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**Thursday 24 June 2021**

**Stroke survivors in Northern Ireland shape stroke research
to rebuild lives**

The Stroke Association, the UK’s leading stroke charity, is announcing the top 10 priorities for stroke research, uncovered by a rigorous study involving stroke survivors like Thomas McGarvey from Lambeg, carers and health and social care professionals in stroke. The charity’s new report - the first UK-wide project to map research priorities across the entire stroke care and treatment pathway - reveals where research can address the issues holding stroke survivors back from rebuilding their lives after a devastating stroke.

Thomas McGarvey is 38 and lives in Lambeg, Co. Antrim, Thomas had a stroke just over three years ago and noticed the symptoms one morning on waking up. He was 34 at the time and was fit and healthy. It was later discovered that he had been living all his life with a hole in the heart or PFO. Thomas would like to see future stroke research focus on brain recovery in stroke survivors, what treatments or activities best promote neurogenesis (The growth and development of nervous tissue).

Thomas says: “When I woke that morning, I just remember the pounding headache and numbness all down one side. I almost fell down the stairs going to get painkillers. Vertigo was the most noticeable thing but I could see my mouth drooping slightly on one side in the mirror. I knew the signs of stroke because of the Act FAST adverts but couldn’t believe it and didn’t go to the hospital until much later.”

Thomas became increasingly concerned when he found that he couldn’t use his left hand to even grab the pain killers and noticed that his speech was affected and he was saying words in the wrong places.

Thomas says: “Physically I recovered quite quickly. My speech improved and my limp slowly got better. I had a patch of my vision that was affected too but that’s more or less gone now. The thing was, I didn’t realise how much the whole experience had hit me until months after my stroke. I started getting panic attacks which I’d hardly even heard of before my stroke. They would be so strong and I’d be convinced I was having another stroke. Thankfully I was offered cognitive behavioural therapy which helped me accept the changes in my brain. Stroke can affect any part of your brain and therefore change your emotions. I was really concerned that I wasn’t the same person as before. I had questions about my identity after stroke which really affected my recovery. I started second guessing what I was doing or saying in a given situation. Would I have said that before? Would I have handled that the same way?”

“I would say that I went back to work too soon but had little option financially. I know that there were definite times when I experienced a delay in my brain function. I’d be responding to a query and find that my chain of thought would just stop and I’d have to begin the process again. It took its toll on me and people would see that I looked perfectly fine but they had, through no fault of their own, little idea of the difficulties inside. It’s very hard for people to appreciate that. It can be overwhelming, especially in the early days. I often thought I just can’t cope with this. People are treating you as if everything’s fine but inside your head, it’s chaos. Anything I can do that helps other people, especially younger people who’ve had a stroke to know that they have to get help as soon as they can. Life goes on and it does get better. I do feel extremely grateful for the treatment I’ve had and that I’ve had a chance to heal and get better. Some days I do feel down about what happened to me but most days I just feel grateful to be here and feel I’ve been given a wonderful chance to continue recovering and be the best I can be. A quote I heard once really helped me understand. Your mind is a garden, it’s up to you what you want to grow in it.”

Each year there are over 100,000 strokes in the UK, that’s over 4,000 here in Northern Ireland. As a result, there are now over 1.3 million stroke survivors in the UK. In NI the figure is over 39,000. However, according to the most recent figures from the UK Medical Research Council [3], only £30m of public and charity health research spending goes on stroke. This equates to less than £25 per stroke survivor per year compared to £161 per person living with cancer [4].

Juliet Bouverie, Chief Executive of the Stroke Association said: “One in five people will have a stroke in their lifetime. Stroke happens in the brain, the control centre for who we are and what we can do. Every stroke is unique because the brain is so complex and stroke can happen in any part of it. This means there are as many different impacts of stroke as there are stroke survivors, posing a huge challenge for research.

“Despite major breakthroughs over the last 10 years, we now know where there are significant blind spots in treatment and care. These are holding people back from rebuilding their lives. With the number of people having strokes set to rise – it’s predicted that the number of stroke survivors aged 45 and over could rise to 1.4 million in 2025, and 2.1 million in 2035 [5], we must act now and invest in the research that will make the biggest difference to the lives of people affected by stroke.”

Over 1,400 people affected by stroke and professionals in stroke took part in the project, which was carried out in partnership with the James Lind Alliance (JLA), as well as individuals and organisations representing stroke patients, carers and professionals in stroke.

The Stroke Association is sharing the findings as part of its new report **“**Shaping Stroke Research to Rebuild Lives: The Stroke Priority Setting Partnership results for investment.” The report sets the agenda for stroke research and identifies the areas that most urgently need investment.  There are two lists of ten priority areas: the first in stroke prevention and acute care, and the second in rehabilitation and long-term care, ranked in order of importance.

The top priorities in each list are:

* Interventions to stop stroke. Stroke strikes every 5 minutes in the UK, but we know that most (80-90%) strokes are preventable [1,6]. We need increased investment in research so people can avoid the devastating effects of stroke in the first place.
* Understanding of, and treatment for mental and emotional problems. Three quarters of stroke survivors experience a change in their mental health [7], we need research so that people can overcome significant effects such as anxiety and depression after stroke.

Dr Rubina Ahmed, Director of Research and Policy at the Stroke Association, said: “Charities like ours need to look for new ways to help stroke survivors with emotional, mental and communication problems. Establishing what research will make the biggest difference to stroke survivors and those caring for them is just the first step. Stroke research is severely underfunded.  Just £1 in every £100 of public and charity spend in health research is on stroke and this just isn’t enough to solve the big and complex issues caused by stroke.

“The stroke funding crisis has been worsened by the coronavirus (Covid 19) pandemic, which has had a devastating impact on our income, halving the charity’s research budget.  Stroke research is at risk, which means recoveries like Thomas’s are at risk too. Your support can fund the research that will lead to breakthroughs in treatment and care. If you can, please donate so that we can make sure more stroke survivors can rebuild their lives after stroke.

“We would like to thank everyone who took part in this project: stroke survivors, their carers, professionals in stroke, the James Lind Alliance, the Steering Group members and our partners. By having your say for stroke, you have helped to shape stroke research to rebuild lives.”

Over the past 30 years the Stroke Association has played a crucial role in supporting stroke research in the UK. By establishing these priorities our charity can support the research that can make the biggest difference to the lives of people affected by stroke.

Find out how stroke research helps rebuild lives at stroke.org.uk/rebuildinglives or to donate, please visit: stroke.org.uk/savingresearch

To read the full list of priorities and the report visit: www.stroke.org.uk/psp

**-Ends-**

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**Notes to editors:**

The James Lind Alliance (JLA) Stroke Priority Setting Partnership (Stroke PSP), led by the Stroke Association, brought stroke survivors and carers together with professionals across the stroke pathway, including GPs, neurologists, occupational therapists and physiotherapists. Over 1,400 people affected by stroke took part in the research, which was carried out in partnership with the James Lind Alliance (JLA) and other charities. Please see [www.stroke.org.uk/jla](http://www.stroke.org.uk/jla) for a list of Steering Group members and partners.

1. [Sentinel Stroke National Audit Programme (SSNAP)](https://www.strokeaudit.org/results/Clinical-audit/National-Results.aspx) and [Scottish Stroke Care Audit (SSCA)](https://www.strokeaudit.scot.nhs.uk/Publications/Main.html)
2. [England (NHS Digital)](https://digital.nhs.uk/data-and-information/publications/statistical/quality-and-outcomes-framework-achievement-prevalence-and-exceptions-data); [Scotland (ISD)](https://beta.isdscotland.org/find-publications-and-data/health-services/primary-care/general-practice-disease-prevalence-data-visualisation/); [Wales (StatsWales)](https://statswales.gov.wales/Catalogue/Health-and-Social-Care/NHS-Primary-and-Community-Activity/GMS-Contract); [Northern Ireland (DoH)](https://www.health-ni.gov.uk/publications/202021-raw-disease-prevalence-trend-data-northern-ireland)
3. UK Clinical Research Collaboration, UK Health Research Analysis 2018, 2020 <https://hrcsonline.net/reports/analysis-reports/uk-healthresearch-analysis-2018/>
4. Macmillian Cancer Support, Statistic fact sheet <https://www.macmillan.org.uk/_images/cancer-statistics-factsheet_tcm9-260514.pdf>
5. The Future Incidence, Prevalance and Costs of Stroke in the UK. Age and Aging 2020: 49:277-282.
6. Global and regional effects of potentially modifiable risk factors associated with acute stroke in 32 countries (INTERSTROKE): a case-control study, VOLUME 388, ISSUE 10046, P761-775, AUGUST 20, 2016
7. Stroke Association, Lived Experience of stroke: Chapter 1 – Hidden effects of stroke. <https://www.stroke.org.uk/lived-experience-of-strokereport/>chapter-1-hidden-effects-of-stroke

**About the Stroke Association**

* Stroke strikes every five minutes in the UK and it changes lives in an instant.
* 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/TheStrokeAssoc), [Facebook](https://www.facebook.com/TheStrokeAssociation/) and [Instagram](https://www.instagram.com/thestrokeassociation/?hl=en).