

Health, Wellbeing and Local Government Committee

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Inquiry into stroke services in Wales – Evidence from Consultant Clinical Psychologists

Purpose

The Health, Wellbeing and Local Government Committee has agreed to undertake an inquiry into the provision of stroke services in Wales and is calling for those with an interest or expertise in this area to submit evidence. We are asking the Committee to consider our recommendations in this paper.

Background

This paper examines the psychological consequences of stroke and the increasing recognition and evidence that clinical psychologists need to be integral members of stroke services.

Stroke is one of the leading causes of morbidity in the UK. Eleven thousand people in Wales have a stroke each year and 25% of them are under the age of 65. As well as physical and speech problems following stroke, most will have some degree of cognitive impairment like memory, language, perception and attention problems and reasoning, problem-solving, planning, organising and inhibition difficulties.

One in three have significant intellectual impairments, 30% suffer from depression and a significant minority experience personality change and behavioural problems. Research shows that abnormal mood and cognitive difficulties impede rehabilitation and prolong the adjustment process. This increases the costs of rehabilitation and impacts on long-term outcomes such as relationship breakdown, return to employment and childcare issues.

The Royal College of Physicians National Service Framework for Older People of 2008 and the National Stroke Strategy in England have recognised the importance of effective multi-disciplinary teams that include clinical psychology in the care of stroke survivors.

Access to specialist psychological services should be integral to assessment, rehabilitation and longer-term adjustment - **yet there are only three full-time psychology posts dedicated to stroke care in Wales.** These posts are located in each of the three NHS Trusts in South East Wales. Mobile or early support discharge teams rarely have any access to psychology.

Given the unequivocal impact of unidentified and untreated cognitive and emotional problems on short and long-term outcomes, as well as guidelines emphasizing that clinical psychology should be an integral part of stroke

services, it is of grave concern that psychology appears to be regarded as a 'luxury' rather than a necessity.

Clinical psychologists have the background and training to oversee the psychological needs of stroke survivors and their families from a variety of perspectives. Key contributions include:

- Assessment of mood and adjustment
- Identification of the nature and degree of cognitive impairment
- Specific interventions to improve emotional adjustment and cognitive rehabilitation
- Promotion of long term psychological adjustment
- Assessment of impact on families and their needs
- Interventions to help families and to get people back to work where possible
- Assessments of risk
- Assessments of capacity

Recommendations

The National Guidelines for Stroke (Royal College of Physicians, 2008a) have called for a significant increase in clinical psychology services for stroke survivors. There is a considerable evidence base for its effectiveness. There are a wide range of roles clinical psychologists can adopt not just within specialist stroke services but also in other services involved in preventing or managing stroke on a long-term basis:

1. Routine assessment of mood and cognition should be in place in each stroke service.
2. Psychologists are specially trained in the assessment and management of emotional, behavioural and cognitive problems for both the stroke survivor and their family. They can advise on the most appropriate means for effectively conveying information to stroke survivors and their carers.
3. Psychologists can assist with the long-term adjustment of stroke survivors, as well as having involvement in co-ordinating appropriate support to carers. They can play an important role in helping stroke survivors and carers overcome psychological barriers to participation in community life.
4. Psychologists can be involved in overcoming psychological barriers, including cognitive deficits, emotional difficulties and confidence issues that may block return to work by the person with stroke or their carer.
5. Psychologists can train other members of the stroke rehabilitation team in psychological aspects of stroke thereby contributing to holistic management of cognitive, behavioural and emotional changes after stroke and in meeting the needs of carers.
6. Psychologists are well placed to provide advice and education regarding effective strategies to change lifestyle and thus alter stroke risk.

7. All chartered psychologists have research training and are thus well placed to initiate, support and develop service audit and stroke research in their area of clinical endeavour.

The Provision of Clinical Psychology Services for Stroke Survivors and their Carers in Wales.

A recent National Sentinel Stroke Audit (2008) indicated a marked reduction in the percentage of patients receiving mood screening in Wales (from 53% in 2006 to 46% in 2008).

Mood assessed by discharge:-

Average for UK	England	Wales	Ireland
65	66	46	80

This confirms that the provision of clinical psychology services continues to lag behind provision of new stroke units because attention to psychological issues in stroke rehabilitation has not been seen as a priority. The issue was raised in the Stroke Association submission for the Inquiry into Stroke Services in Wales.

The British Psychological Society recommended that for the catchment area of an 'average' general hospital (approx 500,000), an adequate level of staffing would be two whole time equivalent qualified clinical psychologists (one of whom should be at consultancy level) and one whole time equivalent psychology assistant. There are only three full-time posts dedicated to stroke in Wales and all three are in South East Wales. Within this region there is considerable demand for psychological services but there remains large gaps and considerable inequity owing to the size of the region and the population.

A. Psychological Consequences of Stroke

(i) Impact on Cognition & Behaviour

- All patients admitted with cerebrovascular disease are at risk of cognitive loss and some cognitive loss is probably present in almost all patients (Royal College of Physicians, 2008).
- Cognitive problems are wide ranging (e.g. there are many different types of memory, attention, perceptual, language or executive problems etc. see Appendix A). Most patients with cognitive problems will have impairments in several domains.
- Cognitive impairment can lead to uninhibited or disorganised behaviour or difficulty moderating emotional expression or impulses, leading in many cases to challenging behaviour. These behavioural and cognitive changes are often the most distressing consequences of stroke for carers (Low *et al.*, 1999).
- People ask more questions about psychological matters, particularly memory and concentration than they do about medical or physical matters (Hanger *et al.*, 1998).

- It is well established that the presence of significant cognitive impairment following stroke is a predictor of poorer functional outcome (e.g. Diller, 2000; Denti *et al.*, 2007).
- Early neuropsychological screening is crucial in identifying predictors of poor functional and cognitive outcome in people with stroke (Nys *et al.*, 2005).
- In mild to moderate strokes recovery of motor and speech problems is generally better than certain types of cognitive impairments (e.g. working memory/executive functioning). In contrast, ongoing cognitive problems have major implications for emotional adjustment, functional rehabilitation and quality of life (Langer, Laatsch & Lewis, 1999). Recent research in the *Journal of Neurological and Neurosurgical Psychiatry* (2009) indicated that 70% of patients continue to experience cognitive impairments (especially executive impairments) leading to social dysfunctioning (a major dimension of quality of life) even several months after a first ever mild to moderate stroke (Hommel *et al.*, 2009).
- A consistent finding which needs to be addressed is how well information about stroke is understood and used by both patients and carers (Pain and McLellan, 1991).
- Clinical experience indicates that general stroke information may be helpful for some patients and their families but, as no two individuals have exactly the same impairment, individual assessment is frequently required with the provision of specific, tailored information and advice. This enables patients to develop improved awareness and understanding of their difficulties, helping adjustment and encouraging use of compensatory and remediation strategies.
- Evidence from general neurorehabilitation indicates that earlier neuropsychological assessment and intervention increase the likelihood that patients can be effectively supported to return to work (Johnson, 1998).
- Accurate and reliable cognitive assessment is important to indicate whether a person is likely to be safe to return to driving and can alleviate the need for an on-road assessment (McKenna *et al.*, 2004).
- Challenging behaviours such as disinhibition, anger, and aggressiveness can also occur after stroke (Aybek *et al.*, 2005; Santos *et al.*, 2006;). In the absence of specialist information a family may attempt to explain the person's behaviour in terms with which they are familiar (e.g. physical, psychological or even moralistic). This conflict within the family frequently arises from such misconceptions and the patient is deprived of opportunities for use of better management strategies (Langer, Laatsch & Lewis, 1999).
- The long-term effects of cognitive impairment are as significant, if not more so, than physical impairments in the person's efforts to re-establish family and social activities (Dijkerman *et al.*, 1996).

(ii) Impact on Emotional Adjustment

- In the majority of cases a stroke is a devastating life event and it is common for patients to experience intense and pervasive emotional or

behavioural disturbances, such as depression, anxiety and impulse control post-stroke.

- The prevalence of clinical depression following stroke is about 33% (Hackett, 2005) and research shows that abnormal mood states impede rehabilitation (Parikh *et al.*, 1990).
- Mood disorders are associated with worse outcomes in the longer term, including increased morbidity and mortality (House *et al.*, 2001).
- There has been a research focus on post stroke depression. But the impact of other mood disorders, especially anxiety, is also significant (Astrom, 1996; Gillespie, 1997).
- Emotionalism (uncontrolled crying or laughing not apparently connected to external stimuli), and changes in arousal (emotionally flat, or agitated and unsettled) are often ascribed to damage caused by a stroke. These reactions occur frequently and can be distressing for both the patient and family (Greveson *et al.*, 1991).
- In some cases emotionalism is viewed as pathological (Anderson *et al.*, 1995; House *et al.*, 2001). But changes in emotional expression can also be understood as part of an adjustment reaction to the trauma of having a stroke (Starkstein *et al.*, 1993).
- Diagnosing emotional difficulties following stroke can be a complex task (Gordon & Hibbard, 1997). There is a need for further detailed study of this area, in order to gain a better understanding and conceptual clarity. This is important as different causes may well require a different treatment approach.

(iii) Impact on Carers

- Serious psychological problems and strain are common in carers (Draper & Brocklehurst, 2007; Hann & Haley, 1999). Carers often find it most difficult to cope with changed personality and there is evidence having a full understanding of the nature of their loved ones' difficulties can help them to cope (Mant, 2001).
- Carers may adopt counterproductive approaches and become over-protective or do too much for the sufferer (Palmer & Glass, 2003) and inadvertently encourage dependency.
- Carers consistently express a wish for information, emotional support and assistance with the care-giving task (Mant *et al.*, 2000; Morris *et al.*, 2007). They frequently report that services often fail to meet their needs, and this may be even more marked for young carers and those from ethnic minority groups (Commission for Health Improvement, 2004).

(iv) Impact on Younger People with Stroke

- The risk of stroke increases markedly with age. About 21% of new strokes occur in those under 65 and at any one time about 25% of all stroke survivors are under 25 (Kersten *et al.*, 2002; Royal College of Physicians, 2008a).
- The National Stroke Guidelines (Royal College of Physicians, 2008a) acknowledge that younger stroke survivors have special, different needs and that "*Some younger adults feel that general stroke services, of which*

the majority of users are older adults, do not meet their needs”.

Psychological issues for young survivors and their carers are centred on their life-stage, with employment, childcare and marital relationships being prominent concerns (Teasell *et al.*, 2000).

B. The Role of the Clinical Psychologist

Clinical psychologists offer a flexible range of skills including assessment, psychological formulation, direct intervention, consultation, clinical supervision, and teaching. The focus of their knowledge base is on reaching a *psychological* understanding of an individual's behaviour, thoughts and feelings, and to use this explanation to guide maximally effective interventions. Clinical psychologists also possess applied research skills, with most having received research training at doctoral level. These skills equip them to participate in service development and audit.

The interventions listed below are an indication of the range of activities that have been undertaken by clinical psychologists working with stroke survivors in a variety of settings. As above, they are divided into sub-categories for clarity. Where available, references are used to refer to research that demonstrates and/or supports the effectiveness of these interventions.

(i) Identifying and Managing Stroke Related Cognitive Impairments

- The psychologist is able to provide systematic cognitive and mood screening of patients to improve discharge planning, rehabilitation treatment, and long-term outcome of people with stroke (Edwards *et al.*, 2006).
- At the acute stage many patients are not transferred for further inpatient rehabilitation. In these cases it is essential that neuropsychological screening is provided to ensure that patients are not being discharged with cognitive/behavioural impairments or emotional problems.
- Even subtle cognitive impairments can have a devastating impact on quality of life and relationships. A sub-group of patients do not have on-going language and/or physical problems and these patients are typically discharged home without inpatient rehabilitation. Psychologists have an important role to identify those patients at risk of cognitive/emotional/personality or behavioural impairments, thus encouraging early discharge whilst appropriately identifying, monitoring and intervening to promote better long-term adjustment (e.g. support with return to work, parenting or relationships).
- The earlier psychological/neuropsychological problems are identified, and specialist advice and support provided for patients and families, the better will be long-term outcomes. There are many cases to demonstrate that where this does not occur patients are re-referred in the long-term with affective disorders. Once patterns of behaviour are well established and family relationships have broken down it is much harder to intervene effectively (see Lincoln, 2005). Thus there are important cost-effective reasons for early intervention.

- Occasionally other professionals will administer simple bedside screening tools but staff generally lack the training and skills to interpret this information for the patient and family (e.g. understanding how impairments are likely to impact on everyday functioning, behaviour, relationships, return to work, childcare etc.).
- Psychologists particularly contribute to the assessment of complex cases, where a combination of impairments renders the use and interpretation of standardised assessments inappropriate and inadequate.
- Existing bedside cognitive screening tools frequently miss certain types of cognitive problem (e.g. executive dysfunction) and unidentified subtle cognitive problems can have a profound impact on long-term recovery (changes in function, personality and behaviour). Clinical psychologist/neuropsychologists have the knowledge and skills to identify the cases when this might occur and to follow up patients with further specialist assessment and intervention.
- Psychologists are able to undertake detailed assessment of memory, executive functioning, and perceptual disorders in order to inform the design of cognitive rehabilitation strategies (Wilson, 1999).

(ii) Psychosocial Adjustment and Emotional Disorders

- Psychologists play an important role in effective management of patients who present with disinhibition, anger, and aggressiveness (Goldstein, 2003).
- Depression is not an inevitable long term consequence of stroke and much can be done to help those who do have a depressive episode (Kneebone and Dunmore, 2000). Identification and discrimination between adjustment disorder, emotionalism and depression can be difficult, and requires the development of specific expertise (Kneebone and Dunmore, 2000; House et al., 2001). This is important as each person requires a different treatment.
- There is increasing evidence that psychological interventions reduce the risk of depression after stroke and that the evidence is limited on the effectiveness of pharmaceutical interventions (House *et al.*, 2001; Watkins *et al.*, 2007; Buchanan, 2009).
- Clinically, therapy may be preferred especially where there are side effects associated with medication (Diller, 2000; Kneebone & Dunmore, 2000).
- Approximately 10% of stroke patients present with post-traumatic stress. Psychologists possess the knowledge and skills to recognise the indicators of this, to train staff in recognition and design individualised approaches to help patients adjust.

(iii) Supporting Carers

- Carer needs include psychological support with adjustment to role changes, identification and treatment of depression, and the need for education regarding cognitive and other changes in their loved one.
- Carers help to maintain survivors' psychological well-being (Morris *et al.*, 1991) and better short and long-term outcomes can be achieved with early engagement and emotional support.

- Carers often find it most difficult to cope with changes in personality, and there is evidence that having a full understanding of the nature of their loved one's difficulties can help them to cope (Mant, 2001).
- The psychologist has an important role to play in the provision of education to patients, carers and staff on what to expect following a stroke. Attention to psychosocial aspects is of great importance, as evidence suggests conventional rehabilitation focusing on physical improvement and the provision of information can still leave people socially restricted and emotionally distressed (Pain & McLellan, 1990; Young & Forster, 1992).

(iv) Improving Service Delivery in Stroke

- Psychologists are an important resource in the promotion of partnership working and can be involved in establishing systems to obtain users' views about services. This information can provide feedback on services which can drive improvement.
- Psychologists' training equips them with an understanding of team dynamics and to work at an organisational level to support and enhance team functioning (Onyett, 2007). As the key to successful stroke rehabilitation is seen as the multi-disciplinary team (Royal College of Physicians 2008a), this will be invaluable in stroke services.
- Conveying information about the outcome of psychological assessment and intervention is important with stroke survivors. Additionally there are areas in which psychological information can be conveyed more generally via teaching input to, and consultation with, other members of the stroke team.
- Clinical psychologists also have an important role in relation to teaching and consultation with staff groups other than the immediate stroke team. In particular, engaging with social/community services, staff in nursing homes and residential placements where there is a need to manage behavioural difficulties. Similarly important is teaching and consultation within primary care. This is required for both long-term follow up of stroke survivors as well as working on primary preventive strategies.
- Clinical psychologists have also made an important contribution to existing research into the field of stroke.

(v) Capacity

- Where there is doubt about a person's ability to make decisions following a stroke, clinical psychologists are trained to use cognitive assessment, interview and observational data to assess decision-making capacity in the context of the Mental Capacity Act (2005). Such decisions can involve medical treatment, hospital discharge destination, and other social or financial issues.

CASE STUDY 1 - Mental Health Capacity Decision

A psychological assessment was undertaken to judge whether a patient, following a stroke, had the capacity to make the decision to return home. In

particular, did he have insight into his physical limitations and therefore recognise the need for a package of care. The situation was made more complex due to the breakdown of this patient's relationship with his wife. It was recognised that his wife was under a great deal of stress and was physically unwell herself. She actually did not want him to return home as he had been, according to his wife, increasingly verbally abusive towards her over the last few years and had expected her to carry out all aspects of their domestic life. Their son was fully supportive of his mother and agreed with her that his father should be placed in a residential setting.

The psychological involvement included a full neuropsychological assessment of the patients' cognitive abilities plus observation of the individual in functional tasks (i.e. self care skills), and in physical tasks (during physiotherapy sessions). It also involved a discussion with the patient to gain an understanding of the position from his point of view. In addition the psychologist took a holistic view of the situation and the stress that all members of the family were under. The input included psychological support and understanding for the son and his mother. In addition full recognition of the patient's rights to return home was essential. The psychologist also provided emotional support to the patient. Through these diverse interventions the psychologist provided a detailed formulation of the complex presentation.

As well as the specific clinical skills, the psychologist also provided support to team members to manage and work with such a complex presentation, through consultation, team meetings, and information sharing. The team looked to the psychologist to lead the family/goal planning meetings due to the complexity of the case.

CASE STUDY 2

This case provides an example of a younger stroke patient referred to clinical psychology two years post stroke and where there had been no psychologist in post at the time of the stroke. This illustrates the problems which can occur when patients do not receive appropriate assessment prior to hospital discharge, the lack of understanding of other professionals and families of the problems that can occur afterwards, and their potential consequences.

The patient, in her early forties, was discharged from an acute hospital with severe expressive dysphasia but no on-going physical problems. She was referred for outpatient speech and language therapy, but rarely attended these appointments. Six months later she developed epilepsy and, owing to several other health problems multiple services, agencies and professionals became involved. By the time of referral to psychology she had developed significant emotional and behavioural problems.

She was on anti-depressant medication for her mood swings. She was in a downward spiral as the antidepressants worsened the epilepsy and uncontrolled multiple seizures increased her cognitive, emotional and behavioural problems. Despite multiple health services being involved in her care, the patient was continually distressed and agitated. On a daily basis she

would be found lying on the floor screaming in distress and anger. The support from her relatives had broken down as they were unable to manage and were frustrated by her lack of recovery (unrealistic expectations). The patient depended on the care of her child. The child's mood was low, she rarely attended school or engaged with her peers. She reported waiting for the day when her mother would recover to her 'pre-stroke self'.

Psychology assessment indicated that, in addition to expressive dysphasia, the patient also had a range of cognitive impairments in the executive domain, for example, she was aware of household tasks she needed to do but lacked initiation and motivation to complete them without prompting. Her ability to retain and process verbal information was impaired and, whilst there was no evidence of perceptual impairments, there was evidence of impaired organisation and construction on visuo-spatial tasks. Working memory was poor and her ability to attend to complex auditory information, encode it and transfer it into longer-term storage was poor. Problems in these areas typically have a significant impact on a patient's ability to function (even in cases where patients have intact language and physical function). In addition to cognitive impairment, the patient was focused on her own needs and unable to consider the emotional or practical needs of her child, or show warmth or affection to her.

The patient presented with low mood and anxiety but she was not clinically depressed. She misinterpreted bodily sensations associated with anxiety as signs of an oncoming seizure and her low mood related to her inability to function at the level expected by others. Her cognitive problems had never been assessed and explained to the family. Thus their expectation was of a full recovery and they were attempting to force her to do activities of daily living for herself and her child. This only resulted in the child completing the tasks, leaving the patient feeling disempowered and unhappy. She had many abilities that were unaffected by the stroke but development of these skills to enable her to gain confidence and independence required specialist advice and intervention. Other family members had control of her finances and she was unable to make any decisions about her life.

The role of the psychologist was to provide an assessment and formulation of the patient's cognitive and emotional problems in order to guide intervention. Systemic work was required to engage all the agencies involved in her care. The psychological formulation guided the intervention plan which included education and training of staff/family on the nature of the patient's emotional and cognitive problems. A more appropriate long-term package of support for both mother and child was developed. This was aimed at re-enabling the patient to have control of her own finances and to develop her own goals with appropriate support. Anxiety management was provided but adapted to take into account the nature of her language and cognitive impairments.

Referral and liaison with child services was undertaken, as well as the psychologist engaging with the school to aid understanding and provide the necessary support for the child.

Outcome: The patient's emotional problems were resolved, her epilepsy stabilised as her mood and anxiety states improved. She was provided with more appropriate long-term support, systems and compensatory strategies to enable her to manage her own home and finances. With support she started to participate in a wide range of social activities. Her speech showed some improvement as her mood improved and anxiety decreased. She has gained in confidence and self-efficacy, and both she and her child's quality of life have significantly improved. She no longer requires the input of multiple agencies.

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Appendix A

Stroke related cognitive Impairment

Memory

- Lincoln and Tyson (1989) found that 49% of cases were impaired on memory tests at 7 months after stroke and reports of forgetfulness in everyday life were common.
- Different forms of memory impairment occur: the inability to lay down new memories, difficulty or inability in retrieving old (or new) memories, trouble remembering faces or names (without any evidence of dysphasia), or difficulty in one modality, e.g. verbal or visual memory with relative intactness of the other.
- Hanger *et al.* (1998) confirmed that mild to moderate forgetfulness was common late after stroke and could arise from a variety of underlying cognitive impairments.

Language

- Difficulty producing or understanding speech (expressive or receptive aphasia, dysphasia) are the most obvious problems in mental functioning and are present in up to one third of cases at 1 month after stroke (Wade *et al.*, 1986).
- Difficulty understanding written text, understanding number (dyslexia, agraphia).
- Higher order disturbances of language (high level dysphasia).

Perception

- Visual inattention (neglect) is an inability to attend to visual stimuli in one side of the visual environment. Estimates of incidence vary widely between 8% and 90% of sub-acute cases (Bowen & Lincoln, 2007).
- Intervention can be effective (Bowen & Lincoln, 2007; Riggs *et al.*, 2007).
- Inattention can also be present in other sensory modalities (e.g. hearing and touch).

- Hemianopia, involving loss of perception of one half of the visual field, is common and should be assessed as there is some evidence that intervention for this can be effective (Riggs *et al.*, 2007).
- Additional perceptual problems include lack of ability to orient in space (left/right or up/down discrimination), awareness of position of limbs (proprioception), and inability to identify objects (visual agnosia).

Attention can include impairments of sustained, selective, switching or divided attention (Robertson *et al.*, 1994; Stuss *et al.*, 1989).

- Cognitive rehabilitation techniques can be effective in managing problems with attention (Robertson, 1999).

Controlling action (apraxia)

- Difficulty in thinking about movement (apraxia) may be present in 40% of cases within a month of stroke and leads to clumsiness on dexterity tasks (Sunderland *et al.*, 1999). Problems in spatial awareness and in sustaining attention may also affect control of movement. As yet, there is currently mixed support as to the effectiveness of specific therapeutic interventions for motor apraxia after stroke (Cicerone *et al.*, 2005; West *et al.*, 2008)

Executive functioning

- The 'dysexecutive syndrome' refers to difficulties with planning, organising, problem-solving, initiating, adapting and monitoring behaviour.
- Impairment can lead to disinhibited or disorganised behaviour, or difficulty moderating emotional expression or impulses.
- Clinically significant executive dysfunction is a frequent consequence of stroke, and is associated with dementia and disability (Pohjasvaara *et al.*, 2002).

Psychology Concise Guide for Stroke 2008

This concise guide contains recommendations extracted from the *National Clinical Guideline for Stroke*, 3rd edition¹, which contains over 300 recommendations covering almost every aspect of stroke management.

The recommendations selected for this concise guide have direct implications for psychologists and psychiatrists. However, the psychological sequelae of stroke affect all aspects of stroke management and life after stroke and many of these recommendations are relevant to all service providers.

Recommendations are given below with their number, so that they can be found in the main guideline.

This concise guide was compiled by Audrey Bowen and Peter Knapp, representing the British Psychological Society, and psychology working party members Jane Barton, David Gillespie, Janet Cockburn and Andrew Bateman.

Specialist stroke services (3.2.1)

B All patients not suitable for transfer home after completion of their acute diagnosis and treatment should be treated in a specialist stroke rehabilitation unit which should fulfil the following criteria:

- it should have a co-ordinated multidisciplinary team that meets at least once a week for the interchange of information about individual patients;
- the staff should have specialist expertise in stroke and rehabilitation;
- educational programmes and information are provided for staff, patients and carers.

C All patients discharged home directly after acute treatment but with residual problems should be followed up by specialist stroke rehabilitation services.

Resources (3.3.1)

B Each stroke rehabilitation unit and service should be organised as a single team of staff with specialist knowledge and experience of stroke and neurological rehabilitation including:

- clinical psychologists.

Stroke services for younger adults (3.5.1)

A Younger adults who have had a stroke should be managed within specialist medical and rehabilitation services that:

- recognise and manage the particular physical, psychological and social needs of younger patients with stroke (e.g. vocational rehabilitation, child care activities).

Transfers of care – discharge from hospital (3.7.1)

G All patients should continue to have access to specialist stroke services after leaving hospital, and should know how to make contact.

Goal-setting (3.11.1)

Every patient involved in the rehabilitation process should:

- B** participate in the process of setting goals unless they choose not to or are unable to participate because of the severity of their cognitive and linguistic impairments;
- C** be given help to understand the nature and process of goal setting, and be given help (e.g. using established tools) to define and articulate their personal goals;
- D** have goals that:
 - are meaningful and relevant to the patient;
 - are challenging but achievable;
 - include both short-term (days/weeks) and long-term (weeks/months) targets;
 - include both single clinicians and also the whole team;
 - are documented, with specified, time-bound measurable outcomes;
 - have achievement evaluated using goal attainment;
 - include family members where appropriate;
 - are used to guide and inform therapy and treatment.

Use of assessments/measures (3.10.1)

A stroke rehabilitation service should:

- D** train all staff in the recognition and management of emotional, communicative and cognitive problems.

Rehabilitation treatment approach (3.12.1)

All members of a stroke service should:

- A** use an agreed consistent approach for each problem faced by a patient, ensuring the patient is given the same advice and taught the same technique to ameliorate or overcome it;
- B** give as much opportunity as possible for a patient to practise repeatedly and in different settings any tasks or activities that are affected.

End-of-life (palliative) care (3.14.1)

- A** Teams providing care for patients after stroke should be taught how to recognise patients who might benefit from palliative care.
- B** All staff caring for people dying with a stroke should be trained in the principles and practice of palliative care.
- C** All patients who are dying should have access to specialist palliative care expertise when needed.

Self-efficacy training (6.13.1)

- A** All patients should be offered training in self-management skills, to include active problem-solving and individual goal-setting.
- B** Any patient whose recovery appears delayed or limited should be assessed for changes in self-identity, self-esteem and self-efficacy (as well as changes in mood; see 6.25).
- C** Any patient with significant changes in self-esteem, self-efficacy or identity should be offered additional (to A) interventions that may reduce these impairments such as motivational interviewing and positive therapeutic feedback.

Depression (6.25.1)

- A** Every patient entering rehabilitation should be screened for depression using a validated simple screening test (e.g. asking 'Do you feel depressed?' or the GHQ-12 or PHQ-9 questionnaire). In addition:
 - mood should also be assessed at later times, especially after stopping active rehabilitation or if depression is suspected;
 - screening tests such as 'smiley faces' or observational criteria alone should not be relied upon as the sole means of initial diagnosis;
 - questionnaires may be simplified to a yes/no format for people with communication difficulties;

- the patient's past should be investigated for any history of mood disturbance.

- B** In people with aphasia and other impairments complicating assessment of mood, careful observations over time (including response to a trial of antidepressant medication if considered necessary) should be used.
- C** Any patient with depressed mood should be provided with appropriate information and advice.
- D** Any patient who has depression sufficient to cause distress and/or to impede rehabilitation should be assessed clinically for further treatment by an expert (e.g. clinical psychologist, appropriately trained stroke physician, psychiatrist).
- E** Any patient considered to have depression should be screened for anxiety and emotionalism.
- F** Patients with minor depression should be monitored for progression and worsening and should be especially involved in one or more of:
 - increased social interaction;
 - increased exercise;
 - goal setting;
 - other psychosocial interventions (e.g. using voluntary sector resources).
- G** Patients whose depression is more severe or persistent should be offered one or more of:
 - antidepressant drug treatment;
 - psychological therapy given by an appropriately trained and supervised practitioner;
 - interventions to reduce any contributory factors such as pain and social isolation (e.g. attending voluntary sector stroke groups).
- H** Antidepressant treatment should:
 - not be used routinely to prevent depression developing or to improve other outcomes;
 - be monitored, and continued for at least six months if a benefit is achieved.

Anxiety (6.26.1)

- A** Every patient entering the rehabilitation phase should be screened for anxiety, usually simply by asking about the patient's concerns or by asking family members.
- B** Any patient with anxiety should have the cause(s) established, and should be provided with appropriate information and advice.
- C** Any patient whose anxiety is impeding their

recovery and rehabilitation or causing distress should be:

- assessed and considered for psychological treatment, for example desensitisation or cognitive behavioural therapy;
- be screened for emotionalism and depression.

Emotionalism (6.27.1)

- A** Any patient who cries or laughs in unexpected situations or who is upset by their fluctuating emotional state should be assessed by a specialist able to diagnose emotionalism.
- B** Patients with severe, persistent or troublesome tearfulness (emotionalism) should be given antidepressant drug treatment, monitoring the frequency of crying to check effectiveness.

Cognitive impairments – general (6.28.1)

- A** Every patient seen after a stroke or transient ischaemic episode should be considered to have at least some cognitive losses in the early phase.
- Routine screening should be limited to detecting more severe levels of cognitive impairment using simple standardised measures (e.g. mini-mental state examination or short orientation–memory–concentration test).
- B** Any patient not progressing as expected in rehabilitation should have a more detailed cognitive assessment to determine whether cognitive losses are causing specific problems or hindering progress.
- C** The patient's cognitive status should be taken into account by all members of the multidisciplinary team when planning and delivering treatment.
- D** Planning for discharge from hospital should include an assessment of any safety risks from persisting cognitive impairments.
- E** People returning to cognitively demanding activities (e.g. some work, driving) should have their cognition assessed formally prior to returning to the activity.

Attention and concentration (6.29.1)

- A** Any person after stroke who appears easily distracted or unable to concentrate should have their abilities to focus, sustain and divide their attention formally assessed.
- B** Any person with impaired attention should have cognitive demands reduced through:

- having shorter treatment sessions;
- taking planned rests;
- reducing background distractions;
- avoiding work when tired.

C Any person with impaired attention should:

- be taught strategies to compensate for reduced attention;
- receive repeated practice of activities they are learning.

Memory (6.30.1)

- A** Patients who complain of marked memory impairment and patients clinically considered to have difficulty in learning and remembering should have their memory assessed formally using a standardised measure such as the Rivermead Behavioural Memory Test.
- B** Any patient found to have memory impairment causing difficulties in rehabilitation or undertaking activities should:
- be assessed medically to check that there is not another treatable cause or contributing factor (e.g. hypothyroidism);
 - have their profile of impaired and preserved memory abilities determined;
 - have their nursing and therapy sessions altered to use techniques which capitalise on preserved abilities;
 - be taught compensatory techniques to reduce their disabilities, such as using notebooks, diaries, audiotapes and electronic organisers and audio alarms;
 - be taught approaches aimed at directly improving their memory;
 - have therapy delivered in an environment that is as like the usual environment for that patient as possible.

Spatial awareness, e.g. neglect (6.31.1)

- A** Any patient with a stroke affecting the right hemisphere should be considered at risk of reduced awareness on the left, and should be tested formally if this is suspected clinically.
- B** Any patient with suspected or actual impairment of spatial awareness should have their profile of impaired and preserved abilities evaluated using a standardised test battery such as the Behavioural Inattention Test. The diagnosis should not be excluded on the basis of a single test.

- C** Any patient shown to have impaired attention to one side should be:
- given cues to draw attention to the affected side during therapy and nursing procedures;
 - monitored to ensure that they do not eat too little through missing food on one side;
 - given a trial of visual scanning training;
 - given trials of mental imagery training, structured feedback or using prisms if the unawareness is severe and persistent.

Perception – visual agnosia (6.32.1)

- A** Any person who appears to have difficulty in recognising people or objects should be assessed formally for visual agnosia.
- B** Any person found to have agnosia should:
- have the impairment explained to them, their family and their treating team;
 - be taught strategies to compensate for the specific agnosia(s) as far as possible.

Apraxia (6.33.1)

- A** Any person who has difficulties in executing tasks despite apparently adequate limb movement should be assessed formally for the presence of apraxia.
- B** Any person found to have apraxia should:
- have their profile of impaired and preserved action abilities determined as part of their assessment after their stroke using a standardised approach such as the Naturalistic Action Test or the Apraxia Test;
 - be given therapies and/or taught compensatory strategies specific to the deficits identified;
 - have the impairment explained to them, their family, and their treating team.

Executive functioning (6.34.1)

- A** Any person who appears to have adequate skills to perform complex activities but who fails to organise the tasks needed should be formally assessed for the dysexecutive syndrome, for example, using the Behavioural Assessment of the Dysexecutive Syndrome (BADS).
- B** Any person with an executive disorder and activity limitation should be taught compensatory techniques (e.g. use of electronic organisers or pagers, or use of written checklists).

- C** When a patient's activities are affected by an executive disorder, the nature and effects of the impairment and ways of supporting and helping the patient should be discussed with others involved (e.g. family, staff).

Mental capacity, decision making by the patient (6.35.1)

- B** The patient's mental capacity should specifically be considered and documented when they are being asked to agree to a procedure that involves significant risk, noting that judgements on capacity must relate to the specific decision being made.
- C** In cases of doubt the clinician should determine that the answer to all four of the questions below is positive before concluding that the patient has competence:
- Does the patient understand the information relevant to the decision?
 - Has the patient retained the information relevant to the decision?
 - Can the patient use, or weigh up the information when making a decision?
 - Can the patient communicate their decision by some reliable means?
- D** In patients where the answer to one or more of the above questions is negative or uncertain:
- all attempts should be made to overcome the lack of capacity (e.g. asking a speech therapist to help with communication);
 - a second opinion should be sought if there is doubt or if assistance is needed.
- H** The capacity of the patient to make decisions should be reviewed at an appropriate interval which will be dependent upon the clinical situation.

Reference

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