

Cafodd yr ymateb hwn ei gyflwyno i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#) ar [Flaenoriaethau'r Chweched Senedd](#)

This response was submitted to the [Health and Social Care Committee](#) consultation on [Sixth Senedd Priorities](#)

HSC PSS 48

Ymateb gan: | Response from: Y Gymdeithas Strôc | Stroke Association



Cwestiynau am strôc? Questions about stroke?
Ffoniwch ein llinell gymorth neu ewch at y wefan:
Phone our helpline or visit our website:
0303 3033 100 / stroke.org.uk
(Ffôn testun / Textphone 18001 0303 3033 100)



Russell George MS
Health and Social Care Committee
Welsh Parliament
Cardiff Bay
Cardiff
CF99 1SN

Freepost
Stroke Association Wales

24 September 2021

Dear Mr George,

Priorities for the sixth Senedd

We welcome the opportunity to respond to the initial priorities identified by the Health and Social Care Committee for the sixth Senedd, as well as to highlight two further potential key priorities for the Committee.

Stroke survivors in Wales are struggling to access the treatment and support they need to make the best possible recovery. Stroke survivors are not always able to get timely access to vital rehabilitation, like speech and language therapy or physiotherapy, or find their support is withdrawn earlier than they want.

These are not new problems. Stroke survivors 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. The Welsh Government and NHS needs to put forward solutions to these problems, and Covid-19 must not be used as a reason to delay much needed action to improve stroke services in Wales.

Our research found the Covid-19 pandemic has had a real impact on stroke survivors, with many facing cancelled appointments, increased feelings of isolation and a lack of support for those who care for them. Many stroke services were already struggling even prior to the pandemic. We're concerned they are now at risk of breaking under

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the increased pressure created by a backlog of needs, combined with the impact of long-Covid.

There are more than 70,000 stroke survivors living in Wales¹. 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.

We believe many of the priorities identified by the Health and Social Care Committee are relevant to the challenges encountered by stroke survivors in Wales and are broadly supportive of the initial priorities.

Comments on each of the initial priorities are below.

Public health and prevention

During the Cross Party Group on Stroke's inquiry into implementation of the Welsh Government's Stroke Delivery Plan, held during the previous Senedd term, prevention was an area highlighted as having made good progress in implementation. Projects such as the Stop a Stroke project, have helped increase the number of people who have received interventions to help reduce their risk of stroke. However, further progress can still be made and some ongoing issues were identified.

While an estimated 9 out of 10 strokes are due to modifiable risk factors², many people do not know about their own risk of stroke or the risk factors which may be relevant to their health. This includes risk factors such as atrial fibrillation (AF). Almost 79,000 people in Wales have been diagnosed with AF³, with the condition becoming more common as people age. AF raises the risk of stroke 5 times, and can lead to strokes which are particularly serious⁴. However, estimates are that a further third of people

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 Kings College London, *Stroke pathway – Evidence Base Commissioning: An evidence review*, December 2020.

³ *Quality Assurance and Improvement Framework (QAIF) disease registers by local health board*

⁴ Stroke Association, *Atrial Fibrillation*. Available: <https://www.stroke.org.uk/what-is-stroke/are-you-at-risk-of-stroke/atrial-fibrillation>

are unaware they have the condition. Hypertension (high blood pressure) remains a concern, with over 500,000 diagnosed with the condition in Wales⁵.

Improving public awareness, detection and appropriate interventions for stroke risk factors such as these should be a high priority of the Welsh Government, including in the implementation of the forthcoming Quality Statement on Stroke.

One area of prevention highlighted by the Cross Party Group on Stroke as being in need of improvement was health service responses to transient ischaemic attacks (TIAs, or 'mini-strokes'). One in 12 of those who have a TIA will have a 'full' stroke within a week, with the greatest risk in the first few days⁶. Clinical guidance states that people who experience a TIA should be assessed by a specialist within 24 hours⁷. However, the Inquiry found that isn't routinely the case in Wales and data was not collected in a consistent way⁸.

During any work progressed on public health and prevention, identifying how stroke risk factor identification and treatment can be improved and progressed should be one of the key priorities of the Committee.

The health and social care workforce, including organisational culture and staff wellbeing

There are a number of areas of concern in relation to the stroke workforce, with shortages in appropriately skilled staff impacting services across the stroke pathway. Pressures existed on the workforce prior to the recent new challenges created by Covid-19 and Brexit. These issues create an even greater urgency to address the problems which exist, to ensure we have adequate staff to meet the needs of our stroke services as they continue to develop.

Thrombectomy is a game changing treatment for stroke, which can improve outcomes for patients and save lives⁹. The treatment is performed by interventional neuroradiologists (INRs), however a shortage of trained professionals across the UK is limiting the number of people who can benefit from the treatment. Despite an

⁵ Ibid.

⁶ Welsh Government, *Stroke Delivery Plan 2017-2020*, February 2017. Available: <https://gov.wales/sites/default/files/publications/2018-12/stroke-delivery-plan-2017-to-2020.pdf>

⁷ Royal College of Physicians, *National clinical guideline for stroke Fifth Edition 2016*. Available: [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)

⁸ Cross Party Group on Stroke, *The Future of Stroke Care in Wales*, March 2020. Available: <https://business.senedd.wales/documents/s100374/Report%20of%20the%20inquiry%20into%20the%20implementation%20of%20the%20Welsh%20Governments%20Stroke%20Delivery%20Plan.pdf>

⁹ Stroke Association, *What we think about: thrombectomy*. Available: https://www.stroke.org.uk/sites/default/files/new_pdfs_2019/our_policy_position/psp_-_thrombectomy.pdf

estimated 10% of stroke patients being able to benefit from thrombectomy¹⁰, only University Hospital of Wales performs the treatment in Wales at present, with 10 carried out in 2019/20¹¹. Patients outside of Cardiff and Vale Health Board are able to access commissioned services in Bristol and the Wirral, however these services are not available 24 hours a day. Increasing the number of trained INRs, or accrediting other specialists to deliver the treatment, has the potential to greatly increase the number of patients able to benefit from thrombectomy.

Rehabilitation services are also impacted by staff shortages. The Cross Party Group on Stroke investigated why such a high level of variation exists in the provision of rehabilitation services for stroke survivors in Wales. While clinical recommendations are for stroke survivors to receive 45 minutes of each applicable therapy per day for as long as they require it¹², currently stroke survivors receive substantially less than this. For example, the most recent stats show an average of 13.5 minutes per day for speech and language therapy in Wales¹³. Evidence from organisations such as the Royal College of Speech and Language Therapists and Chartered Society of Physiotherapy showed that a shortage of trained staff to deliver these services was the primary driver of variation¹⁴.

The Cross Party Group on Stroke inquiry also found concerns around the number of stroke skilled consultants available in Wales, with the Welsh Association of Stroke Physicians describing a "crisis of recruitment in stroke medicine"¹⁵. The current Stroke Delivery Plan advocates re-organising existing stroke units in Wales to hyperacute stroke units (HASUs). The development of these units will require additional consultants (as well as other stroke skilled staff). A lack of available consultants risks being a barrier to the development of HASUs, or that those units that are developed are not able to meet clinically recommended levels of staffing.

These issues are examples of how the workforce challenges in stroke have the potential to impact on the services available to stroke patients, and should be considered by the Committee during their work on this topic.

¹⁰ Ibid.

¹¹ Sentinel Stroke National Audit Programme, *SSNAP Annual Portfolio for April 2019-March 2020 admissions and discharges*. Available: <https://www.strokeaudit.org/Documents/National/Clinical/Apr2019Mar2020/Apr2019Mar2020-ThrombectomyReport.aspx>

¹² *National clinical guideline for stroke Fifth Edition 2016*

¹³ Sentinel Stroke National Audit Programme, *SSNAP Portfolio for January - March 2021 admissions and discharges: Country Results Portfolio*. Available: <https://www.strokeaudit.org/Documents/National/Clinical/JanMar2021/JanMar2021-CountryResultsPortfolio.aspx>

¹⁴ *The Future of Stroke Care in Wales*

¹⁵ Ibid.

Access to mental health services

Mental health issues are common following a stroke, with our research showing 76% of stroke survivors experiencing depression, anxiety, a lack of confidence, mood swings or even suicidal thoughts during their recovery from stroke¹⁶. Unfortunately, many stroke survivors in Wales are not able to access the mental health services they need during their recovery. Only 5.1% of stroke survivors in Wales receive psychology services during their recovery¹⁷, and many struggle to access generic mental health services such as counselling, reporting long waiting lists and a lack of understanding from GPs.

Covid-19 has also had detrimental impact on the mental health of both stroke survivors and those who care for them. Almost half of stroke survivors and carers we surveyed in summer said they have felt less able to cope with the effects of their stroke and over two thirds of stroke survivors and carers have felt anxious or depressed¹⁸.

As a service provider, we have also seen a recent increase in complex cases, including those where mental health problems are impacted on the wellbeing of the stroke survivor. This is adding pressure on our services and the staff who work for us, and indicates a strong need for stroke specialist mental health services throughout Wales.

We are aware the Welsh Government plans to continue to invest further in mental health services, but specialised services for those with particular needs, such as stroke survivors, need to be part of this plan for investment. Lower level services, such as those designed to address issues such as isolation, which can be experienced by stroke survivors, are also in need of further improvement.

We support access to mental health services being a priority for the Committee, and ensuring access to services for stroke survivors should be investigated by the Committee.

Evidence based innovation in health and social care

During the Covid-19 pandemic, many people affected by stroke saw the services they need, such as physiotherapy and speech and language therapy, move towards being delivered online or by phone. 23% of those we surveyed had support delivered this way, however 48% had appointments related to their stroke cancelled, suggesting

¹⁶ Stroke Association, *Lived Experience of Stroke: Chapter 1 – Hidden effects of stroke*, 2019. Available: https://www.stroke.org.uk/sites/default/files/final_lived_experience_of_stroke_wales.pdf

¹⁷ SSNAP Portfolio for January - March 2021 admissions and discharges

¹⁸ Stroke Association, *Stroke Recoveries at Risk: How Covid-19 has affected stroke survivors in Wales*, September 2020. Available: https://www.stroke.org.uk/sites/default/files/campaigning/jn_2021-121.5_-_covid_report_wales.pdf

these virtual appointments were not replacing all appointments stroke survivors required¹⁹.

Appointments delivered virtually may present accessibility barriers for people affected by stroke, as stroke survivor's vision, dexterity and cognitive ability may be impacted by their stroke. While we support the use of innovative approaches to the delivery of services, it must only be used where appropriate and access to more traditional approaches of delivery must be equitable for those who need them.

Any work by the Committee which looks at innovation in health care should include the views of those who use these services, such as stroke survivors, and whether services meet their needs and the way they want these services delivered.

Support and services for unpaid carers

Our Recoveries at Risk found the Covid-19 pandemic has had a real impact on carers for stroke survivors in Wales. 57% of those surveyed said they felt overwhelmed and unable to cope during the pandemic. 89% said they are found it more difficult to carry out practical tasks such as shopping for food or picking up prescriptions²⁰.

Even prior to the pandemic stroke survivors struggled to access services. Those we have spoken to tell us they had little confidence in services available for carers, and didn't receive the carer's assessments which they are entitled to under the Social Services and Wellbeing (Wales) Act.

We support the inclusion of carers as a priority for the Committee.

Access to COVID and non-COVID rehabilitation services

Prior to the pandemic, the most common concern expressed to us by stroke survivors was the availability of rehabilitation services to help them in their recovery. Despite rehabilitation being more effective earlier in recovery, stroke survivors faced delays in accessing services, and despite clinical recommendations, often found the amount they were able to access was time limited to just six weeks. Services were stretched, and this was impacting on the recovery of stroke survivors.

The Cross Party Group on Stroke concluded there was "a clear gap between the commitments made in the Stroke Delivery Plan and the reality of life after stroke services in Wales" and "an urgent need to improve therapy provision"²¹.

¹⁹ *Stroke Recoveries at Risk: How Covid-19 has affected stroke survivors in Wales*

²⁰ Ibid.

²¹ *The Future of Stroke Care in Wales*

We now know that one of the impacts of Covid-19 will be the rehabilitation needs of those who experience Long Covid. This risks creating additional pressure on those services which were stretched even prior to the pandemic.

At present, it is not clear how this will be addressed and we are concerned that those existing problems will be further exacerbated by this new pressure on services.

We wrote to the Assistant Committee Clerk in June suggesting this topic as a potential piece of work for the Committee to look at, and are pleased this is included within the initial priorities. Our opinion is this should be one of the main and urgent priorities of the Health and Social Care Committee.

Access to services for long-term chronic conditions, including musculoskeletal conditions

The Stroke Association has no comment to make on this priority.

What other key priorities the Committee should consider during the Sixth Senedd in relation to: health services, social care and carers, and COVID recovery

Further to our email to the Assistant Committee Clerk dated 30 June, we believe the Committee should look at progress made on the implementation of the Welsh Government's existing health delivery plans, including the current Stroke Delivery Plan.

In autumn 2019 there was a plan for the then Health and Social Care Committee to look at the Welsh Government's health delivery plans, as most were due to come to an end. This was an idea we supported, particularly given several Cross Party Groups (including the former CPG on Stroke) were holding their own inquiries into the relevant condition specific delivery plans.

A common finding has been the lack of progress made on implementation of the delivery plans. Given the Welsh Government is undertaking a new approach with the development of quality statements and implementation plans, there would be value in understanding what the barriers to implementation of the current plans have been, and what lessons could be learned for the new approach to ensure a more successful period of delivery in the time spanned by the new documents.

We would suggest this as an ideal topic to be investigated by the Committee.

Funding for third sector organisations remains an ongoing challenge for all those working within the sector, including being a barrier to improved partnership working between different organisations. Partnership working has helped the third sector to

continue to deliver vital services during the Covid-19 pandemic, but the short term funding mechanisms which continue to be used create uncertainty for both those delivering services, but also our service users, including stroke survivors. Regional Partnership Boards have a clear role in addressing the challenges which exist in partnership working and funding, but they can be difficult to engage with, including a lack of clear mechanisms for doing so.

The Committee should give consideration on how they can look at the issues of third sector funding, partnership, engagement and the role of Regional Partnership Boards.

If you would like any further information on any of the topics above, then please do not hesitate to contact me.

Yours sincerely,

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Policy and Influencing Lead (Wales)
Stroke Association