

Stroke survivors face 'invisible impairments' to return to work

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Micrograph showing cortical pseudolaminar necrosis, a finding seen in strokes on medical imaging and at autopsy. H&E-LFB stain. Credit: Nephron/Wikipedia

'Invisible impairments' can make it difficult for stroke survivors to maintain a job, according to a study from the University of Cambridge and Queen Mary University of London (QMUL). The findings, published today in the journal *BMJ Open*, suggest that more needs to be done to make survivors, their GPs and employers aware of the

difficulties that they may face.

Each year, 110,000 people in England alone suffer a [stroke](#), a quarter of whom are of working age. The UK's stroke strategy highlights the importance for people who have had a stroke of returning to work: being unemployed is associated with physical and [mental health problems](#), while working has positive effects on the health of people with [chronic conditions](#). A recent study estimated the cost of [stroke care](#) in the UK to be £9 billion a year, of which almost a third (30%) is due to loss of income and productivity.

To explore the experiences of people who have returned to work after a stroke, researchers analysed the archives of TalkStroke, a UK-based online forum hosted by the Stroke Association, across a seven year period (2004-2011). It is believed to be the first study to utilise data from such forums to study barriers to staying in work after stroke.

The researchers searched more than 20,000 posts for the phrases "return to work" and "back at work" and identified 60 people who had posted about the issue during the seven year period. Almost all of those who managed to return to work still experienced a range of residual invisible impairments, including memory and concentration problems and fatigue.

On the online forums, some commenters described the problems with looking 'normal', but not feeling the same way and how this led to a lack understanding among co-workers, but also to their own sense of feeling a fraud.

Having a supportive employer helped people ease themselves back into work and enabled survivors to make adjustments, including a gradual return to work, reduced hours and working from home. But when employers were unsupportive, survivors found this particularly distressing and stressful; some posters even reported being bullied by

colleagues.

Some commenters gave specific advice to others, such as recommending speaking to their GP, but awareness was low of what to do and where to seek advice if stroke-related problems persisted long-term.

"Although a stroke survivor may look like they have recovered, they can be still be affected by invisible impairments that make work difficult," says Dr Anna De Simoni, a lecturer in Primary Care Research at QMUL and visiting researcher at the Department of Public Health and Primary Care, University of Cambridge.

"Conversations in the internet forums suggest we need to raise awareness of the support available to individuals, but also more widely amongst [primary care](#) professionals and employers of how they can best accommodate and support their staff."

Perhaps surprisingly, the forums also highlighted that GPs themselves did not always understand the impairments and could often do more to support their patients. One man, aged 61 at the time of his stroke, reported that his GP was unwilling to extend his sick leave as he said the man could sit at a desk and move all his limbs and so was fit to work, yet the man suffered impairments such as walking and communication problems, limb spasms and fatigue.

In a sister paper, also in BMJ Open, the authors report how TalkStroke proved to be a powerful tool for providing advice and support for survivors and their carers. The study found that 95% of information and support requests by patients with stroke and their families in the online forum were answered in replies.

The main reasons for taking part in online discussions were requests and offers of information and support, and sharing own experiences of

stroke. Most information needs were around physical impairments, understanding the cause of stroke and the potential for recovery.

Professor Jonathan Mant from the Cambridge Primary Care Unit says: "Almost all requests of information and support on the forums receive an answer. In a time when GP surgeries are full and patients are waiting weeks for community appointments, these online forums can provide a way for [stroke survivors](#) and their carers to receive helpful advice and support."

The researchers were funded by the National Institute for Health Research and the Evelyn Trust.

Kate Pieroudis, Manager of the Back to Work Project at the Stroke Association said: "Employers can have a vital part to play in helping stroke survivors get back into the workplace and on the road to recovery. Stroke is incredibly complex and affects every person differently. In some cases, the long-term effects of the condition, such as communication problems or memory loss, may only become apparent in a work environment.

"With the right support, many stroke survivors can and do go back to work successfully. Planning with employers is essential so they understand how a stroke has affected an individual, and can put necessary support and adjustments in place. The Stroke Association provides information and practical advice on work and stroke to both employers and stroke survivors."

More information: Balasooriya-Smeekens, C et al. Barriers and facilitators to staying in work after stroke: insight from an online forum. *BMJ Open*; 6 April 2016; [DOI: 10.1136/bmjopen-2015-009974](https://doi.org/10.1136/bmjopen-2015-009974)

De Simoni, A. et al. Stroke survivors and their families receive

information and support on an individual basis from an online forum: descriptive analysis of a population of 2,348 patients and qualitative study of a sample of participants. *BMJ Open*; 6 April 2016; DOI: [10.1136/bmjopen-2015-010501](https://doi.org/10.1136/bmjopen-2015-010501)

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