

Long-term Needs of Stroke Survivors



Written by Professor Charles Wolfe, Head of the School of Population Health and Environmental Sciences, King's College London

Author biography: Professor Charles Wolfe is Head of the School of Population Health and Environmental Sciences at King's College London and leads a Stroke epidemiology and health services research group. He has been involved in over 350 stroke publications and is an Emeritus National Institute for Health Research Senior Investigator. The focus of his research is on the risk of stroke over time in a multi ethnic population of south London, with EU comparisons and trials of early supported discharge and carer support.

Stroke remains a major cause of death and adult physical disability internationally. Death from stroke has fallen by around 60% over the last 30 years in high income countries, most likely through better prevention and acute stroke treatments. However, there remains much to be done to ensure evidence-based care is provided to all stroke survivors and there are many unanswered questions that need further research, particularly in rehabilitation and improved longer term physical and mental health. A 'Burden of Stroke' report for the European Parliament found shocking disparities between and within countries in regard to stroke care and many countries do not have a strategy to tackle these issues.

While the incidence of stroke is declining, increasing life expectancy means that the number of people having a stroke may increase by 2035 by as much as 44%. Stroke is typically thought of as affecting older people but occurs in people of all ages including children. The impact of stroke is considerable. Two thirds of stroke survivors live with mild to moderate deficits in function including mobility and self-care and around 30% of survivors have mental health needs as a consequence of cognitive impairment, anxiety and depression. Self-reporting from stroke survivors indicates that around half of stroke survivors have a range of unmet medical, rehabilitation and social needs in the first five years after stroke. Improvements in the delivery of follow up care, including secondary

prevention (prevention of a further stroke or vascular event), could reduce the risk of further vascular events, disability and death. It could also improve stroke survivors' and carers' psychological status, social participation and emotional well-being.

So, what are the effective post stroke management strategies and treatments and what is the evidence they are well used? It is not well established how often and where stroke survivors should be followed up, particularly if survivors have multiple long-term conditions and there is little evidence that a 6-month review is effective. Guidelines for the secondary prevention (e.g., blood pressure, lipid lowering, antiplatelet and anticoagulation treatments) exist,

yet their successful implementation to those at risk in practice lacks evidence. Changes in lifestyle (smoking, exercise, drinking) are also important in secondary prevention, however there is again limited evidence of lifestyle modifications translating into a reduction in stroke recurrence or mortality.

Many stroke survivors wish to continue rehabilitation longer term, either continuously or on an intermittent basis. As well as facilitating recovery, exercise or rehabilitation delivered later after stroke may prevent regression of physical or cognitive gains of recovery. Research has identified the benefits of ongoing rehabilitation for stroke survivors in certain groups only. The evidence suggests a need for continuing rehabilitation post-stroke, however, the Burden of Stroke in Europe report found inadequate ongoing rehabilitation and long-term support for stroke survivors across Europe.

Guidelines for Stroke often recommends that stroke survivors should be offered self-management support based on self-efficacy, aimed at the knowledge and skills needed to manage life after stroke, with special attention given to this at reviews and transfers of care and this is intuitively what survivors and carers feel offers hope. The current advice and guidance, despite a relatively weak evidence base, advocates patients with stroke whose motivation and engagement in rehabilitation appears reduced should be assessed for changes in self-esteem, self-efficacy or identity and mood and cognitive impairment. Patients with

significant changes in self-esteem, self-efficacy or identity after stroke should be offered information, support and advice and considered for specific psychological therapy.

Self-management in the context of therapy rehabilitation delivered soon after stroke has been found to lead to short-term improvements in basic and extended activities of daily living, and a reduction in poor outcomes. Use of personalised stroke management tool kits have successfully been shown to aid patients through ongoing education after discharge and improve patient experience and empowerment. Furthermore, self-management programmes may benefit people with stroke who are living in the community.

Research has historically focused on the recovery and rehabilitation of the stroke survivor with little attention paid to the needs of those caring for them beyond hospital discharge. Families of stroke survivors can suddenly find themselves in a caring role for which they have received little warning and are ill prepared to undertake.

In summary, the impact of stroke after the acute event is considerable and will increase over the next few decades, affecting survivors, their families and carers as well as the health and care systems. A joined-up approach to follow up across the system is the ambition with an improved choice of effective treatments and management plans. The focus has to become more patient centred and with better communication between all stakeholders enabling the impact of stroke to be reduced.

