

# insights

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life after stroke:  
the long-term emotional  
and psychological  
needs of stroke survivors  
and their carers

## Key points

- Stroke is a long-term condition that has significant implications for social services in Scotland.
- Stroke can negatively affect the mental health of stroke survivors and their carers, leading to depression, anxiety and low self-esteem.
- Communication impairment following stroke has a profound impact on stroke survivors.
- Better information provision, effective communication, social support and scheduled reviews of support needs can help address the long-term emotional and psychological difficulties of stroke survivors and their carers.

## 1.

## Stroke

A stroke is a brain attack which happens when the blood supply to part of the brain is cut off and brain cells are damaged or die. Stroke is the third most common cause of death in Scotland and a major cause of severe disability in adults (Adamson et al, 2004). It is estimated that about 12,500 people have a stroke in Scotland each year and that there are 110,000 stroke survivors (Stroke Association, 2010). There is also evidence of a north-south gradient in stroke mortality, with rates in Scotland around 50% higher than in London (British Heart Foundation, 2009).

A stroke can cause brain damage which can affect physical and sensory functions, cognition, communication and / or psychological health. This includes:

- mild to severe problems with movement, usually one sided
- visual problems (eg visual field problems)
- emotional lability (eg uncontrolled crying or laughter which may also be out of context)

Half of those who survive a stroke have some level of impairment:

- one-third have a communication impairment such as aphasia
- over a third have cognitive problems and stroke is the second major cause of dementia after Alzheimer's
- between 20-50% experience depression.

(Scottish Government, 2009, p70)

Stroke is linked to health and social inequalities:

- premature death rates in the most deprived areas are around three times higher than in the least deprived (British Heart Foundation, 2009)
- stroke survivors with impairments and their unpaid carers are likely to experience a range of social challenges, including low income and social isolation (Stroke Association, 2010)
- people from certain minority ethnic groups living in the UK including South Asian and Black and Afro Caribbean are at greater risk of stroke (Scottish Government, 2009)

Multiple and complex needs can arise in the aftermath of a stroke. These include:

- everyday living needs; physical needs; emotional and well-being needs; social needs; communication and cognition needs; financial, legal and care needs; re-enablement needs and carer needs. The services required may include personal care, meals on wheels, respite care, aids and adaptations as well as the opportunity to attend day centres (Stroke Association, 2009, p2).

## Policy context: Scotland

The White Paper *Towards a Healthier Scotland* (Scottish Office, 1999) set a target to half the death rate from cerebrovascular disease in people under 75 between 1995-2010. This was followed in 2001 by the *Coronary Heart Disease (CHD) and Stroke Task Force Report* (Scottish Executive, 2001) which focused on the management of CHD and stroke. A year later, the *CHD and Stroke Strategy* (Scottish Executive, 2002) was published which highlighted the key priorities for stroke treatment: accurate diagnosis, rapid assessment and improved rehabilitation. The *CHD and Stroke in Scotland Strategy Update* (Scottish Executive, 2004) recommended that all health boards have managed clinical networks (MCNs) for stroke services. *Better Heart Disease and Stroke Care Action Plan* (Scottish Government, 2009) was launched following consultation to reinforce CHD and stroke as national clinical priorities in Scotland.

## The evidence

Neurological impairments resulting from stroke may improve with rehabilitation but often stroke survivors are left with considerable, permanent impairment. Evidence shows that after a stroke depression and anxiety are prevalent and often long-term for survivors, continuing up to five years after an incidence of stroke (Murray et al, 2003; Young et al, 2003;

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Hare et al, 2006). Depression has been found to slow recovery from stroke (West et al, 2010) and is associated with increased mortality (Salter et al, 2008). Carers of stroke survivors also suffer from 'significant psychological distress' which can begin early in the caregiving experience (Simon et al, 2009). Some carers report a struggle to adjust to life after stroke and to grieving the loss of the person they knew whilst trying to remain strong for the survivor (Backstrom and Sundin, 2009).

Emotional and psychological problems can be compounded by communication difficulties, both in terms of the information provided to survivors and carers by professionals but also the impact of communication impairment on survivors.

Studies have found that there is confusion and a lack of information about surviving stroke, prevention of subsequent strokes, treatment, services, benefits and adaptations to property (Hare et al, 2006; Mackenzie et al, 2007; CHSS, 2009). Some stroke survivors experienced a lack of information about what had actually happened to them and did not realise they had had a stroke (Ch'ng et al, 2008). Relevant information was required at different times after a stroke, for example information about benefits and services was most needed after discharge from hospital (Mackenzie et al, 2007). Some survivors and carers 'were unsure which profession offered which service, and there was particular role confusion about the differences between an Occupational Therapist, a Home Care

Assessor and a Social Worker' (Hare et al, 2006, p133). Carers also reported 'major information deficits' about the emotional and psychological impact for survivors and how the carer was expected to handle these problems (Mackenzie et al, 2007; CHSS 2009).

One of the most profound consequences of stroke for survivors, their families and carers is communication impairment. The *Back to a Life after Stroke survey* (2008) conducted with 280 people in Scotland with communication difficulty following stroke found that:

- nearly 90% of respondents had difficulties speaking, explaining things and talking on the phone
- over 80% had difficulties writing
- almost 60% had difficulties reading letters, leaflets and newspapers
- 80% had difficulties using the internet
- a third had difficulties understanding what people are saying
- nearly 90% said communication difficulties had affected their independence
- 80% reported their confidence had suffered, that communication problems had impacted on their social life and adversely affected their work.

Communication deficit has been described as 'overwhelming', leading some stroke survivors to become preoccupied with

regaining their communication abilities, to the extent that other physical needs are ignored (Ch'ng et al, 2008). For carers 'handling communication difficulties' is also a priority concern (Mackenzie et al, 2007, p114). Anderson and Marlett (2004) argue that 'communication is key to identity' and therefore losing the ability to communicate can have a significant impact on how survivors see themselves. A stroke can also cause a crisis of identity for carers, for example, when a spouse becomes a carer (Greenwood and Mackenzie 2010). Parr and colleagues (2004) highlight that 'particularly in residential and nursing care settings, people with severe aphasia were in danger of losing their identity as staff often knew very little about them and didn't know how to find out' (p1). Communication difficulties such as aphasia can lead to little consultation or choice for survivors and they risk being seen by service providers as 'non-compliant' or 'unmotivated' (Parr et al, 2004). A number of research studies highlight the need for improved communication from professionals to survivors and carers (Anderson and Marlett, 2004; CHSS, 2009) as well as better connections between agencies such as rehabilitation therapies, employment, benefits agencies and those in the home or care setting (Parr et al, 2004).

Communication impairment contributes to social problems for survivors and their carers (Mackenzie et al, 2007). Social exclusion and feelings of isolation are common (Murray et al, 2003; Parr et al, 2004; Hare et al, 2006). The perceived

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stigma of stroke further isolates survivors (Bendz, 2000; Hare et al, 2006). After a stroke, survivors can experience a decline in social network relationships as they lose the opportunities for contact through employment and recreation. Social support is central to wellbeing and it has been found to protect against depression (Salter et al, 2010) and to help recovery from stroke (Ch'ng et al, 2008). The findings from a care coordination model where social workers proactively contacted stroke patients to assess and address unmet mental health, psychosocial and environmental needs, showed decreased symptoms of depression and improved mental health (Clairborne, 2006). This suggests that 'social workers, family support organisers or community outreach nurses... may have the potential to become part of an individual's social network and provide support that could be perceived as effective' (Salter et al, 2010, p623).

#### Implications for practice

The evidence in this summary highlights that survivors and carers have long-term emotional and psychological needs. Most importantly, the research shows that poor mental health directly affects the survivor's ability to recover from stroke.

It is important to emphasise that some stroke survivor's mental health problems are neurological in cause and may not improve and so there are considerable implications for long term support,

depending on the nature and impact of their impairment. As many stroke survivors access social services it is important to highlight the implications of the research for practice.

One key issue is ensuring sufficient support to either prevent a stroke survivor from becoming depressed or where they do, supporting recovery.

An understanding of stroke will enable social services staff to be instrumental in identifying emotional and psychological issues such as depression, anxiety, loss of self-esteem and other mental health problems after stroke. Local protocols for referral for specialist help when depression or other mental health problems are suspected is important. Staff can then help to enable survivors and carers get psychological support from GPs, mental health services, voluntary organisations and local support groups. Effective knowledge of and links with the voluntary sector that may be able to provide additional support such as self-management training and carers training is also key.

The evidence points to a high risk of social isolation for stroke survivors so staff awareness of this can enable them to help survivors and carers access day centres, befriending schemes, vocational rehabilitation, respite and other sources of social support.

Effective communication through appropriate and considerate information provision is also essential to supporting the

needs of survivors and carers. Staff need to be able to deliver relevant and timely information that is suitable to the stage the survivor is at, whether they have just been diagnosed and are in hospital or are being discharged. Good communication also facilitates the involvement of survivors and carers in decision making during discharge planning and care assessments to ensure transition to community or residential care is as effective as possible. Alternative communication tools such as Talking Mats [www.talkingmats.com](http://www.talkingmats.com) that use symbols and pictures to help support decision making for people with communication difficulties can be effective. It is also important that staff communicate clearly with carers to help support them in their caring role which can require a significant adjustment.

With improved medical treatment, more people are surviving stroke and living with support needs in the community. While it is important that physical impairments associated with stroke are addressed it is also vital that mental and emotional wellbeing are not neglected as they underpin recovery. Scheduled reviews of stroke survivors' and their carer's support needs can help ensure that services are responsive and facilitate long-term recovery.

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## 4.

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