriate to their needs as they are willing and able to tolerate.

8.6 Appropriate clinical assessments or measures are used to inform the user and carer about the users cognitive impairments.

8.7 Staff promote the integration and practice of skills gained in therapy into the users' daily routine.

### **The emerging themes:**

- The role and function of the Stroke Association family support workers should be reviewed to make better use of their time and provide a more equitable service.
- To prevent delayed hospital discharges, Social Services should increase the social work representation at Stroke related multi-disciplinary meetings and take a more active role in contributing to multi-disciplinary meetings, preferably via dedicated Social Work ward links.

## **9. Secondary prevention**

9.1 Individual needs assessments and care strategies include secondary prevention.

9.2 Risk factors for cerebrovascular disease (such as severe hypertension) are treated appropriately, or the patient is referred for a specialist management.

9.3 All users are given appropriate information on lifestyle factors e.g. regular exercise, diet, reducing salt intake, avoiding excess alcohol, and stopping smoking.

9.4 There is regular blood pressure monitoring.

9.5 Medication is reviewed regularly by a stroke specialist in collaboration with their GP.

### **The emerging themes:**

- An audit of secondary prevention practices for all people who are currently on the stroke register is needed.
- A stroke register needs to be established.
- Supervision and support should be offered by an experienced stroke specialist to develop the role of the family support worker in secondary prevention with a strong community focus linking into the voluntary sector.
- Specialist stroke provision should be made available to work in partnership with GPs to undertake medication reviews of stroke survivors and increase awareness of TIA and stroke.
- Specific accessible information about stroke and medication needs to be developed for patients and carers.

## **10. Rehabilitation**

10.1 A comprehensive, multidisciplinary, and user centred needs assessment is carried out.

10.2 There is evidence that needs assessment informs the care planning process.

10.3 There is goal setting with the user/carer and goals are reviewed regularly.

10.4 All users for whom rehabilitation is indicated are referred to a specialist rehabilitation team as soon as possible after admission.

10.5 An appropriate range of interventions, including psychological therapies, is available and frequency is determined by individual need (e.g. age, severity of stroke).

10.6 Users are given the opportunity to repeatedly practice functional skills and activities.

10.7 There are clear arrangements for access to later or continuing rehabilitation if required.

10.8 On discharge all users and carers are given information on how to contact their local social care services and care managers ( in order to gain information regarding benefit entitlements etc.).

### **The emerging themes:**

- Social Services need to provide information to the stroke wards and units in appropriate formats relating to carer's rights to assessment.
- Carers support workers should prominently publicise their role in GP surgeries.
- Guidelines for outpatient physiotherapy should be reviewed to ensure access for stroke patients who require on-going therapy prior to the development of a community based service.
- Service users and carers should be routinely consulted in relation to their discharge plan before it is signed off and the service user returns home. Named contacts for each service must be provided to all service users and carers verbally and in writing at a time when the information can be internalised and relevant questions answered.
- A multi-disciplinary discharge information pack should be developed for service users. This should include contact details and eligibility criteria for all relevant services. The information pack should be personally discussed with the service user and or carer prior to discharge.
- Social Services should further promote the uptake of Direct Payments and Carers Assessments through the provision of training for ward based health staff to ensure improved understanding of Direct Payments and Carers Assessments and how service users may access them.

## **11. Medium term care (up to six months)**

11.1 Users have continuing access to specialist stroke care and rehabilitation after leaving hospital.

11.2 Users have their individual psychological and support needs reviewed on a regular basis.

11.3 Users have their individual social needs reviewed on a regular basis.

11.4 Needs for special equipment at home are assessed on an individual basis, and aids, adaptations and equipment are supplied as soon as possible.

11.5 Support from specialist stroke services continues to be available if the user is in residential care.

11.6 Financial aspects of support, including use of Direct Payments, are reviewed to establish entitlement to benefits.

### **The emerging themes:**

- There should be a review of current posts within, and associated with, the stroke service with a view for an option appraisal and role development. For example; the role of the community matron should be explored to provide long term care for the more complex stroke patients; the development of a therapy consultant as a joint post across the hospital and community for specialist input into residential care; respite, intermediate care and subcontracted care; the use of therapy assistants to support long term care at home; the role of the stroke nurse specialist and practice development nurse.
- The provision of, and access to, psychology, CPNs and counselling services should be increased to provide better emotional and psychological outcomes for service users and carers.
- Consideration should be given to the development of a specialist community based stroke team, or that staff currently providing community based services to stroke survivors, including paid carers, receive specific stroke related training.
- Service users' psychological and emotional needs should be reviewed by appropriate community based services on a regular basis and services and provided appropriately to meet identified needs.
- In areas where occupational therapy remains managed by Social Services, Social Services should undertake a review of the occupational therapy service, giving consideration to the benefits of integrating this service with health, and developing closer professional links with the PCTs and occupational therapists in the Acute Trusts to work towards a more timely and seamless service.

## **12. Longer term care**

12.1 Users have continuing access to specialist stroke care after six months according to their needs.

12.2 There is access to social and vocational activities including support clubs.

12.3 There is a review, at least annually, of the continuing care needs of users and carers.

12.4 The balance of therapeutic input is reviewed to ensure therapy matches current presenting problems.

12.5 Advocacy services are available to users aged over 60 years.

### **The emerging themes:**

- The provision of day services should be reviewed to promote a philosophy of empowerment, enablement and social inclusion by forging links with other community facilities, e.g. life-long learning.
- The role of the community matron should be explored to provide long term care for the more complex stroke patients. This could develop into a specialist role.
- There should be a consultation exercise with all relevant and appropriate stakeholders, e.g. Stroke Association, Age Concern, Relate, Physical Disabilities Alliance and Mental Health Liaison, to begin to develop a community strategy for stroke services and promote a cultural shift in service design.
- An evaluation of the secondary prevention guidance should be commissioned.
- Business Plans should be developed to recommend longer term specialist follow up in the community in the most cost effective manner, e.g. by exploring the role of the specialist nurses nationally, the use of a consultant therapist/nurse, the use of mobile clinics as used for dentistry and breast screening. It may be possible to approach local universities to undertake this work as part of a research project for a higher management qualification.
- The PCT should commission an audit of secondary prevention practices for all the people who are currently on the stroke register.
- The stroke care pathway should be extended and developed to include longer term care and promote a community focus. This is a consistent message from service users and carers who feel recovery and optimum functioning, are not reached for several years after the stroke, however often services are not available to promote long term recovery.

### **13. Support for informal carers**

13.1 There is access to a stroke co-ordinator, or a named key person to enable the coordination of care.

13.2 A range of information on stroke, and on services for carers, is available, and carers are supported in understanding the information.

13.3 Carers are informed of their right to a carers assessment.

13.4 Carers (and other members of the user's immediate social network) have their individual emotional needs and support needs assessed and reviewed on a regular basis.

13.5 Carers (and other members of the user's immediate social network) have their individual social needs assessed and reviewed on a regular basis.

13.6 Visiting hours policies (where relevant) accommodate carer's needs.

13.7 Users and carers are involved in the process of proposed discharge arrangements as early as possible.

13.8 Support for carers is locally available.

13.9 Information about how to access respite care is available.

13.10 Users and carers have access to a stroke specialist (who maybe from a variety of professions).

#### **The emerging themes:**

- The support available for carers should comprise part of the core role for the family support workers regardless of where the service user is in the stroke pathway.
- Local information about resource availability (including respite care) should be developed for carers and distributed with Stroke Association information. Carers must be given the opportunity to discuss written information given with an appropriately qualified staff member.

### **14. Support for paid carers (employed either by voluntary services, social services, or NHS)**

14.1 Paid carers receive both initial and ongoing training which is specific to stroke care.

14.2 There are arrangements for regular supervision and support of paid carers.

#### **The emerging themes:**

- Specific stroke training should be provided for paid carers.
- A supervision policy should be developed and implemented to provide regular professional supervision to those involved in caring for stroke survivors in all settings. The policy should include arrangements for the provision of ongoing support of paid carers outside of formal planned supervision sessions.

## **15. Clinical and service outcomes**

15.1 The service has appropriate clinical and service governance mechanisms.

15.2 There is a framework for regular audit of the services to ensure quality and efficiency.

15.3 Users and carers are actively involved in evaluation procedures.

15.4 Relevant outcome measures are used.

15.5 The user and carer experience of medium and longer-term support is regularly evaluated (using standardised questionnaires where appropriate).

### **The emerging themes:**

- Specific stroke outcome measures need to be incorporated into the strategy development to include feedback from service users and carers.
- An audit strategy for stroke services should be developed and implemented.
- Services user and carer feedback should be gained from all areas of the service and incorporated into the stroke services clinical governance system and service development.
- Mechanisms should be developed to ensure the involvement of service users and carers in all stroke related service development and evaluation forums.

The standards have been derived from a number of sources, including:

- Standard Five (and other sections) of the *National Service Framework for Older People* (Department of Health, 2001), and sections of the *National Service Framework for Chronic Conditions* (Department of Health, 2005)
- *National Clinical Guidelines for Stroke* (Intercollegiate Stroke Working Group, 2004: and associated guidelines, such as those by National Association of Neurological Occupational Therapists guidelines)
- *It's Just Not Good Enough* (The Stroke Association, 2003).
- *Standards for Health and Social Care Services for Older People* (1999: published by Pavilion) and *Standards for Stroke Care* (2003), both produced by the Health Advisory Service
- *Stroke Units: an evidence-based approach* by P Langhorne & M Dennis (1998)
- Meetings of the Steering Group and Reference Group for this HASCAS project

## Appendix A Specialist stroke team

Effective stroke rehabilitation requires the co-ordinated skills of a wide range of professionals.

A **specialist** is defined as a healthcare professional with the necessary knowledge and skills in managing people with the problem concerned, usually evidenced by having a relevant further qualification and keeping up to date through continuing professional development.

A **specialist team or service** is defined as a group of specialists who work together regularly, managing people with a particular group of problems (for these guidelines, stroke) and who between them have the knowledge and skills to assess and resolve the majority of problems.

The precise composition and numbers for such a team will vary according to the size of the unit and its objectives. The range of staffing levels has been described in the British Association of Stroke Physicians' benchmarking survey (Rodgers *et al* 2003a). Each profession is responsible for defining the levels of expertise required.

A specialist stroke team should include staff with specialist knowledge of stroke, specifically:

- i. a consultant physician specialising in stroke medicine
- ii. nurses
- iii. a physiotherapist
- iv. an occupational therapist
- v. a speech and language therapist
- vi. a neuroradiologist
- vii. a dietitian
- viii. a clinical psychologist
- ix. a pharmacist
- x. a social worker

## Appendix B Range of Interventions

- i. Anti-thrombotic treatment
- ii. Other drug treatments for the management of specific diagnoses
- iii. Management of swallowing, feeding and nutrition
- iv. Bladder and bowel management
- v. Psychological impairment
- vi. Cognitive impairment
- vii. Communication: aphasia, dysarthria and articulatory dyspraxia
- viii. Improving motor control
- ix. Motor impairment
- x. Managing sensory impairment and pain
- xi. Drugs reducing impairment
- xii. Functional rehabilitation interventions