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**Thousands of stroke survivors in Northern Ireland deserted after leaving hospital**

Shocking new figures reveal that more than half (59%) of stroke survivors in Northern Ireland feel they did not receive enough support with their recovery.

This World Stroke Day, the Stroke Association published new findings(i) that show thousands of stroke survivors in Northern Ireland said they struggle to access the support they need to rebuild their lives after stroke.

There are currently more than 38,000 stroke survivors in Northern Ireland, and these latest findings show that many people feel let down by the health and social care system. The charity’s Lived Experience report is compiled from a large survey of people affected by stroke to find out more about their experiences.

This final chapter, *Rebuilding Lives after Stroke*, reveals that in Northern Ireland:

* One in five (20%) of stroke survivors said they did not have the information they needed when they left hospital
* Although more than four out of five (86%) survivors were left with mobility problems, almost half (48%) said they needed longer or more frequent support from physiotherapy services than was provided.
* One in four (28%) of stroke survivors report not receiving enough emotional support leaving them struggling to cope.

**Jackie Convey is 57 and lives in Omagh. Jackie was first diagnosed with a brain aneurism but during subsequent surgery, Jackie had a stroke. She was 53 years old.** Jackie then spent almost two months in hospital in Belfast where she received physiotherapy, speech and language and occupational therapy but was shocked at the poor level of care she received once she was discharged from hospital and returned to her home.

Jackie says: “On leaving hospital I was assured I’d be receiving all sorts of therapy from the Community Stroke Care team. I was even told that they’d provide transport from my house to the clinics. I was shocked that when I got home, nobody contacted me at all for weeks. Eventually someone did phone to check how I was getting on with my therapy and when I said I wasn’t receiving any, they advised me to go to my GP who had to make another referral.

“I then did get physiotherapy and occupational therapy but I felt it wasn’t hands-on enough for what I needed. I still have problems with my left shoulder and arm and I do wonder if I’d had more physiotherapy, would it have improved my recovery.

“In the hospital they did warn me about fatigue but I don’t think what they tell you goes far enough. I just simply wasn’t prepared for what followed. It was awful. There were times after I got home when I thought I was suffering from depression or something like that but I now think that it was all part of the fatigue. I’d meet people out in public and just burst in to tears. I eventually went to my GP and started a course of anti-depressants which did help at that point but I didn’t receive any emotional support at all and I do think that would have helped me.

“If it wasn’t for my family, especially my daughter Sarah, I really don’t know where I’d be today. My daughter was the one who worked with me to stay focused on my recovery. When I would say I can’t do it, she was the one who said yes you can. I’ll always remember the day we were driving somewhere and my daughter Sarah stopped the car, got out and said, right mum get in there and you drive. That’s what got me back driving and that was a huge step in rebuilding my life again”.

“In the early days, just after I left hospital, it felt like I was just sitting on the sofa doing nothing, waiting for death to come. Back then I felt like I’d stepped out of my life. I’m so thankful that now I feel that I’ve got my life back again. As well as going back working three days per week, I’m now volunteering on my days off as well.

“I know that I’ve made a good recovery but stroke survivors shouldn’t have to worry about how to get their own therapy and rehabilitation. The system needs to work more for the patient especially in those early days after a stroke to give you the best chance of rebuilding your life”.

**Barry Macaulay, Director of the Stroke Association Northern Ireland** said: “Stroke turns lives upside down, robbing you of your mobility, your speech and often your independence. We know there are hospitals, stroke units and dedicated stroke professionals throughout Northern Ireland providing excellent stroke rehabilitation.

“But there are still thousands of stroke survivors across Northern Ireland being let down by the health and social care system when they leave hospital. This is putting people’s recoveries at risk. Surviving a stroke is the first challenge; recovery is tough, but it’s only possible when stroke survivors can access the range of support services that they need, and deserve, to rebuild their lives.”

The Lived Experience of Stroke report also exposes the realities of living with stroke in Northern Ireland:

* Around a third (36%) of stroke survivors feel their support focused on their medical condition and not them as a person.
* Half (50%) of stroke survivors who also had other health conditions, felt the support was more focused on their other conditions rather than the impact of their stroke.
* Around a quarter (23%) said they didn’t receive enough practical support for things like driving after stroke.

Barry continued: “It takes a lot of effort and determination to keep going with rehabilitation after stroke but with the right specialist support, the brain can adapt. Even months and years after stroke, it’s possible to make a recovery.

“It’s important that everyone affected by stroke in Northern Ireland can access the support they so desperately need. Over the last decade there have been significant advances in hospital based stroke treatment in Northern Ireland. While acute stroke services are developed and improved further, it is vital that rehabilitation and long term support for stroke survivors is given the same priority. We’re pleased that the Department of Health has committed to improving rehabilitation and long term support in their proposals to reshape stroke services and we urge them to implement the necessary changes as soon as possible. No stroke survivor should be denied the chance to rebuild their life.

“We’re here for everyone affected by stroke. We offer vital support and information through our Stroke Helpline. We also have a number of stroke clubs and groups that you can join to meet other stroke survivors, so you don’t feel alone in your recovery. I’d also encourage all stroke survivors to refer to the national guidelines that we developed with the Royal College of Physicians ([www.stroke.org.uk/stroke-care](http://www.stroke.org.uk/stroke-care)) so that they know their rights to rehab. My Stroke Guide is our online community of over 11,000 people affected by stroke, which many people said helps with their recovery.”

The Stroke Helpline (0303 3033 100) offers information and support to people who have been affected by stroke. For more information about the Lived Experience of Stroke report – Rebuilding lives after stroke - visit [www.stroke.org.uk/livedexperience](http://www.stroke.org.uk/livedexperience)

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Notes to editors:

About the Stroke Association

* Stroke strikes every five minutes in the UK and it changes lives in an instant.
* Each year around 4000 people will have a stroke in Northern Ireland and there are more than 38,000 stroke survivors currently living in Northern Ireland.
* The Stroke Association is a charity working across the UK to support people to rebuild their lives after stroke. We believe that everyone deserves to live the best life they can after stroke. From local support services and groups, to online information and support, anyone affected by stroke can visit stroke.org.uk or call our dedicated Stroke Helpline on 0303 3033 100 to find out about support available locally.
* Our specialist support, research and campaigning are only possible with the courage and determination of the stroke community and the generosity of our supporters. With more donations and support, we can help rebuild even more lives.
* You can follow us on [Twitter](https://twitter.com/strokewales), [Facebook](https://www.facebook.com/StrokeAssociationWales/) and [Instagram](https://www.instagram.com/thestrokeassociation/?hl=en).
1. The Lived Experience of Stroke is the UK’s largest ever survey of people affected by stroke (i) with over 11,000 responses. The survey was carried out by 2CV (June-August 2018) 9,254 stroke survivors completed a postal survey, 1,880 stroke affected people completed the survey online. In Northern Ireland more than 200 people closely affected by stroke took part.