

Cyflwynwyd yr ymateb i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#)
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[Committee](#) consultation on [mental health inequalities](#)

MHI 42

Ymateb gan: | Response from: Cymdeithas Strôc | Stroke Association



Stroke Association response to the Health and Social Care Committee call for evidence on mental health inequalities

There are more than 70,000 stroke survivors living in Wales¹, and an estimated 7,400 people experience a stroke each year². Stroke happens in the brain, the control centre for who we are and what we can do and can strike anyone at any time.

A stroke changes life in an instant. 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. Recovery is tough but with the right specialist support and a ton of courage and determination, the brain can adapt.

The Stroke Association is here to support people to rebuild their lives. We believe everyone deserves to live the best life they can after stroke.

Summary

Many stroke survivors experience difficulties with their mental health and emotions as a result of their stroke. A stroke is sudden and shocking, and affects every part of a survivor's life. Most people who've had a stroke will experience some form of emotional change afterwards³. For many survivors, this may be general feelings of helplessness, loss, or anger. However, some survivors experience more substantial mental health difficulties. Around one-quarter of people who have a stroke will experience anxiety within the first five years, and a third of stroke survivors will have some form of depression within the first year⁴.

Mental health inequalities affect stroke survivors and their overall recovery in a number of ways. Below are the key areas for improvement that we have identified through our research:

¹ StatsWales, Quality Assurance and Improvement Framework (QAIF) disease registers by local health board. Available: <https://statswales.gov.wales/Catalogue/Health-and-Social-Care/NHS-Primary-and-Community-Activity/GMS-Contract/qualityassuranceandimprovementframeworkqaifdiseaseregisters-by-localhealthboard>

² Welsh Government. 2021. Quality Statement for Stroke. Link: <https://gov.wales/quality-statement-stroke.html>

³ Stroke Association. Emotional Changes after a stroke. Link: <https://www.stroke.org.uk/effects-of-stroke/emotional-changes#:~:text=You%20may%20get%20angry%20more,hard%20to%20control%20your%20emotions.>

⁴ NHS Improvement. 2011. Psychological care after stroke: Improving stroke services for people with cognitive and mood disorders. Link: https://www.nice.org.uk/media/default/sharedlearning/531_strokepsychologicalsupportfinal.pdf

- There is an unmet need for low level and early intervention mental health services in the community. Current provision across Wales of all forms of mental health and psychology is not meeting the demand, and Covid-19 has only further intensified this problem. There needs to be increased provision of mental health and wellbeing services across Wales.
- Barriers stroke survivors may face in accessing mental health services are complex and multifaceted, and should be addressed when designing new service provision, recognising that support for Welsh language and rural communities should be targeted.
- Local health boards in Wales should implement a personalised stroke record, which would contain relevant information to help stroke survivor's recovery and improve hospital discharge. Communication between community and acute services needs to improve to provide more holistic mental health support and rehabilitation services.
- Welsh Government need to implement clear standards on health boards for six month reviews and rehabilitation services to ensure accountability and consistency. This should be committed to by Welsh Government as part of the new national plan for stroke.

This response will include quotes and lived experience from stroke survivors, as well as evidence of the unmet need for mental health support in community settings. We will make a number of recommendations within this response based upon the testimony of stroke survivors, their experiences with the health system, and our own research.

Which groups of people are disproportionately affected by poor mental health in Wales? What factors contribute to worse mental health within these groups?

Stroke impacts the brain, and the brain is responsible for our behaviour and emotions. For this reason, a survivor may struggle to control their mood and emotions. This is called emotionalism, sometimes known as 'emotional lability'. Emotionalism is most common in the early stages of stroke, when about one-fifth of people experience it⁵.

When a physical illness like stroke is accompanied by mental illness, it risks impacting on an individual's outcomes, including a survivor's life expectancy. Healthcare costs for patients with long-term conditions, who also have depression

⁵ Stroke Association. 2020. Emotional changes after stroke. Link: https://www.stroke.org.uk/sites/default/files/publications/jn_2021-167.22_-_depression_and_other_emotional_changes_a5_f10_web.pdf

or another mental illness, are typically 45% higher than those without⁶. These changes can be difficult for the person experiencing them, as well as having impact on family members and carers. This makes access to mental health services and rehabilitation vital.

Unfortunately, stroke survivors across Wales are still struggling to access the psychological support they need to make the best possible recovery. Stroke survivors have already faced barriers in accessing services prior to the pandemic, but Covid-19 has put even further pressure on fragile services which already struggled to meet their needs.

Recommendation 1: Welsh Government, health boards and local authorities should prioritise increasing the provision of, and access to, mental health services, to respond to the significant demand and unmet mental health and wellbeing needs of people affected by stroke, to improve their health outcomes and emotional wellbeing.

For the groups identified, what are the barriers to accessing mental health services? How effectively can existing services meet their needs, and how could their experience of using mental health services be improved?

"I felt left to my own devices after leaving hospital, with no advice on where to get any support physically or psychologically."

Stroke survivor, Neath Port Talbot

For people who have experienced a stroke, there can be many barriers to accessing services directly linked to their condition. Stroke happens in the brain, and this means that it affects people in a number of ways. Survivors may experience difficulty with their speech (aphasia), and this can make accessing services and communication very difficult. Research shows that communication and processing difficulties (which arise in approximately 1/3 of all stroke cases⁷) adversely affect an individual's ability to access healthcare services, which often rely on effective communication. Stroke survivors have reported that their healthcare needs were often not supported because of the inadequate communication with their health professional; staff would only generally 'check-in' rather than perform a thorough mood screen, which usually deterred patients from seeking assistance⁸. This gap in

⁶ Centre for Mental Health. 2012. Long-term conditions and mental health: The cost of co-morbidities. Link: https://www.kingsfund.org.uk/sites/default/files/field/field_publication_file/long-term-conditions-mental-health-cost-comorbidities-naylor-feb12.pdf

⁷ National Aphasia Association. Link: [https://www.aphasia.org/aphasia-resources/aphasia-statistics/#:~:text=About%201%20third%20\(225%2C000\)%20of,in%20Great%20Britain%20with%200aphasia.](https://www.aphasia.org/aphasia-resources/aphasia-statistics/#:~:text=About%201%20third%20(225%2C000)%20of,in%20Great%20Britain%20with%200aphasia.)

⁸ Baker et al., 2019

mental health provision has only widened with the impacts of the Covid-19 pandemic.

There are also other barriers to access, such as where they live, the provision of mental health services in their local area, and simply not knowing there are services they can access to help with their emotional recovery. In particular, many stroke survivors tell us that they often feel that they do not receive enough information or support when leaving hospital, nor do they know where they can access specialised services to support their recovery.

“I was trundled out to the car park in a wheelchair, given a bag of pills, and told that arrangements for further rehab and support would be scheduled. But I never heard anything and didn’t know who to speak to.”

Malcolm, Conwy

For many survivors, the first and only time they may see a psychologist is during their inpatient stay, and currently this support is only applicable to 3.8% of stroke patients in Wales⁹. Clinical psychology is not available in all post-acute stroke care, with 9 out of 24 (37.5%) post-acute stroke teams in Wales not offering clinical psychology at all¹⁰.

We recently conducted a short survey of people affected by stroke (n=29) to understand their experiences of being discharged from hospital. Of these, 71% of stroke survivors and carers told us they did not have enough information on recovery when they left hospital¹¹. Without adequate information, many stroke survivors do not know of the local mental health services they can access, or routes to referral and access. We are concerned that this means there are a cohort of patients who are unable to have the best possible recovery after stroke due to lack of ongoing support and information on the services, clubs and groups available to them.

“I received six weeks of mental health therapy, but was then dropped by the system and I have been struggling with my depression ever since. In a way I was disappointed that the stroke didn’t leave me with a physical disability instead, because everyone who saw me thought, ‘You look well’. You just end up lying and saying you’re doing fine”

Stroke survivor, Risca

⁹ SSNAP. 2021. Country Results Portfolio. Link:

<https://www.strokeaudit.org/results/PostAcute2021/National.aspx>

¹⁰ SSNAP. 2021. Post-acute Organisational Audit. Link:

<https://www.strokeaudit.org/results/PostAcute2021/National.aspx>

¹¹ Hospital discharge survey carried out by Stroke Association. 2021.

Our lottery-funded Community Steps project worked with a group of stroke survivors who have decided to campaign for better information on discharge for stroke survivors. They identified the availability of information on discharge as a common concern within the group, with the majority having had a negative experience of discharge during their own recovery. Campaigners also highlighted that the cognitive impact of a stroke can make it difficult to recall information, meaning having it in a written form is essential. It also enables information to be shared with carers and loved ones, as well as other medical professionals the stroke survivor encounters.

They are calling on local health boards in Wales to implement a new personalised stroke record, which would contain relevant information to help their recovery. This information would include details such as the type of stroke they have experienced, common symptoms which may occur after a stroke, medication they are on, who will be in contact with them next and who they can contact for further information. This work is based on an approach currently being developed by the Stroke Association in conjunction with NHS England.

Another barrier that stroke survivors may experience is lack of available services in their first language. Stroke survivors tell us that they have difficulty accessing mental health services available in Welsh. This is of particular concern to us, as the Welsh Language Commissioner's report *My Language, My Health*¹² noted that the Welsh language is crucial for health and social care service quality, and a Welsh language service is vital for the recovery of Welsh-speaking patients. For many survivors across the country, Welsh is their first language, and as such there needs to be mental health services in the community which support people in Welsh.

Evidence shows that when services can be delivered in an individual's first language, this can accelerate recovery and lead to better outcomes¹³. Welsh Government released an evaluation last year of the *More than just words* strategic framework 2016-2019¹⁴, which highlighted that "for many Welsh speakers being able to access services in Welsh made a significant positive difference to their overall experience as well as in many cases, the health and well-being outcomes they gained as a result"¹⁵. This evaluation also uncovered the barriers native Welsh speakers may experience when trying to access health and social care services in

¹² Welsh Language Commissioner. 2014. Link: [www.comisiynyddygyymraeg.org/English/Publications List/Health inquiry full report.pdf](http://www.comisiynyddygyymraeg.org/English/Publications/List/Health%20inquiry%20full%20report.pdf)

¹³ Welsh Government. 2021. Evaluation of *More than just words*: final report. Link: <https://gov.wales/evaluation-more-just-words-final-report>

¹⁴ Welsh Government. 2016. *More than just words* strategic framework 2016-2019. Link: <https://gov.wales/sites/default/files/publications/2019-04/follow-on-strategic-framework-for-welsh-language-services-in-health-social-services-and-social-care-2016-2019.pdf>

¹⁵ Welsh Government. 2021. Written Statement: Strengthening Welsh language services in health and social care. Link: <https://gov.wales/written-statement-strengthening-welsh-language-services-health-and-social-care>

their first language, and are often reluctant to ask for these services when not offered them.

Current provision of mental health support needs to vastly improve to address the unmet need of individuals recovering from stroke. 25% of stroke units in Wales do not provide psychology at all, and the amount provided in units that do is significantly lower than average. (1.8 minutes per day in Wales compared to the SSNAP average of 3.9 minutes per day)¹⁶. Low level and early intervention mental health support is equally as vital as specialist support for stroke survivors as it can prevent mental health emergencies and give survivors ongoing support in community spaces they feel comfortable in.

“The peer support groups and exercise classes I attend are vital for me and my mental health. Meeting other stroke survivors and sharing our stories helps me to feel less alone.” **Stroke survivor, Wrexham**

Peer to peer support groups are vital for many stroke survivors in rebuilding their lives after stroke. We have collaborated with MIND in Neath Port Talbot to deliver bespoke low level mental health support to the stroke survivor group in the area. The initial project has been a success, with many stroke survivors saying that the group was essential to their wellbeing.

We are currently in discussions with MIND in the Neath Port Talbot (NPT) area looking at how we can enhance the successful project they have been running in the area. We will be in further conversations with other MIND organisations across Wales and the UK to identify how we can work in partnership with them, building on the learnings of the NPT initiative.

We welcome the commitments set out in the Quality Statement for Stroke, and Welsh Government’s intention to improve partnership working across sectors to streamline the stroke pathway and rehabilitation.

Recommendation 2: As part of developing a new plan for stroke, the Welsh Government should develop national standards for stroke rehabilitation, as well as prioritising increasing the provision of, and access to, mental health services in the community for stroke survivors. The complexities of health inequalities and barriers to accessing health services should also be considered when increasing the mental health provision across Wales, recognising that provision for Welsh language and rural communities should be targeted.

¹⁶ SSNAP. 2021. Country Results Portfolio. Link:
<https://www.strokeaudit.org/results/PostAcute2021/National.aspx>

Recommendation 3: Local health boards in Wales should implement a personalised stroke record, which would contain relevant information to help stroke survivor's recovery and improve hospital discharge. The personalised stroke record also enables information to be shared with carers and loved ones, as well as other medical professionals the stroke survivor encounters on their journey to recovery.

To what extent does Welsh Government policy recognise and address the mental health needs of these groups? What further action is needed to improve mental health and outcomes for the groups of people identified and reduce mental health inequalities in Wales?

In the months that follow a stroke, many people experience changes in their needs and struggle to adjust to the often devastating impact of their stroke. A formal person-centred review at approximately six months after stroke identifies such needs. The review enables action to be taken to improve recovery and wellbeing, help prevent further stroke and support people to live the life they want to live.

Prior to the pandemic, stroke survivors were already struggling to access psychological support in Wales. Six-month reviews have been a national policy requirement since 2000, yet they are not routinely undertaken by health boards. Figures show only 31% of stroke survivors received a six month review between July and September 2021¹⁷. These reviews are crucial for identifying survivors who may be struggling with their emotional recovery. Our research shows evidence of the need to improve access to psychological support and reviews for stroke survivors.

Clinical guidance, along with the previous Stroke Delivery Plan, supported the undertaking of stroke survivor reviews. Evidence showed the importance of reviews in understanding the mental health needs of stroke survivors. The Cross Party Group on Stroke recommended during the 5th Senedd that the Welsh Government should provide direction to health boards to ensure all stroke survivors are offered six month, annual and twelve month reviews as recommended by guidance¹⁸. We hope this recommendation will be implemented as part of the Welsh Government's forthcoming delivery plan.

Recommendation 4: Local health boards should ensure all stroke survivors receive six-month reviews as standard. This should be committed to by Welsh Government as part of the new national plan for stroke.

¹⁷ SSNAP. 2021. Country Results Portfolio. Link:

<https://www.strokeaudit.org/results/PostAcute2021/National.aspx>

¹⁸ Cross Party Group on Stroke. 2020. The Future of Stroke Care in Wales. Link:

<https://business.senedd.wales/documents/s100374/Report%20of%20the%20inquiry%20into%20the%20implementation%20of%20the%20Welsh%20Government's%20Stroke%20Delivery%20Plan.pdf>

For further information on any of the points raised in this response please contact Emma Burke, Public Affairs and Campaigns Officer, Wales on

Mae'r ddogfen hon ar gael yn Gymraeg ar gais