

Rebuilding Minds After **Stroke**

Supporting the emotional and
mental wellbeing of people
affected by stroke in Wales

Working in partnership

Cymdeithas
Strôc | **Stroke**
Association

 **Mind**
Cymru



Summary

The impact of stroke on a person's mental health is well-documented, yet there is little specialised support available.

Following a local project in Neath Port Talbot, the Stroke Association and Mind Cymru have worked together to further explore the experiences of stroke survivors and their mental health.

Through this work, we spoke with more than 100 people affected by stroke across Wales. We gained insight and understanding of the day-to-day issues facing a diverse range of people.

The key themes from our discussions were:

- **People do not expect the negative impact on their mental health after experiencing a stroke.**
- **Stroke survivors feel alone and uncertain in their recovery.**
- **Stroke affects people's identity, and they can struggle to adapt.**





Working with people with lived experience, we identified and prioritised potential solutions to support stroke survivors struggling with their mental health. We then prioritised, tested and refined these solutions to define recommended next steps to ensure the continuation of this work.

The Stroke Association and Mind Cymru now plan to further explore several solutions, which stroke survivors tell us will have the biggest impact for them. These include a wellbeing recovery group for stroke survivors, one-to-one talking therapies and a practitioner-led facilitated group for loved ones of stroke survivors.

Based on this project, the Stroke Association and Mind Cymru have made five joint recommendations;

1. **The Stroke Association and Mind Cymru should continue to work together to explore, iterate and deliver these ideas.**
2. **People working in stroke should recognise the impact of stroke on people's mental health and deliver services accordingly.**
3. **Plans to transform stroke services in Wales should include a focus on mental health support.**
4. **Public bodies should raise awareness of stroke, particularly among racialised communities and areas of social deprivation.**
5. **The next Welsh Government's mental health strategy needs to include reference to how people with specific physical health conditions are able to access mental health support tailored to their needs.**

Foreword

When stroke strikes, part of your brain shuts down. And so does a part of you. That's because stroke happens in the brain, the control centre for who we are and what we can do.

The impact varies depending on which part of the brain is affected. It could be anything from wiping out your speech and physical abilities, to affecting your emotions and personality. Lives change in an instant. As a result, people who survive a stroke often experience significant mental health struggles, including depression, anxiety, mood swings, panic attacks and suicidal thoughts.

Right now, there are more than 70,000 stroke survivors living in Wales. Yet there is little specialised support available to help them address their mental health.

A recent survey conducted by the Stroke Association found that around three quarters of stroke survivors experience at least one mental health problem following a stroke. Yet only 3% received support when they needed it the most.

"My mental health hit rock bottom. I was struggling every day. I wanted to cope, I wanted to be me again."

Freya, stroke survivor

The Stroke Association currently offers 'tier 1' psychological support to address this gap; via our coordinators in the community, our helpline, peer support from other stroke survivors, and social activity groups. But there's a gap in 'tier 2' support for stroke survivors struggling with mild/moderate depression and/or anxiety. We'd like to change that.

This report explores the lived experience of a diverse range of people who struggled with their mental health after stroke. It also highlights proposed solutions designed by stroke survivors and makes recommendations to improve mental health support for people who have a stroke and their carers.

We're calling on those who plan and provide health and social care to work with us to ensure that people affected by stroke receive quality, timely support for their mental health and wellbeing.

Recovery from stroke is tough, but with the right support and a ton of courage and determination, the brain can adapt. We want to support more people to adapt to their new life after stroke.



Katie Chappelle,
Associate Director - Wales,
Stroke Association

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To Note

Throughout this report we use the term 'racialised communities' when referring to groups of people who are non-white.

The term Black, Asian and Minority Ethnic and its various acronyms, has been the dominant term for some time. This is now, rightly and understandably, contested as it homogenises the experience of people from different backgrounds and has become a 'catch-all' which avoids the complexity of race and ethnicity, obscures identities and the particular challenges experienced by those groups referred to by it.

Instead we use the term racialised communities, particularly when speaking to race inequity, as this relates to the phenomenon of being categorised by race because of White-led systems and how this categorisation is used to label and oppress people. Racialised does not define people's community or identity and we may personally feel that Race describes an important part of our identity.

Project background

Following an impactful local collaboration in Neath Port Talbot, which tested a group-based community programme for people struggling emotionally after a stroke, the Stroke Association and Mind Cymru decided to embark on a service design process.

We wanted to gain an in-depth understanding of the experience of people struggling with their mental health post-stroke; to identify, test and prioritise potential solutions.

We worked with Shift, a research consultancy that creates on-the-ground social change to improve the lives of people negatively impacted by systemic inequality. Together we explored sustainable solutions to respond to the gap in support for people who are experiencing emotional and mental health problems after stroke in Wales.

The key objectives of this work were to:

- **Gain an in-depth understanding of the lived experience of a diverse range of people struggling with their emotional and mental health post-stroke.**
- **Identify and prioritise solutions to the challenges faced by stroke survivors struggling with their mental health.**
- **Test and refine these potential solutions and define recommended next steps to ensure the continuation of this work.**



The shared vision for this collaboration between the Stroke Association and Mind Cymru is for stroke survivors, their carers and families in Wales to receive the mental health support they need following their stroke, enabling them to rebuild their lives.

Why we chose Shift

The Stroke Association, Mind Cymru and people with lived experience of stroke looked at several research consultancy companies. Stroke survivors were involved in designing the brief for agency recruitment and a stroke survivor sat on our shortlisting and interview panel. Stroke survivors chose Shift and gave feedback on how they felt about the company taking on something so personal to them.

"I felt safe with Shift. I could be open and honest with them about my experience as a stroke survivor and I knew they would support me to tell my story."

Stroke survivor



The approach

At the heart of this work was the desire to develop solutions with and for stroke survivors. At each stage of the service design process - research, generating ideas, testing and prioritising - we were led by people with lived experience of stroke.

You can read more about the approach in Shift's project report, **Appendix One**, which can be found on our website.



Who was involved?



110 people across Wales helped shape this work.

This included:

- **48 stroke survivors**
- **48 people who work with stroke survivors**
- **14 loved ones of stroke survivors**

Within this, the following took place:

- Research conversations with 12 stroke survivors. They shared their experiences of struggling with their mental health after stroke.
- One co-design workshop with 15 people with experience of stroke (including seven stroke survivors) to generate ideas for potential support.
- Two testing workshops with 15 stroke survivors to help develop and refine ideas.
- 66 people with experience of stroke gave their feedback on three ideas for support.
- A lived experience storyteller, who has used creative writing to tell the story of his own stroke, and the experiences of the other survivors who took part in our project. You can read his full essay in [Appendix Two](#), which is available on our website.



Key findings

The Stroke Association and Mind Cymru do not easily reach people from racialised communities in Wales. Both organisations are committed to changing this.

More needs to be done to make sure that the solutions we are putting forward as part of this work are accessible to, and effective for, people from racialised communities.

Charities have a part to play to ensure that they reach seldom heard individuals and communities. We know that reaching people from diverse backgrounds is a much broader issue that needs to be addressed within the wider health and social care system. This was recently highlighted in Healthcare Inspectorate Wales's (HIW) National Review of Patient Flow: a journey through the stroke pathway.



To develop a solution that we felt confident would support stroke survivors, we spent the initial phase of this work listening directly to them; learning about their experience of having a stroke and how this affected their mental health and wellbeing.

We spoke with 12 stroke survivors. We held individual conversations with each person in a way that worked best for them; whether that was in-person, over the phone or online.

We also spoke with four people with learned experience of stroke including a clinical psychologist, a loved one, Mind Neath Port Talbot and a Stroke Association Coordinator.

Three overarching insights emerged from these discussions:

1. **People do not expect the negative impact on their mental health after experiencing a stroke.**
2. **Stroke survivors feel alone and uncertain in their recovery.**
3. **Stroke affects people's identity, and they can struggle to adapt.**

Using what we found, we worked with stroke survivors and professionals to develop ideas for solutions that could address these insights. We prioritised the ideas with a focus on impact for stroke survivors.

The four ideas were;

1. A hospital information pack about mental health
2. A practitioner-facilitated course for loved ones of stroke survivors
3. A wellbeing recovery group for stroke survivors
4. One-to-one talking therapies

We tested and refined these ideas with stroke survivors and professionals.

In addition to feedback on the ideas themselves, a key theme we heard is that there is no 'silver-bullet' solution for helping stroke survivors rebuild their mental health. What is needed is an holistic response to a complex issue: a variety of offers to meet stroke survivors where they are at.



A way forward

In discussions we were able to de-prioritise the idea of a hospital information pack.

It's important to recognise that 'not knowing what to expect' came up repeatedly in conversation with stroke survivors, yet further exploration identified that this idea could quickly be integrated into a hospital pack project already being developed by a team at the Stroke Association, to be launched in 2024.

One of the four ideas outlined above was the key forerunner. We heard that the wellbeing recovery group for stroke survivors would potentially have the biggest positive impact for stroke survivor mental health, and the most potential for the Stroke Association and Mind Cymru as an official partnership.

The idea to develop

A wellbeing recovery group for stroke survivors

For:

Stroke Survivors experiencing poor mental health and actively seeking support.

Who want to:

Share and process their experience of stroke - in a group setting with other stroke survivors.

When?

After initial physical and cognitive recovery, e.g. 3+ months post-stroke.

The benefits:

- Share and process with people who get stroke so they don't feel in it alone.
- Build new relationships.
- Get professional and peer support.



Connect with a small group of 6 stroke survivors.



A place to talk about how stroke has affected your mental health.



Facilitated by a stroke-experienced mental health practitioner.



Runs for 10 weeks - each week covering a topic like "sharing your stroke story", "talking to your loved ones" and "creating a personal wellbeing plan".



Join either an in-person group locally or an online group with similar people.



Option to join a wider stroke community afterwards.

However, we recognise that group solutions won't work for everyone. We also heard clearly about the key role of loved ones and carers in a stroke survivors' recovery. As a result, we will also explore being able to offer one-to-one counselling for those who a group setting is not appropriate for. When testing and iterating the next phase of this project, we will also investigate how the active partners course could work to complement a stroke survivor group, to equip loved ones of stroke survivors with the understanding of the mental impact of stroke.

What?	 <p>A wellbeing recovery group for stroke survivors.</p>	 <p>One-to-one stroke counselling.</p>
When?	After initial recovery, e.g. 3+ months.	On self-acknowledgment of wellbeing issues.
Why?	To speak to other stroke survivors, share and process personal experiences.	To speak to a mental health professional who "gets stroke" to help with coping and wellbeing.
Who?	Stroke survivors who want to talk about wellbeing with a group.	Stroke survivors who want to talk about wellbeing one-to-one.

Details of all ideas developed and explored, can be viewed in more detail in Shift's full report in the Appendix.

Conclusion

The findings of this project are clear; **there is a gap in 'tier 2' specialist mental health and wellbeing support after someone has a stroke.**

Mental health assessment and support should start when a stroke survivor is still in hospital, as is outlined in the National Clinical Guidelines for Stroke for the UK and Ireland (available at: www.strokeguideline.org). This means that clinical staff should have discussions with stroke-survivors to check on their wellbeing, make them aware of the potential impact of their stroke on their mental health, encourage ongoing and open discussion about how they are feeling and subsequently refer them for support that meets their needs.

Mental health support in the community can then be provided through life after stroke services. For this process to work smoothly and effectively, they should be integrated as an essential part of the stroke pathway in a way that makes it easily accessible for everyone. The only way to ensure that they are accessible and relevant to people affected by stroke is to engage directly with stroke survivors to listen, understand and act on their feedback to ensure that these services are co-designed, reflect their needs and regularly reviewed. The best way to do this is by engaging with charities and community organisations who are directly connected to people with lived experience.

These services should be sustainable rather than one-off projects, given the benefit that they provide to people who are affected by stroke. They must therefore be appropriately funded and resourced and integrated as an integral part of the stroke pathway in Wales.

14 loved ones took part in this project. It should be noted that the focus of mental health support has been directly on those who experience a stroke. More needs to be done to explore the impact of a stroke on carers and what support they might need. It is often a family member or partner who takes the main responsibility for supporting someone after a stroke and their mental health and wellbeing is vital to them being able to continue doing this.

This project focused on adults (over the age of 18). In addition, the National Clinical Guidelines for Stroke are targeted at adults. More needs to be done to explore the mental health needs of children and young people who experience a stroke.

The concluding message we hear from people affected by stroke is that **mental health and wellbeing should be equally as important as assessing and treating the physical symptoms of stroke.**

Stroke Association and Mind Cymru Recommendations

1. The Stroke Association and Mind Cymru should continue to work together.

The Stroke Association and Mind Cymru will continue to work together, to prototype and pilot the idea for a Wellbeing Recovery Group for stroke survivors, along with one-to-one counselling for those that need it and support for loved ones.

This will involve sourcing funding for this exploratory work and ongoing sustainable funding to deliver the final tested programme.

2. People working in stroke should recognise the impact of stroke on people's mental health and deliver services accordingly.

We urge GPs, Health Boards and clinical staff across the NHS to recognise that identifying and managing mental health issues post-stroke are an essential part of clinical rehabilitation and long-term stroke recovery.

Professionals working in stroke should follow the National Clinical Guidelines for Stroke, including ensuring that mental health and wellbeing are included for discussion in rehabilitation goal setting meetings and in six-month post-stroke reviews.



3. Plans to transform stroke services in Wales should include a focus on mental health support.

The Stroke Implementation Network, which sits under the NHS Executive, should ensure that ongoing plans to transform stroke services in Wales include the delivery of mental health support to all stroke survivors, in line with National Clinical Guidelines and other best practice recommendations.

The solutions outlined in this report should be supported to be implemented and delivered sustainably, should they be shown to be effective at addressing this long-standing and critical need. Service specifications should include ensuring that mental health assessment and support can be inclusive and accessible for all, for example, considering language needs for those who speak Welsh as a first language.

The introduction of a national Patient Reported Experience Measure survey (PREMs) will also support better understanding of how stroke survivors experience their care, including mental health support.

4. Public bodies should raise awareness of stroke, particularly among racialised communities and areas of social deprivation.

We urge Public Health Wales and Local Health Boards to implement the recommendations outlined in the HIW report. These public bodies should focus on ensuring that important campaigns reach a diverse range of people and work with those communities to truly understand the issues that they face. Only then will we see significant improvement in outcomes for a more diverse range of people affected by stroke. They can achieve this by engaging with and involving organisations that directly service those communities.

5. The next Welsh Government mental health strategy needs to include reference to how people with specific physical health conditions are able to access mental health support tailored to their needs.

As the Welsh Government is in the process of developing a new mental health strategy to replace Together for Mental Health we recommend that reference is made to conditions such as stroke and the need for mental health support to be available alongside physical health support. This would contribute to making parity a reality between physical and mental health as well as supporting recovery.

Acknowledgements

We would like to express our deepest appreciation to all those who helped us to complete this report.

We give a special gratitude to the 110 people across Wales who helped shape this work, including the stroke survivors, their loved ones and to all those people who supported them and who helped us along the way.

We also give thanks to the organisations who helped spread the word of the project and for their commitment to engage and involve people with lived experience in shaping the decisions. Their contributions helped us to coordinate this project and report.

Furthermore, we would also like to acknowledge, with much appreciation, the crucial role of the staff at Shift who undertook this research with us with passion and for providing us with crucial evidence to make a difference for people affected by stroke.

Last but not least, many thanks go to Stroke Association staff who work tirelessly to directly support stroke survivors and their carers and local Mind organisations across Wales who make sure everyone in Wales has access to the mental health information, support and services they need.



Working in partnership

