

Struggling to recover

Life after stroke in Northern Ireland

#strugglingtorecover



Developed in partnership with
Dr Niamh Kennedy, Ulster University



Foreword

Stroke is a brain attack and can happen at any age, from birth to old age, causing lifelong impacts. However, with the right treatment, care and support stroke survivors can make a good recovery and maintain their independence and quality of life.

More than a decade has passed since the 2008 Northern Ireland stroke strategy. However, too many stroke survivors and their carers still tell us they feel abandoned when they leave hospital. They struggle to access the rehabilitation and support they need to recover. Our highly skilled and dedicated stroke workforce say they don't have the resources and time they need to help people make the best recovery they can. This needs to change.

Over the last ten years there have been significant advances in hospital stroke treatment in Northern Ireland with access to lifesaving clot removal treatment Thrombectomy – amongst the best in the UK. But we can still do better.

The Bengoa Report stated that radically reorganising hospital stroke services should be a priority and that this would help save lives and reduce disability. We agree. But it is equally important that there is urgent investment and reform of stroke services across the entire pathway – from prevention through to long term support.

Rehabilitation services and post-hospital support have long been identified as the 'Cinderella' services of stroke services. The 2008 stroke strategy recommended all stroke patients should have access to specialist community stroke care including physiotherapy, speech and language therapy, counselling as well as more support for carers. But unfortunately there hasn't been adequate investment in these important services and many people affected by stroke still struggle to recover.

We are at now at a key juncture for stroke services in Northern Ireland. We call on everyone involved to seize this opportunity to work together to make the best possible recovery from stroke a priority.

Thanks to Dr Niamh Kennedy from Ulster University who conducted research in 2018 which informs this report.

Barry Macaulay,
NI Director, Stroke Association

We believe that every stroke survivor has the right to make the best possible recovery they can after stroke

Coping with life after stroke can be challenging in many ways. Many people leave hospital feeling frightened, confused and having to face physical, psychological, financial and practical challenges. Too many stroke survivors struggle to access appropriate support once they leave hospital including physiotherapy, speech therapy, emotional support and help to get back to work and family life.

Best practice guidelines recommend at least 45 minutes a day of each type of rehabilitation therapy needed by stroke survivors for as long as it's of benefit to them¹. However, the reality is that, on average, stroke survivors in Northern Ireland only receive around a third of that. According to the latest Sentinel Stroke National Audit Programme (SSNAP) report for 2016-17, stroke survivors in Northern Ireland received²:

 **between 10 and 20 minutes of physiotherapy per day**

 **between 9 and 13 minutes of occupational therapy per day**

 **between 4 and 7 minutes of speech and language therapy per day.**



45% of all stroke survivors

feel abandoned when they leave hospital.

They tell us that there is a big-drop in care from hospital to home and that they are not getting the support they need which puts their recoveries at risk. For too many the support comes too late, stops too soon, or they are not offered all the specialist therapy they need.

This needs to change.

While it is great that more people are surviving stroke it is vital that everyone affected by stroke receives the right support, at the right time when they leave hospital so they can make the best recovery possible.

Northern Ireland needs a new stroke pathway which is properly resourced to provide the lifelong support stroke survivors need.

"I'm so grateful for the great care I received in hospital but I felt very lost when I was sent home. My brain had just had the biggest shock of its life and I was feeling shell shocked. I didn't know where to turn and felt a bit abandoned for few weeks. When I was sent home from hospital I was given a few leaflets but I don't think my brain could really process that information at the time. It was just all too much."
-stroke survivor

A decade of unmet needs

- 2008**
Stroke strategy
Every stroke patient should have access to appropriate community rehabilitation services and psychological and emotional support.
- 2014**
RQIA review of stroke services
Communication with stroke survivors about treatment and support needs to be improved.
- 2017**
Pre-consultation on reshaping stroke services
Long-term support and psychological and emotional support for those affected by stroke identified as particular areas of need.
- 2019**
Key juncture of the future of stroke services
Many of the recommendations of the 2008 Strategy and 2014 Review have still not been implemented fully.

We need action to be taken now to improve stroke care and support for people affected by stroke.

Our key findings

Over the past year, the Stroke Association have undertaken a number of engagement activities across Northern Ireland with people affected by stroke, carers and professionals about current stroke services and opportunities to develop them in the future.

We spoke to:



305
stroke survivors



75
carers of stroke survivors



101
professionals who work in stroke services



142
individuals from our voluntary stroke support groups

In particular there are gaps in:

- the length and intensity of post-hospital rehabilitation
- the provision of information to stroke survivors and their families
- emotional support
- support for carers
- help getting back to work
- public awareness of stroke.

In 2019 the Department of Health will consult with the public on the future of stroke services in Northern Ireland. It is vital that, as well as reshaping how acute stroke services are delivered, we seize the opportunity to develop and implement a new system of long-term support for those affected by stroke. This must address the areas of unmet need identified here and take action on the recommendations made in this report.

The right rehab, at the right time

There is good evidence linking the quality, intensity and promptness of rehabilitation with improved outcomes and reduced long term costs.



78% of stroke survivors said that the care and support they received at home was poor or very poor.

“After hospital I received very little support”

- stroke survivor

Rehabilitation therapies, such as speech and language therapy and physiotherapy, are vital in helping stroke survivors to manage and recover from any communication, physical or other disabilities as a result of their stroke.

However, many told us that they just did not receive enough rehabilitation, particularly when they went home, and that this made their recovery from stroke very difficult or impossible in some cases. Not having adequate rehabilitation undermines improvements in acute treatments.



Recommendation 1: The right therapy and support should be provided for people when and where they need it and for as long as they need it.



A third of stroke survivors have **problems with communication** following their stroke.

We don't have enough staff to provide the recommended amount of daily therapy”

- speech therapist

Better access to stroke information and support

Leaving hospital and returning home was identified by many stroke survivors as a period of uncertainty. They told us that one of the main reasons they feel abandoned when they leave hospital is because they don't know where to turn to for information or support.

Many say they are not even told basic things about how a stroke could affect them or about how to prevent another stroke. Some need signposting to peer support or other services to help their recovery. Others need help in navigating the benefits system which can be confusing and complicated for a stroke survivor with communication difficulties such as aphasia.



Recommendation 2: We encourage everyone involved in supporting people affected by stroke to use and share the information and support provided by Stroke Association and other charities so that no one affected by stroke feels abandoned.



67% of stroke survivors do not feel their physical needs are well met after hospital.

“When I was sent home from hospital I was given a few leaflets but I don't think my brain could really process that information at the time. But when I was referred to the charities later for help with speech therapy and exercise, it made a really positive impact on my recovery”

- stroke survivor

Increase psychological and emotional support for people affected by stroke



A shocking 90% of stroke survivors in Northern Ireland told us that their emotional and cognitive needs were not met once they left hospital.



54% of stroke survivors said they 'often' or 'always' feel anxious and worried following their stroke.



50% 'often' or 'always' feel depressed or have a low mood.

Many stroke survivors told us that the focus was often on their physical recovery, with little, if any, attention paid to the emotional and psychological impact of their stroke. This is worrying given that many stroke survivors talk about a sense of loss and grief following their stroke and many experience depression and anxiety.

We know that psychology services in Northern Ireland are under pressure. While it is vital that there is increased investment in statutory services, we also believe that the voluntary sector is ideally placed to help support people through services such as the Stroke Helpline, counselling services and peer support groups.



Recommendation 3: Increase investment in statutory services and commission the voluntary sector to meet unmet emotional and psychological needs

Stroke Association Emotional Support Service

The Stroke Association Emotional Support Service has been operating successfully in England. It provides counselling and emotional support for stroke survivors, their carers and families. With the help of a qualified counsellor, attendees explore issues arising from a stroke such as loss, adjustment, depression, relationship issues, anger and how to build confidence. We are piloting this service in Northern Ireland in 2019.

“I was discharged from hospital with no emotional support to help me deal with the after-effects of my stroke”

- stroke survivor

“Everyone underestimates the difficulty and frustration of not being able to communicate”

- stroke survivor

More support for carers

Caring for someone affected by stroke can be physically and emotionally demanding. In some cases, the lives of carers can be radically changed with some having to give up their jobs and spend most of their time at home. This can have a detrimental impact on their social lives and mental well-being.



Recommendation 4: The rights of family carers must be put on a legal footing, as outlined in *Power to People* and all carers must receive the support they need. We support Carers NI's call for an appropriately funded cross-government plan which sets out how improved support for carers will be achieved.



85% of carers do not feel prepared for their loved one to come home from hospital following a stroke.



98% of carers say they find it sometimes difficult to cope.



28% of carers know who to contact if they need more help.

"As a close family, this was our families' stroke - it has affected us all"

- stroke survivor

Caring and you

The Stroke Association Caring and You programme supports carers in a role that can often be emotionally and physically demanding.

Through the weekly sessions, carers will learn about:

- stroke and the hidden effects
- how to safely support someone who has had a stroke
- where to go for support and advice
- practical tips on caring with confidence
- the importance of looking after their own health and well-being.

The goal of the programme is for carers to be equipped in providing appropriate and optimal care to their loved ones, whilst also being able to look after their own emotional and physical health. We are piloting this programme in Northern Ireland in 2019.

More support for people who wish to return to work

The average age of stroke is falling, however younger stroke survivors have told us there isn't enough specific support for them. In some cases, younger stroke survivors require support with returning to work or coping with family life, as many may have young children.

Health professionals we spoke to also feel that there is a lack of community services to meet the needs of younger stroke survivors.

"No consideration given that I was young, had kids and needed to return to work"

- stroke survivor

"I was young and this was not taken into consideration - I felt I became an 80 year old overnight"

- stroke survivor

"Fatigue is a massive problem - no one could help me"

- stroke survivor

"We're not staffed to provide the degree of intensity required for some patients. I feel they need longer term input, particularly to deal with issues such as return to driving or work."

- health professional



Around 1 in 4 strokes happen to people under the age of 65.



Recommendation 5: The new stroke pathway must be designed and resourced to meet the needs of younger stroke survivors and those who wish to return to work.



Young stroke survivors Lisa, Laura and Clodagh at the Stroke Association's Step Out for Stroke event in Antrim.

Increase public understanding of the hidden effects of stroke

Stroke causes more disabilities than any other conditions. Almost two thirds of stroke survivors in Northern Ireland leave hospital with a disability.

Many of the people affected by stroke and carers that we spoke to highlighted that there is often low public awareness and understanding of stroke, particularly the hidden effects such as emotional issues and fatigue. Many people also stated that these invisible effects can be a barrier to them carrying out day-to-day tasks independently or returning to work.

As well as raising awareness of ways to lower your risk of stroke, we believe it is important for everyone working in stroke to enhance public understanding of the range, severity and long lasting impacts of stroke. This will help more people affected by stroke to feel supported and empowered to become socially active in their communities

We need greater awareness of aphasia and recognition of stroke as a long term chronic condition which requires support"

- health professional



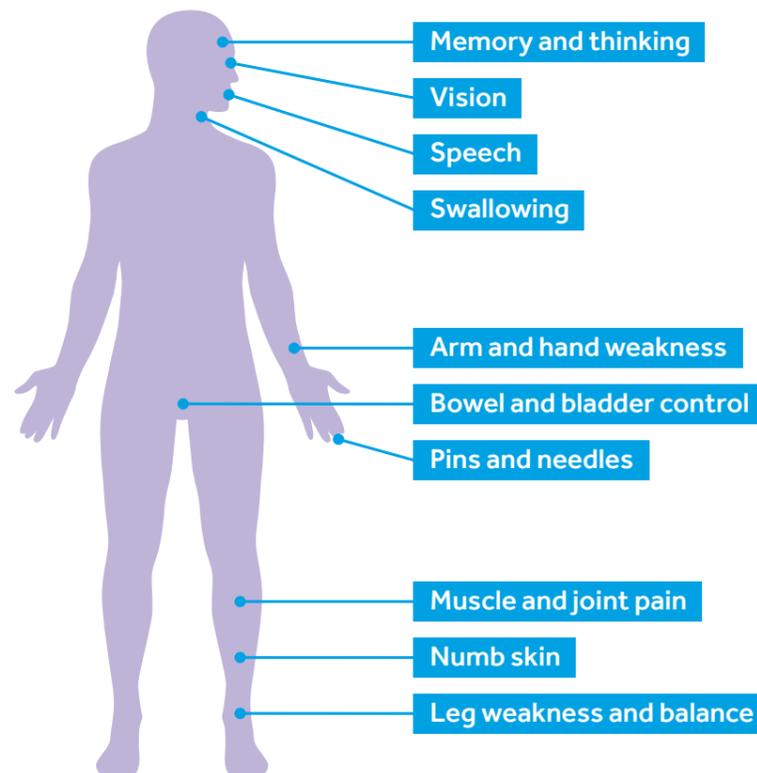
of stroke survivors experience some level of fatigue following their stroke.



Recommendation 6: Enhance public awareness and understanding of stroke and its effects.

"Everyone thought I'd had a miracle recovery because I wasn't in a wheelchair and I "looked fine". But every day is a struggle. My speech is still badly effected and I feel trapped and lonely"

- stroke survivor



What Next?

The long awaited public consultation on reshaping stroke services in Northern Ireland will begin in the coming months.

People affected by stroke in Northern Ireland deserve the best possible treatment and care. This will improve their quality of life and support them to make the best recovery possible.

We cannot have another decade of unmet needs and underfunding of community based stroke care. While hospital stroke services are developed and improved, it is vital that rehabilitation and long term support for stroke survivors is not left behind and we invest in community based stroke care. Not receiving appropriate rehabilitation undermines the improvements in acute care.

We're calling for the development and implementation of a regional stroke pathway, which is appropriately funded, and meets the needs of people affected by stroke from prevention to acute care through to long term support.



"No one should feel abandoned at the hospital gate. Let's work together to seize this golden opportunity to create world class stroke services which save lives, reduce disabilities and support better life after stroke"

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References

- ¹ Royal College of Physicians. (2016). National Clinical Guideline for Stroke. Available at: [https://www.strokeaudit.org/SupportFiles/Documents/Guidelines/2016-National-Clinical-Guideline-for-Stroke-5t-\(1\).aspx](https://www.strokeaudit.org/SupportFiles/Documents/Guidelines/2016-National-Clinical-Guideline-for-Stroke-5t-(1).aspx)
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- ³ Stroke Association. (2016). A New Era for Stroke Campaign Report. Available at: https://www.stroke.org.uk/sites/default/files/anefs_report_web.pdf

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We are the Stroke Association.

We believe in life after stroke. That's why we support stroke survivors to make the best recovery they can. It's why we campaign for better stroke care. And it's why we fund research to develop new treatments and ways of preventing stroke.

**We're here for you. Together we can conquer stroke.
If you'd like to know more please get in touch.**

Stroke Helpline: 0303 3033 100

Website: stroke.org.uk

Email: helpline@stroke.org.uk

From a textphone: 18001 0303 3033 100

We are a charity and we rely on your support to change the lives of people affected by stroke and reduce the number of people who are struck down by this devastating condition.

Please help us to make a difference today.



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Together we can conquer stroke