The Stroke Association Scotland welcomes the Equal Opportunities Committee’s inquiry into Age and Social Inclusion. Our comments and suggestions are set out below.

**The impact of stroke**

Stroke can affect anyone at any age. Although the majority of those having a stroke are over 65, about a third of strokes happen to people of working age, a children and babies.

Despite the fact that incidence and mortality figures for stroke in Scotland have significantly decreased over the last 10 years, there are still around 120,000 people living with the effects of stroke many of whom are dependent on others and are cared for by family and friends.

A stroke happens when the blood supply to part of the brain is cut off. It can cause a number or combination of physical, mental or communication impairments and it is unlikely that person’s life will ever be the same again. Unsurprisingly therefore, stroke is the largest cause of complex disability in Scotland.

There is extensive evidence of a connection between stroke, social isolation and resultant poor health and we know stroke has a significant negative psychosocial impact on the individual with reported changes to self-identity (for example Clarke and Black 2005) and social interaction (for example Hammel et al 2009).

Impairments that impact upon the individual’s ability to carry out ‘self-defining activities’ (activities perceived by the individual as contributing to their identity) have been found to particularly impact upon reported well-being and in turn, quality of life (Clarke and Black 2005).

Social isolation is a risk factor for issues such as low mood and depression and cognitive decline. The Stroke Association estimates that around half of all stroke survivors experience depression in the first year after their stroke (Stroke Association 2013).

**Prevalence of social isolation in urban and rural settings**

There are no figures for the prevalence of stroke and social isolation in rural and urban settings. However, there are prevalence statistics of stroke in urban and more rural areas and the prevalence in both areas appears to be similar. We could assume that given the high incidence of stroke in Scotland (both rural and urban), and its link to social isolation, there are issues around social inclusion that need to be addressed as highlighted in this paper.

**Impact of social isolation**
There is evidence of increased social isolation occurring after stroke for many people who have had a stroke, particularly those with communication, cognitive and visual impairments. Communication is a fundamental self-defining activity and so it is unsurprising that impaired communication skills have been found to impact on an individual’s identity (Parr et al 1997; Brady et al 2007). In addition, aphasia (language impairment subsequent to stroke) and dysarthria (difficulty speaking caused by problems with the muscles used in speech) can isolate both the patient and carer and may intensify the social impacts usually associated with a stroke (for example Parr et al 1997). People with aphasia have been found to have restricted or altered social activities (Dalemans et al 2008; Cruice et al 2006), fewer friendships (Parr et al 1997; Cruice et al 2006; Davidson et al 2008) and smaller social networks (Davidson et al 2008) compared to before the stroke and in comparison to healthy peers (Cruice et al 2006). Such restricted opportunities for social participation results in people with aphasia becoming socially isolated (Parr et al 1997), the consequences of which can be severe, including detrimental impacts on individual’s emotional wellbeing (Cruice et al 2003; Doble et al 2009) and functional outcomes (Boden-Albala et al 2005).

**Good practice across Scotland in supporting stroke survivors with social isolation issues**

Rehabilitation after stroke aims to maximise an individual’s ability to participate within Society. Better or preserved social participation has been linked to greater well-being (Haslam et al 2005), cognitive scores (Glymour et al 2008) and functional outcomes following stroke (Kulzer et al 2008). Stroke clubs are a good example of how people who have had a stroke are enabled to meet, share, and gain confidence by participating in a social environment with others who are experiencing similar challenges. We know from our contact with stroke survivors and carers how beneficial this can be in tackling social isolation. Groups often have a particular focus for example, for people with stroke related communication difficulty or with a physical impairment. The Stroke Association is working closely with partners and people affected by stroke to identify where gaps exist and where clubs may not be readily available, such as in more rural areas. Following discussion with people who are living with the long term effects of stroke, and professionals (research teams and clinicians) we are aware of the need for improved access to exercise during the rehabilitation period and beyond. We know that improved physical health can lead to greater independence and more opportunity to travel, get back to work, volunteer or partake in hobbies – a good way of tackling social isolation and loneliness.

**Potential ideas for improvement and influencing policy**

There are two active Scottish Government policies in relation to stroke:
Long term care and support for people living with the effects of stroke are referenced in both stroke policies, but we believe there there should be a greater focus on addressing issues that can affect people for many years after their stroke, including
social isolation. We believe developing befriending, advocacy and peer support are ways in which social isolation can be minimised

**Effective awareness-raising within communities**

There are many hidden effects of stroke which can be challenging in carrying out day to day activities in the community. For example, fatigue is common after stroke so can be a barrier in getting out and about and doing simple everyday tasks that we all take for granted such as going shopping and going out with friends. Difficulty with memory and concentration can be a hindrance to getting a job or volunteering in the community. Partaking with most activities in the community is challenging for people with a stroke-related communication difficulty.

Campaigns including the FAST campaign (to help recognise the signs of a stroke), ‘Feeling Overwhelmed’ about the emotional impact of stroke and the ‘Not just a funny turn’ campaign around issues associated with recognising the symptoms of a mini stroke also known as a transient ischaemic attack help to raise awareness of stroke.

The Stroke Association and other charities have produced communication aids for people with aphasia to help members of the community understand and know what to do when communicating with someone with aphasia.

However, the lack of knowledge about stroke and associated issues with social isolation are nonetheless challenging. One third of people do not know what a stroke is and many would not know what to do if they saw someone having a stroke. Many people think strokes only happen to older people and that they die from it—a myth that still exists; stroke survivors tell us that the impact of stroke (particularly the more hidden effects of stroke), often go un-noticed and are misunderstood. All of this can lead or contribute to feelings of social isolation. The Stroke Association, voluntary organisations and others go some way to tackling aspects of social isolation through information, education and stroke clubs, but there is a long way to go.

We must continue to do what we are doing well and we need more investment to improve the issue of stroke and social isolation issues to ensure they are not ‘struck off.’

With an ageing population and with the rise of type 2 diabetes and obesity, we face a very real challenge in incidence and prevalence of stroke. We hope therefore that this response will go some way to highlighting that a stroke can happen at any age and that much needs to be done to tackle social inclusion issues for stroke survivors.

There is Life After Stroke and Together We Can Conquer it!

*Angela MacLeod*
*Communications Manager – Scotland*
*The Stroke Association*
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