



The
British
Psychological
Society

Division of Neuropsychology
Division of Clinical Psychology

Psychological Services for Stroke Survivors and their Families

Briefing Paper 19

January 2010 revision

Contents

Foreword to this revision	1
Foreword to the original paper	1
Executive Summary	2
Introduction to this Briefing Paper:.....	3
Key stroke facts.....	3
Outlining the need for provision of clinical psychology services for stroke survivors and their carers.....	4
Psychological aspects of stroke.....	4
Psychological input to stroke services in the UK.....	8
The cost effectiveness of psychological services in stroke	9
Outlining the roles that clinical psychologists can adopt within stroke services and the effectiveness of such services	10
The role clinical psychology can play in specialist stroke services.....	10
Young people with stroke	13
The National Stroke Strategy.....	16
Recommended service structure for psychological services to stroke	18
Service specifications	18
Service organisation.....	18
Service standards	18
Staffing levels.....	18
Mechanism for monitoring quality and outcome.....	21
References	22
Appendix A.....	31

If you have problems reading this document and would like it in a different format, please contact us with your specific requirements.

Tel: 0116 252 9523; E-mail: P4P@bps.org.uk.

Price: DoN and DCP members, £3.75; Non-members, £5.00.

ISBN: 978-1-85433-701-6

Printed and published by the British Psychological Society.

© The British Psychological Society 2009.

The British Psychological Society

St Andrews House, 48 Princess Road East, Leicester LE1 7DR, UK

Telephone: 0116 254 9568 Facsimile 0116 227 1314

E-mail: mail@bps.org.uk Website: www.bps.org.uk

Incorporated by Royal Charter Registered Charity No 229642

Foreword to this revision

‘A lot of the recovery from stroke takes place in your mind, and we need information and also help with stress. It’s good to see that something is being done to acknowledge this, and we are not left adrift and unsupported psychologically.’

Stroke Survivor, 2009.

‘As a carer for a stroke survivor who, after 18 months, still has residual cognitive problems, I feel that is good to ‘know what is out there psychologically’ for future survivors and carers, and of course ourselves. Rehabilitation tends to concentrate more on the physical side of recovery with psychological therapy rather on ‘the back burner’. It is encouraging to know that this is being addressed.’

Carer, 2009.

Acknowledgments – revision

This revision was drafted by Ian Kneebone, Reg Morris and Jamie Macniven with support from Sophie Dewar and Katy Lee. Members of OPSYRIS (Organisation for Psychological Research into Stroke) provided comments that shaped the final document.

Foreword to the original paper

‘We greet this document with positive enthusiasm as the psychological effects of stroke, and in particular the cognitive changes, are far too often ignored.’

Donal O’Kelly, Director, Different Strokes, 2002.

‘Good to see this topic tackled as it is very much an area that receives little attention and is potentially a great problem to the NHS and Social Services. I was also pleased to see that consideration has been given to the carers and family.’

Eoin Redahan, Director of Public Relations, the Stroke Association, 2002.

Acknowledgements – original paper

We would like to thank the significant number of individuals who have made substantive contributions to this final paper. Particular acknowledgement is due to Nadina Lincoln, Mary O’Reilly and Alan Sunderland, who initiated the process with a first draft in 1999. The contributions of Irene Aggus, Jonathan Evans, Peter Knapp, Ian Kneebone, Catherine McDonagh, and Brenda McLackland were also important to the final shape and scope of the paper. The final co-ordination of this paper was undertaken by Mary O’Reilly.

Executive Summary

Stroke is one of the leading causes of morbidity in the UK, with over 100,000 people experiencing a stroke each year. These patients occupy 20 per cent of all acute hospital beds and 25 per cent of all longer-term beds. In addition to the physical problems following stroke, at least 35 per cent of patients will have cognitive impairment, 30 per cent will suffer from depression at some point post-stroke, and a significant minority will develop challenging behaviours. Such difficulties impede rehabilitation and prolong the adjustment process that increases the costs of rehabilitation to already stretched services.

It is now well established that organised stroke care reduces mortality and can improve functional outcome. There is also a need to engage the family in the rehabilitation process as there is a proven link between level of family involvement and successful rehabilitation. The National Service Framework for Older People and the National Stroke Strategy for England recognise that the complexity of stroke is such that it requires treatment and care by a multidisciplinary team. A psychological perspective is important in assessment, rehabilitation and longer-term adjustment in stroke. Drawing upon a variety of different perspectives, clinical psychology training develops a unique combination of skills that underpins psychological care of stroke survivors and their families. In addition to direct assessment and treatment, the skills of the clinical psychologist also enables them to support the work of teams and to contribute to research, service development and training.

Key contributions made by psychologists in the field of stroke rehabilitation are as follows:

- Assessment of mood and adjustment;
- Identification of the nature and degree of cognitive impairment;
- Specific interventions to promote emotional adjustment and cognitive rehabilitation;
- Promotion of long-term psychological adjustment;
- Assessment of impact on family and their needs;
- Family interventions;
- Dissemination of psychological skills/understanding of stroke issues;
- Contributions to service development, team working and to research.

The mixture of clinical and consultancy skills indicated above dictate a primary post at Consultant Grade (band 8c/8d). For the catchment area of an 'average' general hospital (approximately 500,000) an adequate level of staffing would be two whole time equivalent qualified clinical psychologists and one assistant clinical psychologist.

This paper looks at the need for the provision of clinical psychology services for stroke survivors and their families/carers. It examines the evidence base for the effectiveness of psychological assessment and interventions and describes the roles clinical psychologists can adopt not just within specialist stroke services but also in other services that are involved in preventing or managing stroke on a long-term basis. Recommendations are made for service specifications, structure, and staffing with the key recommendation being that psychological screening for both cognitive impairment and mood disorder should become routine within all hospitals admitting stroke patients.

Psychologists can be involved in devising health promotion strategies and other interventions to alter health-related behaviours to prevent a first-time stroke, however, as this paper concentrates on services to stroke survivors and their families these roles are not considered in detail here.

Introduction to this Briefing Paper

This briefing paper is intended for use by clinical psychology service managers and commissioners of stroke services, in both health and social care. It has four main aims:

1. To brief service managers on the broader provision of stroke services, and to place psychological aspects firmly within this context.
2. To outline the psychological consequences of stroke and review the evidence base for psychological approaches to intervention.
3. To provide information on the role and function of clinical psychologists and clinical neuropsychologists in the provision of services to stroke survivors and their family.
4. To offer recommendations as to how clinical psychology input may be structured within specialist stroke services.

Key stroke facts

- Every year approximately 110,000 people in England and Wales have a stroke.
- 25 per cent of strokes occur in people under the age of 65.
- 20 to 30 per cent of people who have a stroke die within a month.
- There are 900,000 people living in England who have had a stroke.
- Stroke is the single largest cause of adult disability.
- 300,000 people in England live with moderate to severe disability as a result of stroke.
- People from certain ethnic minorities are at higher risk of stroke

Outlining the need for provision of clinical psychology services for stroke survivors and their carers

Psychological aspects of stroke

The current paper examines the psychological aspects of stroke from six different perspectives; cognitive impairment, psychological adjustment, mood disorders, the needs of carers stroke service delivery and the special circumstances of younger people with stroke. Whilst such a division is helpful for the current discussion, there may of course be more than one psychological aspect involved in any one stroke survivor's rehabilitation.

1. Stroke-related cognitive impairments

- All patients with cerebrovascular disease are at risk of cognitive loss and some cognitive loss is probably present in almost all patients (Royal College of Physicians, 2008a).
- At the acute stage, a majority of stroke victims are disorientated and confused (Wade, 1994), but over the first few days this confusion typically resolves to leave more selective residual cognitive problems. Although cognitive impairments may partially recover over the first six months post-stroke, permanent residual difficulties are common.
- At least 35 per cent of stroke survivors have significant cognitive impairment (Tatemichi et al., 1994). This figure has been identified as considerably higher in acute settings in some studies (e.g. Macniven et al., 2005). Nys et al. (2007) found that 74 per cent of patients with a cortical stroke, 46 per cent with a subcortical stroke and 43 per cent with an infratentorial stroke demonstrated acute cognitive impairment.
- These cognitive problems can include difficulties with memory, language, perception, attention, controlling action (apraxia) and executive tasks such as reasoning, planning, organising and inhibition (see Appendix A).
- It is well established that the presence of significant cognitive impairment early after stroke is a predictor of poorer long-term functional outcome (e.g. Denti et al., 2007, Diller, 2000, Galski et al., 1993; Robertson et al., 1997). However, people with post-stroke cognitive impairment do benefit from rehabilitation and should be given the same access to acute rehabilitation services as stroke patients who are cognitively intact (Rabadi et al., 2008).
- Early cognitive assessment can be helpful in tailoring rehabilitation advice, and reducing strain in carers (Lincoln, 2005). It also is crucial in identifying predictors of poor long-term cognitive and functional outcome in people with stroke (Nys et al., 2005; Paolucci et al., 1996).
- Systematic cognitive screening is critical in identifying subtle neuropsychological impairments that might otherwise remain undetected (Edwards et al., 2006). Accurate identification of these impairments is likely to improve discharge planning, rehabilitation treatment, and long-term outcome of people with stroke.
- Cognitive impairment can lead to disinhibition or disorganised behaviour, or difficulty moderating emotional expression or impulses. These emotional,

behavioural and cognitive changes are often the most distressing consequences of stroke for carers and may not be evident in the pre-discharge phase unless specialist psychological screening is undertaken (Low et al., 1999).

- Over time, people may ask more questions about psychological matters, particularly memory and concentration, than they do about medical/physical matters (Hanger et al., 1998).
- There is evidence of slowing in rehabilitation when there are attentional problems (e.g. Robertson et al., 1997). Early identification of attentional problems can therefore be helpful in setting realistic expectations.
- Accurate and reliable cognitive assessment using a brief cognitive screening measure (e.g. Stroke Drivers Screening Assessment; Nouri & Lincoln, 1992) can indicate whether a person is likely to be safe to return to driving following their stroke (Nouri & Lincoln, 1993; McKenna et al., 2004).

2. Reaction to physical illness and disability

- The changes in an individual's life and relationships after stroke usually follow a known process of adjustment (Alvarez, 1997).
- A significant number of individuals, who may be either the stroke survivor or a family member, do not adjust to the changes. This can be considered an adjustment disorder, defined as 'clinically significant emotional or behavioural reactions (e.g. upset, anger, sadness, bad dreams, grief, avoidance, reliving the event) which do not resolve within three to six months of the onset of an event' (American Psychiatric Association, 1994).
- Alternative ways of understanding adjustment utilise psychosocial approaches and include the use of attachment theory or family therapy models.
- Psychological variables such as how an individual copes can affect stroke outcome (e.g. Elmståhl et al., 1996; Johnston et al., 2004).
- Pain can be a significant problem for up to 32 per cent of patients after stroke (Jonsson et al., 2005).
- Fatigue can occur in up to 68 per cent of stroke survivors (Ingles et al., 1999) and is a major concern (Staub & Bogousslavsky, 2001).

3. Mood disorders

'It is difficult not to be depressed when your life has been fundamentally changed for the worse.'

Anonymous Service User Comment.

- Intense and pervasive emotional or behavioural disturbances, such as depression, anxiety, and impulse control difficulties can occur post-stroke.

Depression

- The prevalence of depression following stroke is around 33 per cent (Hackett et al, 2005).
- Research has indicated that abnormal mood impedes rehabilitation (Parikh et al., 1990).
- Diagnosis of depression can be a complex task following stroke (Gordon & Hibbard, 1997) though a range of screening instruments is available to aid identification (Bennett & Lincoln, 2006).

- There has been a research focus on post-stroke depression. However, the impact of other emotional disorders, particularly anxiety, is also significant (Astrom, 1996; Bishop & Pet, 1995; Forster & Young, 1995; Gillespie, 1997).

Emotionalism

- Emotionalism or emotional lability (usually experienced as uncontrolled crying or less usually laughter in the context of minimal provocation) can occur after stroke.
- Some authors view emotionalism after stroke as pathological (Andersen et al., 1995; House et al., 2001a).
- Such reactions occur frequently and can be distressing for both the patient and family (Greveson et al., 1991).

4. Needs of carers

'Difficulty coping with the changed personality and understanding the problem the ... [person] ... is trying to express and cope with.'

'I'm just struggling to live. Because I'm not free, I can't go out anywhere, I can't go to have a holiday.'

Carers' views

- Over a third of stroke survivors depend on support from family carers to enable them to live in the community. About two-thirds of main carers are spouses and around one-fifth offspring (Wilkinson et al., 1997), but caring is often shared by members of a family.
- Family carers promote successful rehabilitation (Glass et al., 1993; Palmer & Glass, 2003) and involvement of carers in treatment is a characteristic of effective stroke services (Stroke Unit Trialists' Collaboration, 2007)
- Carers help to maintain survivors' psychological well-being (Morris et al., 1991) and greatly reduce the economic impact of stroke on health and social services (Hirst, 2002).
- Serious psychological problems and strain are common in carers (Carnwath & Johnson, 1987; Draper & Brocklehurst, 2007; Hann & Haley, 1999; Low et al., 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 (Greveson & James, 1991; Mant, 2001).
- Carers may adopt counterproductive approaches and become over-protective (Kinsella & Duffy, 1980) 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 (Franks & Stephens, 1992; Hanger et al., 1998; Mant et al., 2000; Morris et al., 2007). Many carers experience major loss of activities and independence (Hunt & Smith, 2004; Kerr & Smith, 2001) and carers require measures to help them maintain their own health, obtain respite from caring responsibilities and to have activities in their life other than caring (Department of Health, 2000).
- Carers 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).

- A number of positive benefits can emerge from care giving. Personal growth, acceptance and satisfaction can be experienced (Sawatzky et al., 2003).

5. Stroke service delivery

‘... my husband couldn’t get any information even when I’d been in a week or 10 days, still couldn’t get anybody to speak to who either would say anything or could say anything ...’

Stroke survivor

‘... there’s no real information or after-care with stroke people. Once you leave hospital, you’re on your own I’m afraid. Well that’s how it seems.’

Carers view

- Lack of information makes it hard to make good decisions. Not having enough information about stroke, stroke treatments and stroke services is an almost universal experience of stroke patients and their carers (Bakas et al., 2002; Morris et al., 2007; Smagt-Duijnsteet et al., 2000). People who have had strokes some years ago and their carers may be especially lacking in information about stroke and available services (Hare et al., 2006).
- Participation in decision-making increases sense of agency and control and can promote satisfaction, well-being and physical health (Kunzmann et al., 2002; Rodin, 1986).
- Studies of stroke patients (Healthcare Commission, 2005; Kelson et al., 1998; Scholte op Reimer et al., 1996; Stroke Association, 2001; Tyson & Turner, 1999) typically report high overall levels of satisfaction with inpatient care, especially when provided in specialist stroke units (Healthcare Commission, 2005). Nonetheless a substantial proportion of patients are dissatisfied with at least one aspect of hospital care and many have unmet needs (Scholte op Reimer et al., 1999).
- Experiences with community care are also generally positive, but users report fewer positive experiences with community care than with hospital care (Healthcare Commission, 2006). Problem areas include; lack of information, especially about available services, lack of involvement in decision-making, reduced access to therapies, lack of emotional and psychological support and insufficient help with everyday activities.

6. Young people with stroke

Although risk of stroke increases markedly with age, about 21 per cent of new strokes occur in under 65s, and at any one time about 25 per cent of all stroke survivors are under 65 (Kersten et al., 2002; Royal College of Physicians, 2008a). Strokes in younger people are more often haemorrhagic than strokes in older people that are more often caused by clots (Gandolfo & Conti, 2003). Several hundred children in the UK suffer strokes each year, but because of their special circumstances children are not treated in specialist stroke care pathways, but in paediatric neurology services which have the necessary expertise and links with other children’s services (Royal College of Physicians, 2004). The National Stroke Guidelines (Royal College of Physicians, 2008a) acknowledge that younger stroke survivors have special, different 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). Some find the incongruity of having an ‘old

person's' condition difficult to accept, and many find that stroke services are overly focussed on older people and do not meet their particular needs (Kersten, et al., 2002; Low et al., 2003; Banks & Pearson, 2000)

Psychological input to stroke services in the UK

'Stroke has a major impact on people's lives ... It is the biggest cause of severe disability and ... [a] ... common cause of death in the UK and other developed countries. A substantial proportion of health and social care resources are devoted to the immediate and continuing care of people who have had a stroke.'

National Service Framework for Older People, 5.1, p.61, Department of Health [DoH] (2001).

Stroke is a complex condition that affects many aspects of life; physical, emotional, cognitive personality and relationships. Psychologists have unique skills that enable them to work with stroke survivors and their carers and to engage with staff and services (Division of Clinical Psychology, 2007):

- Broad knowledge base;
- Ability to conduct and review research;
- Range of approaches/modalities;
- Skills in supervision;
- Ability to deal with complex presentations;
- Ability to work with teams, supporting service and organisational development;
- Ability to offer oversight and 'umbrella'/consultancy.

The National Service Framework for Older People (Department of Health, 2001) recommends that specialist stroke services should be developed at every general hospital, that these services be multi-professional, and importantly that clinical psychologists should be members of the services (standard 5). However, while access to stroke units has improved the latest reviews of practice, have found that only a third of these stroke units have access to clinical psychology services (Royal College of Physicians, 2008b). In this context it is perhaps unsurprising that that only a little over half of patients (55 per cent) are having their mood screened (Royal College of Physicians, 2007) in line with national guidelines (Royal College of Physicians, 2008a). These results suggest that the provision of clinical psychology services has lagged behind the provision of new stroke units, and attention to psychological issues in stroke rehabilitation is inadequate. The National Guidelines for Stroke (Royal College of Physicians, 2008a) have called for a considerable increase in clinical psychology services for stroke survivors.

The cost effectiveness of psychological services in stroke

- The life-time costs of care are significant, and seem to be incurred disproportionately by a small number of people with severe disability (Department of Health, 1996; Diller, 2000). It is logical to argue that the provision of effective rehabilitation for people who are severely affected will be cost effective.
- Evidence suggests those with poor prognosis (the elderly with major deficits) benefit just as much from the co-ordinated care provided by stroke units as younger stroke survivors (Kalra & Eade, 1995; Stroke Unit Trialists Collaboration, 2007).
- 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).
- Mood disorders are associated with worse outcomes in the longer term, including increased morbidity and mortality (House et al., 2001; Pohjasvaara et al., 2001).
- Ashburn (1997) estimated that each 'un-rehabilitated' stroke patient cost society £64,000 more over the course of a lifetime compared to a rehabilitated patient.
- The most structured and complete integrated care continuum from hyper-acute admission, through rehabilitation to community/home care provider demonstrates the best outcome results and is the most cost-effective stroke rehabilitation approach (van Exel et al., 2005). Psychological support must, therefore, be available to patients at all stages of the stroke pathway.

Outlining the roles that clinical psychologists can adopt within stroke services and the effectiveness of such services

The role clinical psychology can play in specialist stroke services

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 a doctoral level. These skills equip them well to participate in service development and audit.

Many clinical psychologists working in the area of stroke will also possess further specialist knowledge and training in clinical neuropsychology (e.g. the Practitioner Full Membership Qualification (PFMQ) of the British Psychological Society Division of Neuropsychology). This is a necessity for psychologists undertaking detailed neuropsychological assessment in stroke rehabilitation settings.

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.

Identifying and managing stroke-related cognitive impairments

- Developing and recommending screening assessments (e.g. Kitching, 2000), as well as offering advice on the use of these to other professional staff.
- Undertaking detailed assessment of memory, executive functioning, and perceptual disorders as indicated from screening measures in order to inform the design of cognitive rehabilitation strategies (Wilson, 1999).
- Developing in-depth assessment measures (e.g. Burgess & Shallice, 1997; Wilson et al., 1996).
- Where there is doubt about a person's ability to make their own 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) and the Adults with Incapacity (Scotland) Act (2000) (British Psychological Society, 2006). Such decisions can involve medical treatment, hospital discharge destination, and other social or financial issues.
- Some occupational therapists develop expertise in the area of cognitive screening assessment; inter-professional liaison is essential so that there is clarity in areas of relative expertise and role demarcation. Detailed cognitive assessment should only be undertaken by clinical psychologists/neuropsychologists with the appropriate level of training, expertise and clinical supervision.
- It is usual to seek a specialist Speech and Language Therapy assessment of aphasia and other communication difficulties.

- Clinical psychologists can particularly contribute to the assessment of complex cases, where a combination of impairments renders the use and interpretation of standardised assessments inappropriate and inadequate.
- Feeding back the outcome and implications of cognitive difficulties to stroke survivors and their families.
- Cognitive rehabilitation, in particular neuropsychological rehabilitation in functional tasks, can help people with stroke adjust to, and compensate for cognitive impairment, thus minimising disability (Lincoln, 2005; Manly, 2002; Robertson et al., 2002; Wilson, 1999).
- Evidence of the effectiveness of direct re-training of lost abilities is limited. However, there is some research that suggests that suggests certain approaches that target memory and executive disorders can be very effective (e.g. Wilson et al., 1994; Wilson et al., 2001; Evans, 2001). There are Cochrane Review updates on psychological interventions for attention (Lincoln et al., 2000), memory (Nair & Lincoln, 2007), and unilateral spatial neglect (Bowen & Lincoln, 2007; Manly, 2002). A significant amount of evidence supports cognitive-linguistic therapies for people with language deficits after stroke and visuospatial rehabilitation for deficits associated with visual neglect (Cicerone et al., 2005). The support for training to reduce apraxia is mixed (Cicerone et al., 2005; West et al., 2008).
- 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). It is, therefore, essential those with identified cognitive difficulties be followed up. The cost of not following up people can be severe, both from a psychosocial and a lifetime health costs perspective.
- Assessing cognitive abilities in relation to fitness to drive (McKenna et al., 2004; Nouri & Lincoln, 1993).
- For stroke survivors who do not receive hospital treatment, or those who are discharged ahead of time to early supported discharge schemes, a similar range of inputs should be available as those that are receiving hospital care. This is particularly important when screening for cognitive changes, as the presence of obvious motor impairment or very severe cognitive changes usually precipitate hospitalisation. Thus those who do not seek admission may have less obvious but debilitating cognitive changes. There is a role for the clinical psychologist in educating primary care workers and developing screening methods for staff to use.

Improving psychosocial adjustment following stroke

- Promoting awareness of the wide range of normal reactions to stroke.
- Identifying people at risk of developing an adjustment disorder (Burvill et al., 1995) and those with coping strategies which may need to be reviewed (Morrison et al., 2000).
- Education of patients, carers, and long-term care staff on what to expect following a stroke. Attention to psychosocial aspects is of great importance, as evidence suggests that 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).
- A consistent finding which needs to be addressed is how well information about stroke is understood and used by both patients and carers (Pain & McLellan, 1990).

- Groups for patients and carers, where the key benefits for attendees are the opportunity to share experiences and find mutual support and decreased isolation are also important (Sutherland et al., 2000).
- Challenging behaviours such as disinhibition, anger, and aggressiveness can also occur after stroke (Aybek et al., 2005; Bogousslavsky, 2003; Kim et al., 2002; Santos et al., 2006) and may be managed by specialist psychological interventions (Goldstein, 2003).

Identifying and helping those with mood disorders, pain and fatigue

- Multi-modal assessment using clinical interview, mood rating scales, and interview of staff and relatives.
- Identification and discrimination between adjustment disorder, emotionalism and depression can be difficult, and requires the development of specific psychological expertise (House et al., 2001; Kneebone & Dunmore, 2000).
- While it remains a research opportunity for psychological treatments to be proven specifically within a stroke population (Hackett et al., 2008), it has been suggested much can be done to help those who do have a depressive episode (Kneebone & Dunmore, 2000). National Institute of Clinical Excellence (NICE) guidance indicates that in general psychological therapies are highly effective for psychological difficulties such as depression and are the treatment people choose for mild to moderate difficulties (NICE, 2004). Such therapies are recommended post-stroke by the latest guidelines (Royal College of Physicians, 2008a).
- A recent randomised controlled trial by Watkins et al. (2007) found that motivational interviewing, '*a patient-centred counselling technique*' (p.1), led to improvement in patients' mood at three-month post-stroke follow-up. This benefit was significant over the 'usual stroke care' control group.
- Clinically, psychological therapy may be preferred especially where there are side effects associated with medication (Diller, 2000; Kneebone & Dunmore, 2000).
- Approximately 10 per cent of stroke patients show post-traumatic anxiety in response to their stroke event and its aftermath. There is little published research into interventions for post-stroke anxiety. However, psychologists possess the knowledge and skills to recognise the signs of anxiety, train staff in recognition, and to design individualised interventions to help patients adjust.
- Goal setting has been used with anxious patients to good effect (McGrath & Adams, 1999).
- Fear of falling post-stroke can predict loss of mobility and mortality (Forster & Young, 1995). Psychological interventions that primarily focus on managing anxiety show promise in reducing fear of falling (Childs & Kneebone, 2002; van Haastregt et al., 2007).
- It is vital that patients returning to the community have access to clinical experts (e.g. clinical psychologists) who are able to assess post-stroke mood disturbance. This is necessary both to monitor people after discharge as well as to diagnose newly arising mood disturbance that is not uncommon (Royal College of Physicians, 2008a).
- Post-stroke pain may be able to be reduced via psychological intervention as has pain of other aetiology (Morley et al., 1999)

- Fatigue management after stroke might also benefit from incorporating psychological interventions. Cognitive behaviour therapy has been found useful for fatigue symptoms in other conditions (Gielissen et al., 2006; Price et al., 2008).

Supporting carers

- A variety of programmatic interventions have been used with carers; caregiver training; education and counselling; social problem solving partnerships via telephone; nurse-led post-discharge support and peer support delivered either to groups or individuals. There is evidence for modest benefit from these programmes (Brereton et al., 2007; Heugten et al., 2006; Visser-Meily et al., 2005). Cognitive behaviour therapy may also reduce distress and empower carers to cope (Wilz & Barskova, 2007). Carer groups can be helpful for mutual support, information exchange and to reduce isolation (Sutherland et al., 2000).
- Long-term support, for the stroke patient and their carers is important. A key role for clinical psychologists with the co-ordinator of stroke care is to ensure that ongoing or newly developed psychological needs are addressed appropriately. This may include the psychologist maintaining some ongoing input, with the stroke survivor and/or their carer.

Young people with stroke

- Psychological therapies have not been specifically designed for younger stroke survivors and their carers, but the key to meeting their special psychological needs is a focus on the special issues faced by this group (e.g. employment, childcare, marital relationships) and the way that stroke-related disabilities impinge on these areas.
- Psychologists may need to work with teams that are accustomed to treating older people and help them respond flexibly to these special needs.
- Psychologists may need to use their networking skills and knowledge of organisations to develop links that are not normally associated with stroke care; child support and welfare agencies, marital counselling, employers and human resources departments, job centres and employment rehabilitation providers.
- Peer support is a promising approach that has been little used in stroke, but it features in several places in the national stroke strategy proposals (Department of Health, 2007). It has potential to benefit young (and older) stroke survivors and their carers both as participants (Stewart et al., 1998; Dennis, 2003) and later on as volunteer providers (Pillemer et al., 1996; Mowbray et al., 1996).

Improving service delivery in stroke

- Information giving is a key issue in stroke care. Ensuring that patients and carers have sufficient information involves more than merely giving out leaflets, and has to consider individual factors such as ability to assimilate, understand and retain information, expectations and assumptions and psychological reactions such as 'denial' and 'rationalisation'. Education about stroke, preferably including individualised information, is one way to increase knowledge and satisfaction (Palmer & Glass, 2003; Viesser-Meily et al., 2005) and can be a role for the psychologist.

- 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 that 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 can 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. This too is a key role for the clinical psychologist. Such education can cover topics such as cognitive changes following stroke, key issues in post-stroke adjustment, the ways in which a person with depression might react, behavioural difficulties and effective management techniques.
- Clinical psychologists also have an important role in relation to teaching and consultation with staff groups other than the immediate stroke team. In particular, staff in nursing homes and residential placements where there is a need to manage behavioural difficulties experienced by residents. 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. There may be a need to consider other forms of psychological support for front line staff. For example, clinical supervision may be appropriate for some. Table 2 offers a summary of the different levels of work that it would be appropriate for clinical psychologists to offer, in line with the service model suggested by the National Stroke Strategy.

Research and development

- Clinical psychologists have an important contribution to make to the field of stroke research; most areas would benefit from study using a psychological perspective. Table 1 lists the most relevant for investigation.

Table 1: Research and Development: Clinical Psychology and Stroke.

<ul style="list-style-type: none"> ● Knowledge of effects of stroke 	<ul style="list-style-type: none"> ● Longitudinal epidemiological study of natural history of cognitive and mood disorders following stroke. ● The natural history of adjustment to stroke, and exploring whether there are factors predictive of difficulties in adjustment. ● Effects of pre-morbid personality, social/cultural factors and religious beliefs on eventual outcome following stroke. ● Teasing out the relative contributions of brain impairment, adjustment reactions and mood disorder in post-stroke emotionalism. ● Further examination of links between cognitive impairment and outcome, and effectiveness of cognitive/neuropsychological rehabilitation in improving outcome.
<ul style="list-style-type: none"> ● Developing screening tools 	<ul style="list-style-type: none"> ● Evaluating relative strengths of existing cognitive screening tools. ● Screening for depression/anxiety in those with aphasia and or other stroke-related cognitive impairment.
<ul style="list-style-type: none"> ● Evaluation of services 	<ul style="list-style-type: none"> ● Develop referral pathways for those needing psychological assessment/intervention. ● Relative effectiveness of expert psychological input as integral part of rehabilitation team ('holistic', 'bio-psycho-social' model), compared to psychological training and support of members of a primarily physical rehabilitation team, with referral protocols to separate mental health services (mind/body split). ● Cost effectiveness studies/unpacking 'the black box' of rehabilitation. ● Optimal methods to allow regular consideration of service users views of service provision.
<ul style="list-style-type: none"> ● Evaluation of interventions 	<ul style="list-style-type: none"> ● Effectiveness of different model-based interventions for depression and anxiety. ● Evaluation of effectiveness of cognitive rehabilitation. ● Evaluating the benefits of family therapy for families living with a person severely disabled by stroke. ● Evaluating the effectiveness of psycho-educational and support groups for stroke survivors and for carers. ● Identification of the best means by which to convey information to survivors and carers. ● Effectiveness of psychological interventions in the management of pain and fatigue after stroke.

The National Stroke Strategy

The recent National Stroke Strategy (Department of Health, 2007) provides a framework designed to improve the quality of stroke services. It provides a number of quality markers with respect to stroke, with several being highly relevant to psychological services. Given the importance of this document in the future development of stroke services, the potential contribution of clinical psychologists is outlined below with respect to the quality markers relevant to psychological services:

QM 2: Managing risk

'Those at risk of stroke and those who have had a stroke are assessed for and given information about risk factors and lifestyle management issues (exercise, smoking, diet, weight, and alcohol), and are advised and supported in possible strategies to modify their lifestyle and risk factors.'

Psychologists are well placed to provide advice and education regarding effective strategies to change lifestyle and thus alter stroke risk.

QM 3: Information advice and support

'People who have had a stroke and their relatives and carers have access to practical advice, emotional support, advocacy and information throughout the care pathway and lifelong.'

Psychologists are specially trained to assist in the management of emotional, behavioural and cognitive problems and such intervention can be vital following a stroke for both the stroke survivor and their family. They can also advise on the most appropriate means for effectively conveying information to stroke survivors and their carers.

QM 8: Assessment

'Patients with suspected acute stroke receive an immediate structured clinical assessment from the right people.'

'Patients diagnosed with stroke receive early multi-disciplinary assessment – to include...identification of cognitive and perceptible problems.'

Psychologists, as part of the multi-disciplinary team, can be involved in the identification and management of cognitive, behavioural and emotional changes after stroke.

QM 9: Treatment

'All stroke patients have prompt access to an acute stroke unit and spend the majority of their time at hospital in a stroke unit with high quality stroke specialist care.'

Psychologists can play an important role in high quality specialist stroke teams by contributing to management of cognitive, behavioural and emotional changes after stroke, as well as co-ordinating appropriate support to carers. They can also support initiatives to enhance team functioning.

QM 10: High quality specialist rehabilitation

'People who have had a stroke access high quality rehabilitation and, with their carer, receive support from stroke skilled services as soon as possible after they have had a stroke, available in hospital and immediately after transfer from hospital and for as long as they need it.'

Psychologists can be an important part of high quality specialist stroke teams contributing to management of cognitive, behavioural and emotional changes after stroke, and co-ordinating appropriate support to carers.

QM 11: End-of-life care

'People who are not likely to recover from their stroke receive care at the end of their lives which takes account of their needs and choices, and is delivered by a workforce with appropriate skills and experiences in all care settings.'

Psychologists can be involved in the delivery of high quality palliative care by assisting in the management of cognitive, behavioural, and emotional changes, and end of life concerns of both the stroke survivor and those that care for them.

QM 13: Long-term care and support

'A range of services are in place and easily accessible to support the individual long-term needs of individuals and their carers.'

Psychologists can be an important in assisting the long-term adjustment of those with stroke survivors and their carers by contributing to management of cognitive, behavioural and emotional changes after stroke and co-ordinating appropriate support to carers.

QM15: Participation in community life

'People who have had a stroke and their carers are enabled to live a full life in the community.'

Psychologists can be involved in overcoming psychological barriers to participation in community life.

QM 16: Return to work

'People who have had a stroke and their carers are enabled to participate in paid, supported and voluntary employment.'

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.

QM 18: Leadership and skills

'All people with stroke or at risk of stroke receive care from staff with the skills, competence and experience to meet their needs.'

Psychologists can train other members of the stroke rehabilitation team in psychological aspects of stroke to thereby contributing to holistic management of cognitive, behavioural and emotional changes after stroke and in meeting the needs of carers.

QM 20: Research and audit

'All trusts participate in quality research and audit and make evidence for practice available.'

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.

Recommended service structure for psychological services to stroke

Service specifications

The National Stroke Strategy outlines a service model that addresses four stages:

1. Prevention;
 2. First contact;
 3. Treatment and rehabilitation;
 4. Long-term support and review.
- Clinical psychology input is appropriate at each of the four stages identified (see Table 2).
 - Local priorities will determine how this national strategy is translated into practice.
 - In specifying the focus and domain of clinical psychology services three guidelines drawn from Diller (2000) are particularly important:
 - *All patients should be screened for signs of psychological problems (clinical consensus).*
 - *Cognitive deficits require a treatment plan (strong clinical consensus).*
 - *Depression should be identified and treated (scientific evidence) and the symptoms and cause of depression should guide treatment.*

We recommend that a system to ensure routine assessment of mood and cognition be in place in each stroke service.

Service organisation

- The preferred local organisation of clinical psychology input should be developed with due consideration of the ‘medical emergency’ aspect of stroke, and also with regard to the provision of services that extend beyond the short-term hospital-based inputs.
- The service will usually be provided by or under the auspices of the local older adult or neuropsychology service. Consistent with Government policy, age barriers to referral should be avoided (Department of Health, 2001).

Service standards

Earlier briefing papers on purchasing clinical psychology services for older people, their families and other carers (Division of Clinical Psychology, 2006) and for people with acquired neurological disorders and their carers (Division of Clinical Psychology, 1995) have been published. These set out appropriate care philosophy and standards .

Staffing levels

For the catchment area of an ‘average’ general hospital (approximately 500,000), an adequate level of staffing would be two whole time equivalent qualified clinical psychologists and one whole time equivalent psychology assistant.

Table 2: Summary of possible roles for clinical psychology in stroke services at all levels of the National Stroke Strategy.

Prevention stage	Within primary care based service	Within neurovascular clinics
	<ul style="list-style-type: none"> ● Maximise behavioural (lifestyle) changes, exercise, dietary changes, weight reduction, smoking cessation, adherence to blood pressure medication. ● Health psychology designing interventions and evaluating the effectiveness of these. 	<ul style="list-style-type: none"> ● Lifestyle changes as primary care. ● Assessing and managing anxiety in attenders. ● Improving adherence to medication regimes (secondary prevention).
First contact	Primary or secondary care setting	
	<ul style="list-style-type: none"> ● Working systemically. 	<ul style="list-style-type: none"> ● Develop communication and information giving skills within the staff team. ● Thus ensuring that the information needs of both the patient and their families are met. ● And ensuring support of front-line staff.

Continued

Table 2: Summary of possible roles for clinical psychology in stroke services at all levels of the National Stroke Strategy (continued).

<p style="text-align: center;">Treatment and rehabilitation</p>	<p style="text-align: center;">Within the hospital specialist stroke team/community rehabilitation/intermediate care services/older adult services</p> <p>As an integral part of the specialist stroke team:</p> <ul style="list-style-type: none"> ● Ensure the regular monitoring of mood; ● Identify cognitive impairment and functional sequelae; ● Further detailed assessment of those with cognitive impairment; ● Develop rehabilitation interventions to manage cognitive impairment; ● Implementation of rehabilitation interventions with other team members; ● Assessment of those screened as probably depressed; ● Recommendation of a treatment plan and undertake this if indicated; ● Work with family members; ● Systemic working, to develop communication and information giving skills within team; ● Consultation; ● Input to service organisation and delivery; ● Overseeing psychological aspects of care; ● Assessment of complex cases.
<p style="text-align: center;">Long-term support and review</p>	<p style="text-align: center;">Primary or intermediate care</p> <p style="text-align: center;">Liaison with social services as required</p> <p style="text-align: center;">Services for the stroke patient and their carers</p> <p style="text-align: center;">Liaison with the stroke care co-ordinator</p> <ul style="list-style-type: none"> ● Overseeing psychological aspects of care, ensuring that identified psychological needs are addressed appropriately across the entire patient pathway (i.e. from time of stroke and at all stages thereafter: in hyperacute, acute and longer-term rehabilitation, community services, home, residential and/or nursing home/palliative care settings as appropriate). ● This may include the psychologist maintaining some ongoing longer-term input, with the stroke survivor and/or their carer. ● Alternatively, it may take the form of briefing other direct care staff at primary or intermediate care level, on the nature of the individuals' difficulties and strategies to help the situation. ● Some clinical supervision of front-line staff is appropriate in complex and ongoing casework.

- At least one of these posts would be in addition to the provision recommended for older adult services of ‘two whole time equivalent for services to geriatric medicine’ (Division of Clinical Psychology, 1995, p.11). This is because increasingly hospital services are moving away from ‘geriatric’ provision towards ‘integrated medicine’ with no effective age barrier to service access.
- Similarly, the recommendations for staffing in neuropsychology services refer to younger adults. Local neuropsychology services will need to assess to what extent their existing provision for younger adults is taken up by stroke survivors, and may wish to liaise with older adult services on the impact that removing age barriers to services might have on their staffing needs.
- The exact configuration and responsibilities of these posts would be for local determination. Job descriptions would be developed and reviewed in line with good management practice, taking account of a range of considerations. These would include the above service model, the balance between hospital or community services, the need for secretarial and administrative support, mechanisms for supervision, opportunities for continuing professional development and involvement in programmes of clinical research. A comprehensive listing of general considerations are outlined in guidance on workforce planning (Paxton & D’Netto, 2001).
- The person specification for any NHS level 8c (Consultant) grade post would put specialist expertise in clinical neuropsychology as essential; level 7 to 8b grade posts would have this expertise as desirable.
- In larger clinical psychology services, one stroke post could be rotational training post, of approximately one year’s duration.

Mechanism for monitoring quality and outcome

- Regular clinical supervision, for all grades of staff.
- Engagement in audit programmes.
- Production of an annual report of activity.
- Clear lines of accountability and responsibility, both within the psychology service and within the multi-professional team.

The reader is again referred to the relevant British Psychological Society briefing papers (Division of Clinical Psychology, 1995, 2006) for further elaboration of appropriate targets for monitoring quality and outcome.

References

- Alvarez, M.F. (1997). Using REBT and supportive psychotherapy with stroke patients. *Journal of Rational-Emotive and Cognitive Behaviour Therapy*, 15, 231–245.
- American Psychiatric Association (1994). *Diagnostic and Statistical Manual of Mental Disorders* (4th ed.). Washington, DC: American Psychiatric Press.
- Andersen, G., Vestergard, K. & Ingeman-Neilsen M. (1995). Post-stroke pathological crying: Frequency and correlation to depression. *European Journal of Neurology*, 2, 45–50.
- Ashburn, A. (1997). Physical recovery following stroke. *Physiotherapy*, 83, 480–490.
- Astrom, M. (1996). Generalised anxiety disorder in stroke patients: A three-year longitudinal study. *Stroke*, 27, 270–275.
- Aybek, S., Carota, A., Ghika-Schmid, F., Berney, A., Melle, G.V. Guex, P. et al. (2005). Emotional behaviour in acute stroke: The Lausanne emotion in stroke study. *Cognitive & Behavioural Neurology*, 18, 37–44.
- Bakas, T., Austin, J.K., Okonkwo, K.F., Lewis, R.R. & Chadwick, L. (2002). Needs, concerns, strategies, and advice of stroke caregivers the first six months after discharge. *Journal of Neuroscience Nursing*, 34, 242–251.
- Banks, P. & Pearson, C. (2000). *Improving services for younger stroke survivors and their families*. Edinburgh: Chest Heart and Stroke, Scotland.
- Bennett, H.E. & Lincoln, N.B. (2006). Potential screening measures for depression and anxiety after stroke. *International Journal of Therapy and Rehabilitation*, 13, 401–406.
- Bishop, D.S. & Pet, R. (1995). Psychobehavioural problems other than depression in stroke. *Topics in Stroke Rehabilitation*, 2, 56–68.
- Bougousslavsky, J. (2003). Emotions, mood and behavior after stroke. *Stroke*, 34, 1046.
- Bowen A. & Lincoln N.B. (2007). Cognitive rehabilitation for spatial neglect following stroke. *Cochrane Database of Systematic Reviews*, April 18(2): CD003586.
- Brereton L., Carroll, C. & Barnston S. (2007). Interventions for adult family carers of people who have had a stroke: A systematic review. *Clinical Rehabilitation*, 21, 867–884.
- British Psychological Society (2006). *Assessment of capacity in adults: Interim guidance for psychologists*. Leicester: British Psychological Society.
- Burgess, P. W. & Shallice, T. (1997). *The Hayling and Brixton Tests*. Bury St Edmunds: Thames Valley Test Company.
- Burvill, P.W., Johnson, G.A., Jamrozik, K.D., Anderson, C.S., Stewart-Wynne, E.G. & Chakera, T.M.H. (1995). Prevalence of depression after stroke: The Perth community stroke study. *British Journal of Psychiatry*, 66, 320–327.
- Carnwath T.C. & Johnson D.A. (1987). Psychiatric morbidity among spouses of patients with stroke. *British Medical Journal*, 294, 409–411.

- Childs, L. & Kneebone, I.I. (2002). Falls, fear of falling and psychological management. *British Journal of Therapy and Rehabilitation*, 9, 225–231.
- Cicerone, K. D., Dahlberg, C., Malec, J. F., Langenbahn, D. M., Felicetti, T., Kneipp, S., et al. (2005). Evidence-based cognitive rehabilitation: Updated review of the literature from 1998 through 2002. *Archives of Physical Medicine and Rehabilitation*, 86, 1681–1692.
- Commission for Health Improvement (2004). *Unpacking the patient's perspective: Variations in NHS patient experience in England*. London: Author.
- Dennis, C.L. (2003). Peer support within a health care context: A concept analysis. *International Journal of Nursing Studies*, 40, 321–332.
- Denti, L., Agosti, M. & Francheschini, M. (2007). Outcome predictors of rehabilitation for first stroke in the elderly. *European Journal of Physical and Rehabilitation Medicine*, 44, 3–11.
- Department of Health (1996). *Burdens of disease: A discussion document*. London: Department of Health.
- Department of Health (2000). *Quality standards for local carer support services*. Retrieved 13 September 2001 from: www.carers.gov.uk/qualitystan.htm.
- Department of Health (2001). *National Service Framework for Older People*. London: Author.
- Department of Health (2006). *Our health, our care our say: A new direction for community services*. Norwich: The Stationery Office.
- Department of Health (2007). *National stroke strategy*. London: Author.
- Dijkerman, H.C, Wood, V.A. & Hewer, R.L. (1996). Long-term outcome after discharge from a stroke rehabilitation unit. *Journal of the Royal College of Physicians of London*, 30, 538–546.
- Diller, L. (2000). Post-stroke rehabilitation practice guidelines. In A.L. Christensen & B.P. Uzzell (Eds.), *International handbook of neuropsychological rehabilitation* (pp.167–182). New York: Kluwer Academic/Plenum Publishers.
- Division of Clinical Psychology (1995). *Purchasing clinical psychology services: Services for people with acquired neurological disorders and their carers. Briefing Paper No. 9*. Leicester: British Psychological Society.
- Division of Clinical Psychology (2006). *Purchasing clinical psychology services: Services for older people, their families and other carers. Briefing paper No. 5*. Leicester: British Psychological Society.
- Division of Clinical Psychology (2007). *Marketing strategy for clinical psychologists*. Leicester: British Psychological Society.
- Draper, P. & Brocklehurst, H. (2007). The impact of stroke on the well-being of the patient's spouse: An exploratory study. *Journal of Clinical Nursing*, 16, 264–271.
- Edwards, D.F., Hahn, M.G., Baum, C.M., Perlmutter, M.S., Sheedy, C. & Dromerick, A.W. (2006). Screening patients with stroke for rehabilitation needs: Validation of the post-stroke rehabilitation guidelines. *Neurorehabilitation and Neural Repair*, 20, 42–48.

- Elmståhl, S., Sommera, M. & Hagberg, B. (1996). A three-year follow-up of stroke patients: Relationships between activities of daily living and personality characteristics. *Archives of Gerontology and Geriatrics*, 22, 233–244.
- Evans, J.J. (2001). Rehabilitation of the dysexecutive syndrome. In R.L. Wood & T. McMillan (Eds.), *Neurobehavioural disability and social handicap* (pp.209–227). London: Psychology Press.
- Forster, A. & Young, J. (1995). Incidence and consequences of falls due to stroke. *British Medical Journal*, 311, 83–86.
- Franks, M.M. & Stephens, M.A.P. (1992). Multiple roles of middle-generation care givers: Contextual effects and psychological mechanisms. *Journal of Gerontology and Psychological Sciences*, 47, S123–129.
- Galski, T., Bruno, R.L., Zorowitz, R. & Walker, J. (1993). Predicting length of stay, functional outcome, and after-care in the rehabilitation of stroke patients: The dominant role of higher-order cognition. *Stroke*, 24, 1794–1800.
- Gandolfo, C. & Conti, M. (2003). Stroke in young adults: Epidemiology. *Neurological Science*, 24, Suppl 1, S1–3.
- Gielissen, M.F.M., Verhagen, S., Witjes, F. & Bleijenbergh, G. (2006). Effects of cognitive behaviour therapy in severely fatigued disease-free cancer patients compared with patients waiting for cognitive behaviour therapy: A randomised controlled trial. *Journal of Clinical Oncology*, 24, 4882–4887.
- Gillespie, D.C. (1997). Post-stroke anxiety and its relationship to coping and stage of recovery. *Psychological Reports*, 80, 1059–1064.
- Glass, T.A., Matchar, D.B., Belyea, M. & Feussner, J.R. (1993). Impact of social support on outcome in first stroke. *Stroke*, 24, 64–70.
- Goldstein, L.H. (2003). Behaviour problems. In R. Greenwood, M. Barnes, T.M. McMillan & C.D. Ward (Eds.), *Handbook of neurological rehabilitation* (2nd ed., pp.419–432). Hove: Erlbaum, Taylor and Francis.
- Gordon, W.A. & Hibbard, M.R. (1997). Post-stroke depression: An examination of the literature. *Archives of Physical Medicine and Rehabilitation*, 78, 658–663.
- Greveson, G.C., Grey, C.S., French, J.M. & James, O.F.W. (1991). Long-term outcome for patients and carers following hospital admission for stroke. *Age and Ageing*, 20, 337–344.
- Greveson, G. & James, O. (1991). Improving long-term outcome after stroke – the views of patients and carers. *Health Trends*, 23, 161–162.
- Hackett, M.L., Anderson, C.S., House A. & Xia, J. (2008). Interventions for treating depression after stroke. *Cochrane Database of Systematic Reviews*, July 16(3): CD003689.
- Hackett, M.L., Yapa, C., Parag, V. & Anderson, C.S. (2005). Frequency of depression after stroke: A systematic review of observational studies. *Stroke*, 36, 1330.
- Hare, R., Rogers, H., Lester, H., McManus, R.J. & Mant, J. (2006). What do stroke patients and their carers want from community services? *Family Practice*, 23(1), 131–136.

- Hann, B. & Haley, W.E. (1999). Family care giving for patients with stroke. Review and analysis. *Stroke*, *30*, 1478–1485.
- Hanger, H.C., Walker, G., Paterson, L.A., McBride, S. & Sainsbury, R. (1998). What do patients and their carers want to know about stroke? A two-year follow-up study. *Clinical Rehabilitation*, *12*, 45–52.
- Healthcare Commission (2005). *Survey of Patients 2005: Stroke*. London: Author.
- Healthcare Commission (2006). *Survey of Patients 2006. Caring for people after they have had a stroke: A follow-up survey of patients*. London: Author.
- Hirst, M. (2002). Transitions to informal care in Great Britain during the 1990s. *Journal of Epidemiological Community Health*, *56*, 579–587.
- House, A., Knapp, P., Bamford, J. & Vail, A. (2001). Mortality at 12 and 24 months after stroke may be associated with depressive symptoms at one month. *Stroke*, *32*, 696–701.
- House, A., Hackett, M.L. & Anderson, C.S. (2001). Effects of antidepressants and psychological therapies for reducing the emotional impact of stroke. *Proceedings of the Royal College of Physicians of Edinburgh*, *31*, Supplement 8, 50–60.
- Hunt, D. & Smith, J.A. (2004). The personal experience of carers of stroke survivors: An interpretative phenomenological analysis. *Disability and Rehabilitation*, *26*, 1000–1011.
- Ingles, J., Eskes, G. & Phillips, S. (1999). Fatigue after stroke. *Archives of Physical Medicine and Rehabilitation*, *80*, 173–178.
- Johnston, M., Pollard, B., Morrison, V. & MacWalter, R. (2004). Functional limitations and survival following stroke: Psychological and clinical predictors of three-year outcome. *International Journal of Behavioural Medicine*, *11*, 187–196.
- Jonsson, A.C., Lindegren, I., Hallstrok, B., Norriving, B. & Lindegren, A. (2005). Prevalence and intensity of pain after stroke: A population-based study focusing on patients' perspectives. *Journal of Neurology, Neurosurgery and Psychiatry*, *77*, 590–595.
- Kalra, L. & Eade, J. (1995). Role of stroke rehabilitation in managing severe disability after stroke. *Stroke*, *26*, 2031–2034.
- Kelson, M., Ford, C. & Rigge, M. (1998). *Stroke rehabilitation: Patient and carer views. A report by the College of Health for the Intercollegiate Working Party for Stroke*. London: Royal College of Physicians.
- Kerr, S.M. & Smith, L.N. (2001). Stroke: An exploration of the experience of informal care giving. *Clinical Rehabilitation*, *15*, 428–436.
- Kersten, P., Low, J.T.S., Ashburn, A., George, S.L. & McLellan, D.L. (2002). The unmet needs of young people who have had a stroke: Results of a national survey. *Disability and Rehabilitation*, *24*, 860–866.
- Kim, J.S., Choi, S., Kwon, S.U. & Seo, Y.S. (2002). Inability to control anger or aggression after stroke. *Neurology*, *58*, 1106–1108.
- Kinsella G.J. & Duffy F.D. (1980). Attitudes toward disability expressed by spouses of stroke patients. *Scandinavian Journal of Rehabilitative Medicine*, *12*, 73–76.

- Kitching, N. (2000). *Developing a neuropsychological assessment battery on an inpatient stroke rehabilitation unit*. Poster presented at The Royal College of Physicians of Edinburgh Consensus Conference on Stroke Treatment and Service Delivery, Edinburgh, November.
- Kneebone, I. & Dunmore, E. (2000). Psychological management of post-stroke depression. *British Journal of Clinical Psychology*, *39*, 53–66.
- Kunzmann, U., Little, T. & Smith, J. (2002). Perceiving control: A double-edged sword in old age. *Journal of Gerontology*, *57B*, 484–491.
- Lincoln, N. (2005). Outcome of cognitive rehabilitation in clinical stroke services. In P.W. Halligan & D.T. Wade (Eds.), *Effectiveness of rehabilitation for cognitive deficits*. Oxford: Oxford University Press.
- Lincoln, N. & Tyson, D.J. (1989). The relation between subjective and objective memory impairment after stroke. *British Journal of Clinical Psychology*, *28*, 61–65.
- Lincoln, N., Majid, M.J. & Weyman, N. (2000). Cognitive rehabilitation for attention deficits following stroke. *Cochrane Database of Systematic Reviews*, (4), CD002842.
- Low, J.T.S., Payne, S. & Roderick, P. (1999). The impact of stroke on informal carers: A literature review. *Social Science and Medicine*, *49*, 711–725.
- Low, J.T.S., Kersten, P., Ashburn, A., George, S. & McLellan, D.L. (2003). A study to evaluate the unmet needs of members belonging to a young stroke groups affiliated with the stroke association. *Disability and Rehabilitation*, *25*, 1052–1056.
- Macniven, J.A.B., McKeown, A.C., Chambers, H.M. & Lincoln, N.B. (2005). Identifying cognitive impairment and emotional distress in people admitted to stroke rehabilitation. *International Journal of Therapy and Rehabilitation*, *12*, 258–263.
- Manly, T. (2002). Cognitive rehabilitation for unilateral neglect: Review. *Neuropsychological Rehabilitation*, *12*, 289–310.
- Mant, J., Carter, J., Wade, D.T. & Winner, S. (2000). Family support for stroke: A randomised controlled trial. *The Lancet*, *356*, 808–813.
- Mant, J. (2001). Overview of the evidence for stroke family care workers. *Proceedings of the Royal College of Physicians of Edinburgh*, *31*, Supplement 8, 44–49.
- McGrath, J. & Adams, L. (1999). Patient-centred goal planning: A systemic psychological therapy? *Topics on Stroke Rehabilitation*, *6*, 43–50.
- McKenna, P., Jeffries, L., Dobson, A. & Frude, N. (2004). The use of a cognitive battery to predict who will fail an on-road driving test. *British Journal of Clinical Psychology*, *43*, 325–336.
- Mowbray, C.T., Moxley, D.P., Thrasher S., Bybee D., McCrohan N., Harris S. & Clover G. (1996). Consumers as community support providers: Issues created by role innovation. *Community Mental Health Journal*, *32*, 47–67.
- Morley, S., Ecclestone, C. & Williams, A. (1999). Systematic review and meta-analysis of randomised controlled trials of cognitive behaviour therapy and behaviour therapy for chronic pain in adults. *Pain*, *80*, 1–13.

- Morris, P.L., Robinson, R.G., Raphael, B. & Bishop, D. (1991). The relationship between the perception of social support and post-stroke depression in hospitalised patients. *Psychiatry*, *54*, 306–316.
- Morris, R., Payne, O. & Lambert, A. (2007). Patient, carer and staff experience of a hospital-based stroke service. *International Journal of Quality Health Care*, *19*, 105–112.
- Morrison, V., Johnston, M. & MacWalter, R. (2000). Predictors of distress following an acute stroke: Disability, control cognitions, and satisfaction with care. *Psychology and Health*, *15*, 395–407.
- Nair, R.D. & Lincoln, N.B. (2007). Cognitive rehabilitation for memory deficits following stroke. *Cochrane Database of Systematic Reviews*, *10*(3), CD002293.
- National Institute of Clinical Excellence (2004). *Depression: Management of depression in primary and secondary care. National clinical practice guidelines, No. 23*. Leicester: British Psychological Society & Royal College of Psychiatrists.
- Nouri, F.M. & Lincoln, N.B. (1992). Validation of a cognitive assessment predicting driving performance after stroke. *Clinical Rehabilitation*, *68*, 275–281.
- Nouri, F.M. & Lincoln, N.B. (1993). Predicting driving performance after stroke. *British Medical Journal*, *307*, 482–483.
- Nys, G.M., van Zandvoort, M.J., de Kort, P.L., Jansen, B.P., de Haan, E.H. & Kappelle, L.J. (2007). Cognitive disorders in acute stroke: Prevalence and clinical determinants. *Cerebrovascular Disorders*, *23*, 408–416.
- Nys, G.M., van Zandvoort, M.J., de Kort, P.L., van der Worp, H.B., Jansen, B.P. Algra, A. et al. (2005). The prognostic value of domain-specific cognitive abilities in acute first-ever stroke. *Neurology*, *64*, 821–827.
- Onyett, S. (2007). *New ways of working for applied psychologists in health and social care – Working psychologically in teams*. Leicester: British Psychological Society.
- Pain, H.S.B. & McLellan, D.L. (1990). The use of individualised booklets after a stroke. *Clinical Rehabilitation*, *4*, 265–272.
- Palmer, S. & Glass, T.A. (2003). Family function and stroke recovery: A review. *Rehabilitation Psychology*, *48*, 255–265.
- Paolucci, S., Antonucci, G., Gialoreti, L.E., Traballes, M., Lubich, S. Pratesi, L. et al. (1996). Predicting stroke inpatient rehabilitation outcome: The prominent role of neuropsychological disorders. *European Neurology*, *36*, 385–390.
- Parikh, R.M., Robinson, R.G., Lipsey, J.R., Starkstein, S., Federoff, J. & Price, T. (1990). The impact of post-stroke depression on recovery in activities of daily living over a two-year follow-up. *Archives of Neurology*, *47*, 785–789.
- Paxton, R. & D’Netto, C. (2001). *Guidance on clinical psychology workforce planning. Division of Clinical Psychology Information Leaflet No. 6*. Leicester: British Psychological Society.
- Pillemer, K., Landreneau, L.T. & Sutor, J.J. (1996). Volunteers in a peer support project for caregivers: What motivates them? *American Journal of Alzheimer’s Disease*, *11*, 13–19.

- Pohjasvaara, T., Vataja, R., Leppavuori, A., Kaste, M. & Erkihjuntti, T. (2001). Depression is an independent predictor of poor long-term functional outcome post-stroke. *European Journal of Neurology*, 8, 315–319.
- Pohjasvaara, T., Leskela, M., Vataja, R., Kalska, H., Ylikoski, R., Hiatanen, M. et al. (2002). Post-stroke depression, executive dysfunction and functional outcome. *European Journal of Neurology*, 9, 269–275.
- Price, J.R., Mitchell, E., Tidy, E. & Hunot, V. (2008). Cognitive behaviour therapy for chronic fatigue syndrome in adults. *Cochrane Database of Systematic Reviews*, (3), CD001027.
- Rabadi, M.H., Peterson, L., Rabadi, M. & Edelstein, F.M. (2008). Cognitively impaired stroke patients do benefit from admission to an acute rehabilitation unit. *Archives of Physical Medicine and Rehabilitation*, 89, 441–448.
- Riggs, R.V., Andrews, K., Roberts, P. & Gilewski, M. (2007). Visual deficit interventions in adult stroke and brain injury: A systematic review. *American Journal of Physical Medicine & Rehabilitation*, 86, 853–860.
- Robertson, I.H., Ward, A., Ridgeway, V. & Nimmo-Smith, I. (1994). *Test of everyday attention*. Flempton: Thames Valley Test Company.
- Robertson, I.H., McMillan, T.M., McLeod, M. & Brock, D. (2002). Rehabilitation by Limb Activation Training (LAT) reduces impairment in unilateral neglect patients: A single-blind randomised control trial. *Neuropsychological Rehabilitation*, 12, 439–454.
- Robertson, I.H., Ridgeway, V., Greenfield, E. & Parr, A. (1997). Motor recovery after stroke depends on intact sustained attention: A two-year follow-up study. *Neuropsychology*, 11, 290–295.
- Rodin, J. (1986). Ageing and health: Effects of the sense of control. *Science*, 233, 1271–1276.
- Royal College of Physicians (2004). *Stroke in childhood: Clinical guidelines for diagnosis, management and rehabilitation*. London: Royal College of Physicians.
- Royal College of Physicians (2007). *National Sentinel Stroke Audit, Phase 1 (organisational audit) 2006. Phase 11 (clinical audit) 2006. Report for England, Wales and Northern Ireland*. London: Royal College of Physicians.
- Royal College of Physicians (2008a). *National Clinical Guidelines for Stroke* (3rd ed). London: Royal College of Physicians.
- Royal College of Physicians (2008b). *National Sentinel Stroke Audit, Phase 1 (organisational audit) 2008. Report for England, Wales and Northern Ireland*. London: Royal College of Physicians.
- Santos, C.O., Caeiro, L., Ferros, J.M., Albuquerque, R. & Figuiera, M.L. (2006). Anger, hostility and aggression in the first days of acute stroke. *European Journal of Neurology*, 13, 351–358.
- Sawatzky, J.E. & Fowler-Kerry, S. (2003). Impact of care giving: Listening to the voice of informal caregivers. *Journal of Psychiatric and Mental Health Nursing*, 10, 277–286.

- Scholte op Reimer, W.J.M., de Haan, R.J., Limburg, M. & van den Bos, G.A. (1996). Patients' satisfaction with care after stroke: Relation with characteristics of patients and care. *Quality in Health Care*, 5, 144–150.
- Scholte op Reimer W.J.M., de Haan, R.J., Rijnders, P.T., Limburg, M. & van den Bos, G.A.M. (1999). Unmet care demands as perceived by stroke patients: Deficits in health care. *Quality in Health Care*, 18, 30–35.
- Smagt-Duijnste, M., Hamers, J.P.H. & Huijjer Abu-Saad, H. (2000). Relatives of stroke patients – their experiences and needs in hospital. *Scandinavian Journal of Caring Sciences*, 14, 44–51.
- Staub, F. & Bogousslavsky, J. (2001). Fatigue after stroke: A major neglected issue. *Cerebrovascular Disease*, 12, 75–81.
- Stewart, M., Doble, S., Hart, G., Langille, L. & MacPherson, K. (1998). Peer visitor support for family caregivers of seniors with stroke. *Canadian Journal of Nursing Research*, 30, 87–117.
- Stroke Association (2001). *Speaking out about stroke services: A survey by the Stroke Association*. London: Author.
- Stroke Unit Trialists' Collaboration (2007). Organised inpatient (stroke unit) care for stroke. *Cochrane Database of Systematic Reviews*, Issue 4. Art. No.: CD000197. DOI: 10.1002/14651858.CD000197.pub2.
- Stuss, D.T., Stethem, L.L., Hugenholtz, H., Picton, T., Pivik, J. & Richard, M.T. (1989). Reaction time after head injury: Fatigue, divided and focused attention and consistency of performance. *Journal of Neurology, Neurosurgery and Psychiatry*, 52, 742–748.
- Sutherland, B., Summers, A., McKenzie, S. & Sloan, R.L. (2000). *Addressing the long-term psycho-social issues of brain injury including stroke through group intervention*. Poster presented at The Royal College of Physicians of Edinburgh Consensus Conference on Stroke Treatment and Service Delivery, Edinburgh, November.
- Tatemichi, T.K., Desmond, D.W., Stern, Y., Paik, M., Sano, M. & Bagella, E. (1994). Cognitive impairments after stroke: Frequency, patterns, and relationship to functional abilities. *Journal of Neurology, Neurosurgery and Psychiatry*, 57, 202–207.
- Teasell, R., McRae, M.P. & Finestone, H.M. (2000). Social issues in the rehabilitation of young stroke patients. *Archives of Physical Medicine and Rehabilitation*, 81, 205–209.
- Tyson, S.F. & Turner, G. (1999). The process of stroke rehabilitation: What happens and why. *Clinical Rehabilitation*, 13, 322–332.
- van Exel, N.J.A., Koopmanschap, M.A., Scholte op Reimer, W.J.M., Niessen, L.W. & Huijsman, R. (2005). Cost-effectiveness of integrated stroke services. *Quarterly Journal of Medicine*, 98, 415–425.
- van Haastregt, J.C.M., Zijlstra, G.A.R., van Rossum, E., van Eijk, J.T.M., de Witte, L.P. & Kempen, G.I. (2007). Feasibility of a cognitive behavioural group intervention to reduce fear of falling and associated avoidance of activity in community-living older people: A process evaluation. *BMC Health Services Research*, 7, 156.

- Viesser-Meilly, A., van Heugten, C., Post, M., Scepers, V. & Linderman, E. (2005). Intervention studies for caregivers of stroke survivors: A critical review. *Patient Education and Counselling*, 56, 257–267.
- Wade, D. (1994). Health care needs assessment. In A. Stevens & J. Raftery (Eds.), *The epidemiology-based needs assessment review: Volume 1* (pp.111–255). Oxford: Radcliffe Medical Press.
- Watkins, C.L., Auton, M.F., Deans, C.F., Dickinson, H.A., Cathy I.A., Jack, C.I.A. et al. (2007). Motivational interviewing early after acute stroke: A randomised, controlled trial. *Stroke*, 38, 1004–1009.
- West, C., Bowen, A., Hesketh, A. & Vail, A. (2008). Interventions for motor apraxia following stroke. *Cochrane Database of Systematic Reviews 2008*, Issue 1. Art. No.: CD004132. DOI: 10.1002/14651858.CD004132.pub2.
- Wilkinson, P.R., Wolfe, C.D., Warburton, F.G., Rudd, A.G., Howard, R.S., Ross-Russell, R.W. et al. (1997). A long-term follow-up of stroke patients. *Stroke*, 28, 507–512.
- Wilson, B.A. (1999). *Case studies in neuropsychological rehabilitation*. Oxford: Oxford University Press.
- Wilson, B.A., Alderman, N., Burgess, P., Emslie, H. & Evans, J.J. (1996). *Behavioural Assessment of Dysexecutive Syndrome (BADs)*. Bury St Edmunds: Thames Valley Test Company.
- Wilson, B.A., Baddeley, A.D., Evans, J.J. & Sheil, A. (1994). Errorless learning in the rehabilitation of memory impaired people. *Neuropsychological Rehabilitation*, 4, 307–326.
- Wilson, B.A., Emslie, H., Quirk, K. & Evans, J.J. (2001). Reducing everyday memory and planning problems by means of a paging system: A randomised control crossover study. *Journal of Neurology Neurosurgery and Psychiatry*, 70, 477–482.
- Wilz, G. & Barskova, T. (2007). Evaluation of a cognitive behavioural group intervention programme for spouses of stroke patients. *Behaviour Research and Therapy*, 45, 2508–2517.
- Young, J.B. & Forster, A. (1992). The Bradford Community Stroke Trial: Results at six months. *British Medical Journal*, 304, 1085–1089.

Appendix A

Stroke-related cognitive impairment

- At the hyper-acute stage, a majority of stroke victims are disorientated and confused (Wade, 1994) but over the first few days this confusion typically resolves to leave more selective residual cognitive problems.
- These can include difficulties with memory, language, perception, attention controlling action (apraxia) and executive tasks such as reasoning, planning, problem-solving, judgement and inhibition.

Memory

- Lincoln and Tyson (1989) found that 49 per cent of cases were impaired on memory tests at seven 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, for example, 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 one 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 eight per cent and 90 per cent 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 per cent 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).

The British Psychological Society

St Andrews House, 48 Princess Road East, Leicester LE1 7DR, UK

Tel: 0116 254 9568 Fax 0116 247 0787 E-mail: mail@bps.org.uk Website: www.bps.org.uk