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**Northern Ireland’s stroke survivors battling mental health problems**

More than 34,000 people who have survived a stroke have developed at least one mental health problem, according to new findings(i) published today by the Stroke Association.

There are currently over 37,000 stroke survivors in Northern Ireland. 93% of them are facing a battle with anxiety, depression, lack of confidence and even suicidal thoughts. Yet worryingly, over a quarter (30%) of people say they have not received enough emotional support to help rebuild their lives after stroke.

The Lived Experience of Stroke report is the Stroke Association’s largest ever survey of people affected by stroke, with over 11,000 respondents across the UK (i). The first chapter demonstrates how the hidden effects of stroke affect almost every survivor, yet can often go unnoticed by others including family and friends.

The findings reveal the real impact that stroke has on survivors’ mental health, with many people having to adapt to a ‘new normal’ while still living with the fear of having another stroke.

While fear and anxiety (ii) top the list of emotions that have the most impact on stroke survivors’ lives within the first six months following a stroke, most respondents in Northern Ireland said these effects can improve over time.

The charity’s latest findings demonstrate how stroke changes lives in an instant. As a result, roles within relationships are turned upside down. Overnight, a partner becomes a carer. A breadwinner becomes jobless.

**Ursula Ferguson, Head of Stroke Support for the Stroke Association**, comments: “This report exposes the true devastation stroke can bring. These figures are extremely concerning and show a desperate need for support to cope with the hidden, and often overlooked, effects of stroke. Far too many lives have been destroyed by stroke. No-one should be left feeling anxious or isolated. The evidence highlights how important it is that families, friends and health professionals who support stroke survivors understand what it means to live with these ‘hidden effects’, ask how people are feeling, and provide appropriate emotional and psychological support.”

**Carla Thompson, from Bangor County Down, was just 28 when a stroke in 2016 left her with severe fatigue and emotional changes**. Carla’s mum and dad both had strokes and sadly her dad died following his 4th stroke earlier this year.

Carla (now 31), who is mum to Aimee-Kate (12), Lucy (7) and Myla (5), said:

“The long term effects of the stroke have been life-changing. I still have a lot of weakness on my left side and the fatigue and memory loss is awful. But one of the biggest effects is on my mental health – the fear and dread of it happening again and the sense of loss of your old life and anxiety about the future.

“Physically I probably look normal and people assume I am recovered but I want to scream “*You don’t understand*” because it’s a huge struggle for me, even to do simple tasks. I have to concentrate so hard and I’m exhausted. Simple things like going out for a meal with friends has become an ordeal. I’m anxious and self-conscious about how my swallow has been affected so I have to choose a meal which is easier to eat – not necessarily what I want – because I worry it will take me so much longer to finish my meal. Stroke changed my life overnight and 3 years on I’m still dealing with the impact that’s had on my wellbeing”.

As well as coping with the effects of stroke on her own life, Carla has also supported both her parents who also had strokes. She explains:

“Even though mum’s stroke was 10 years ago it still has a huge impact and like me, she worries terribly that it could happen again. Something as simple as waking up with a headache or a numb arm can make both of us terribly anxious that it’s all happening again”.

Carla’s dad Glenn Thompson passed away earlier this year following a series of strokes. He was just 60 years old.

“Dad was never the same after his stroke – he cried a lot and used to say “I’m useless, I’m useless” over and over and it was heart breaking. Dad definitely needed more support to cope with the emotional impact of his disability but there was nothing.

 “It’s very scary to watch someone you love die of something you have survived but fear could happen again. Someone once said to me I probably have post-traumatic stress and it’s probably true. It’s hard to describe what it’s like to cope with the effects of stroke but I definitely think there should be more support and counselling for the huge emotional impact. It’s like a tidal wave which takes over your life, and in my case, effects the whole family. I’m grateful for the support of my friends and family and my children who keep me going every day”.

Worryingly, the research also revealed that an overwhelming nine out of 10 (97%) stroke survivors in Northern Ireland experience at least one cognitive effect, such as fatigue(iv), problems with concentration, multi-tasking, reading, writing and poorer memory. Of those respondents:

* Almost nine in 10 (97%) experienced fatigue(iv), which can be debilitating and doesn’t get better with rest
* More than eight in 10 (81%) said they have problems with their short or long term memory
* Eight in 10 (83%) reported issues with concentration, which can affect their ability to do more than one thing at a time.

The Stroke Association has published the Lived Experience of Stroke report to expose the realities of living with stroke and highlight the many gaps in support that still exist. The charity wants everyone affected by stroke to have access to the support that they need, when they need it.

Ursula continues: “There is hope. We know from these findings that things can, and do, improve over time for many stroke survivors. Evidence shows that many are still recovering years after their stroke. That’s why we’re working across Northern Ireland to support and drive changes which will improve the lives of people affected by stroke.

“In Northern Ireland we’re working in partnership with the Regional Psychology team to launch a new Emotional Support pilot in the South Eastern Trust area which will deliver one to one counselling for stroke survivors. We hope this will be rolled out across Northern Ireland because we know people need more specialist emotional support. We’re also working with the Health and Social Care Board to develop a new stroke pathway which will help more stroke survivors access more long term support including our Stroke Helpline and peer support groups”.

**Dr Robert Rauch, Consultant Clinical Neuropsycholog­ist in the Northern Health and Social Care Trust**, said: “Many people experience a range of hidden emotions after stroke, such as anxiety or depression, which can really impact their day to day lives and their recovery. It’s important that people can talk about how they feel and access support when they need it to rebuild their lives after stroke. Working alongside partners in local charities like the Stroke Association, we can support more stroke survivors and their families to get emotional support when they need it most”.

The Hidden Effects of Stroke report is part one of a four part series focusing on the Lived Experience of Stroke. For more information about the Lived Experience of Stroke – Hidden Effects report, visit [www.stroke.org.uk/lived-experience-of-stroke-report](http://www.stroke.org.uk/lived-experience-of-stroke-report).

For more details of support available in your area, please contact the Stroke Association helpline on 0303 303 3100. If you’re struggling to cope, you can contact the Samaritans for free any time from any phone on 116 123, even a mobile without credit. This number won’t show up on your phone bill. Or you can email jo@samaritans.org or visit [www.samaritans.org](http://www.samaritans.org/) to find details of your nearest branch, where you can talk to a trained volunteer face to face.

**-Ends-**

For more information on the research, please contact: Brenda Maguire, Head of Communications at the Stroke Association at brenda.maguire@stroke.org.uk or 07947273640 or 02890508051

**Notes to editors:**

* When stroke strikes, part of your brain shuts down. And so does a part of you. That’s because a stroke happens in the brain, the control centre for who we are and what we can do. It happens every five minutes in the UK and changes lives instantly. Recovery is tough, but with the right specialist support and a ton of courage and determination, the brain can adapt. Our specialist support, research and campaigning are only possible with the courage and determination of the stroke community and the generosity of our amazing supporters. We’re rebuilding lives after stroke. We’re here to support you to rebuild your life after stroke. If you need information or just want someone to talk to, call us on 0303 3033 100 or visit stroke.org.uk
1. The Lived Experience of Stroke – Hidden Effects, Stroke Association report surveyed 11,134 people affected by stroke; 1,880 people by online survey, and 9,254 by postal survey, conducted by 2CV (June – August 2018) In Northern Ireland there were more than 200 respondents.
2. Around the time of their stroke, people report feeling anxious (46%), frightened (54%), shocked (39%) and confused (43%). Stroke survivors continue to feel these emotions during the six months following their stroke. Over time these negative feelings diminish, with 56% of stroke survivors saying they now feel positive emotions. (1,880 respondents responded to these questions in the Lived Experience of Stroke – Hidden Effects, Stroke Association, June 2019)
3. 1,880 respondents (stroke survivors and carers) responded to these questions
4. Fatigue, or extreme tiredness, is the most common effect of a stroke. 97% of survey respondents from Northern Ireland experienced fatigue. Fatigue affects almost all stroke survivors and can be far more debilitating than people imagine. It is different from normal tiredness as it doesn’t get better with rest. Fatigue affects people both physically and cognitively.

**About the Samaritans:**

* Samaritans is a charity working in the UK and Ireland to reduce the number of people who die by suicide and help those struggling to cope.
* Anyone can contact Samaritans FREE any time from any phone on 116 123, even a mobile without credit. This number won’t show up on your phone bill. Or you can email jo@samaritans.org or visit [www.samaritans.org](http://www.samaritans.org/) to find details of your nearest branch, where you can talk to one of our trained volunteers face to face.
* Every six seconds, Samaritans responds to a call for help.
* Samaritans is a charity and it’s the public’s kind donations and more than 20,000 volunteers that mean we are always there for anyone struggling to cope. Find out how you can [support us](http://www.samaritans.org/supportus) or [volunteer with us](https://volunteer.samaritans.org/volunteer).
* You can follow Samaritans on social media on [Twitter](https://twitter.com/samaritans), [Facebook](https://www.facebook.com/samaritanscharity/) and [Instagram](https://www.instagram.com/samaritanscharity/).