

Cwestiynau am Covid-19: Dae Strôc  
Ymateb i'r Cwestiynau

Ffoniwch ein llinell gymorth neu ewch at y wefan:

Phone our helpline or visit our website:

0303 3033 100 / [stroke.org.uk](http://stroke.org.uk)

(Ffôn testun / Textphone 18001 0303 3033 100)



Dr Dai Lloyd MS  
Chair, Health, Social Care and Sport Committee  
Welsh Parliament  
Cardiff Bay  
Cardiff  
CF99 1NA

14 October 2020

Dear Dr Lloyd,

### Stroke Association response to the inquiry into the impact of the Covid-19 outbreak, and its management, on health and social care in Wales.

Please find attached a copy of a recent report produced by the Stroke Association, entitled 'Stroke Recoveries at Risk in Wales'. This report focuses on responses from stroke survivors and carers in Wales and accompanies a UK-wide report. This report is being submitted as evidence by us in response to the ongoing inquiry by the Health, Social Care and Sport Committee.

Our research was conducted over the summer and consisted of a survey of more than 2,000 stroke survivors and carers for stroke survivors across the UK, including around 130 in Wales. Our research found three main themes in Wales:

- **Covid-19 has had a negative impact on the mental health of stroke survivors in Wales.** Almost 50% of stroke survivors and carers said they have felt less able to cope with the effects of their stroke and almost 70% of stroke survivors and carers have felt anxious or depressed. Figures in Wales were slightly worse than the whole of the UK.
- **Stroke survivors and carers are struggling to access the support they need.** Almost 65% said they had received less care and support during the pandemic. 77% said they had not received therapies online or over the phone. Only 40% said they had any appointment related to their stroke conducted this way. However the

research also found appointments were slightly less likely to be cancelled in Wales than the whole of the UK.

- **Carers are feeling the impact of the pandemic.** 57% of carers for stroke survivors felt overwhelmed or unable to cope and 68% were carrying out more caring and support. 89% of carers found it more difficult to carry out practical tasks. Welsh carers were more likely to agree they had been given enough support and guidance than the whole of the UK.

The additional pressure created by the pandemic, both due to a backlog of stroke survivors and the rehabilitation needs of Covid-19 patients, means a system that was already struggling will be under even more pressure.

The recommendations of the research are:

- The Welsh Government should replace the Stroke Delivery Plan when it expires with a new national plan for stroke, with hyperacute stroke units as its priority, in order to drive improvement across the stroke pathway.
- Local health board stroke teams should follow up with all stroke survivors who had a stroke this year, to review and address their recovery needs.
- The Welsh Government should develop national standards for stroke rehabilitation.
- Welsh Government, health boards and local authorities should prioritise increasing access to mental health services to respond to the mental health and wellbeing needs of people affected by stroke, exacerbated by Covid-19.
- Local authorities must provide adequate support to carers are able to cope with the additional pressures of Covid-19.
- The Welsh Government must commit to investing in Act FAST public health messaging in preparation for any future Covid-19 waves.
- In the event of further Covid-19 waves, Welsh Government should adopt a clear, comprehensive and reassuring communications strategy to stroke survivors.

If the committee would be interested in seeing the full detailed data which formed our research then please let me know.

We hope this evidence is a useful snapshot of the experiences of those affected by stroke during the pandemic, and would welcome the opportunity to give oral evidence and discuss the findings of our research in more detail.

Yours sincerely,

  
Policy, Information and Campaigns Officer, Wales  
Stroke Association

# Stroke recoveries at risk

How Covid-19 has affected stroke survivors in Wales

September 2020

Rebuilding lives after stroke

Cymdeithas

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# Overview

Our survey of almost 2000 stroke survivors and their carers from across the UK (including 133 responses from Wales) found that the Covid-19 pandemic has affected every aspect of stroke treatment and care.

In Wales, this has included challenges in stroke survivors being able to access rehabilitation and ongoing support, leading to stroke survivors facing significant challenges in rebuilding their lives after stroke. Unsurprisingly, our survey respondents also reported feeling more anxious and concerned about the future. Carers have also said they were carrying out more caring and support.

This mini-report looks specifically at the Wales findings of our research, and is designed to be read in conjunction with our full report **Recoveries at Risk: How the Covid-19 pandemic has affected stroke survivors' lives and recoveries**, which outlines the picture and our recommendations across the UK.

Our key findings in Wales are:

- **Stroke survivors and carers are struggling to access the support they need.** Almost 65% said they had received less care and support during the pandemic.
- **Covid-19 has had a clear negative impact on the mental health of stroke survivors in Wales.** Almost half of stroke survivors and carers 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 depressed.
- **Carers are feeling the impact of the pandemic.** Over half of carers for stroke survivors felt overwhelmed or unable to cope and 68% were carrying out more caring and support. Previous work we have conducted with the Cross Party Group on Stroke to look at implementation of the Welsh Government's Stroke Delivery Plan showed that many of the services needed by stroke survivors were already in need of change prior to the pandemic. The pandemic has heightened the **need for a new national plan for stroke in Wales to replace the Stroke Delivery Plan** when it expires next year.



# How has Covid-19 affected stroke survivors in **Wales**?

In Wales, we heard from 104 stroke survivors and 29 carers and family members of stroke survivors. Our results showed that the Covid-19 pandemic has had a significant impact on the lives of stroke survivors and their families.

In addition to the pressures of the Covid-19 pandemic, we are at a pivotal time for stroke care in Wales. The Stroke Delivery Plan, the Welsh Government's plan for stroke services, comes to an end this year. It is vital that a new plan is created that prioritises strengthening stroke services, to help ensure they are better able to cope with future challenges faced by the health service in Wales.

Many of those we surveyed experienced **challenges in accessing the rehabilitation and support they needed during the pandemic**, putting their stroke recovery at risk. 64% of Welsh stroke survivors agreed that they had **received less care and support to help their stroke recovery** (UK average was 60%). 27% in Wales disagreed that they received less care and support, while the remaining 9% said they didn't know.

Stroke survivors used **virtual rehab and healthcare** in Wales during the pandemic. 40% of stroke survivors have had appointments related to their stroke online or over the phone, and 23% received therapies online or over the phone. However, both these figures are below the figures for the UK as a whole. Although Wales had the lowest number of stroke survivors reporting that they had therapy appointments cancelled (48% compared to 53% across the whole of the UK), this is 25% higher than the number of people who received phone or online therapy. This suggests a **'forgotten' cohort who were not offered or did not take up virtual therapy and have gone without the necessary rehabilitation and support needed to help their recovery.**



Respondents in Wales who've had therapy appointments cancelled or postponed:

- 48% Yes
- 50% No
- 2% Don't know



Respondents in Wales who've had therapy online or over the phone

- 77% Yes
- 23% No



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"I have found all the physiotherapists, on the phone and a home visit, most helpful. Also the general follow-up care has been excellent. Thank god for the NHS workers!!"

**Stroke survivor, Colwyn Bay**

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We're concerned that the pandemic could make it even harder for stroke survivors to access the rehabilitation they vitally need. A recent report by the Cross Party Group on Stroke, carried out prior to the pandemic, found that only a small amount of stroke survivors in Wales received therapies at the recommended levels. At some stroke units in Wales, patients had less than ten minutes of speech and language therapy and 15 minutes of physiotherapy per day[1], despite guidance stating they should receive 45 minutes.

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"Patients are being discharged from hospital sooner than they would, so they are getting less rehab' in hospital, and maybe they are going back to environments where the support is not suitable"

**Stroke Professional, Wales**

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The additional pressure created by the pandemic, both due to a backlog of stroke survivors who require therapy, and the rehabilitation needs of Covid-19 patients, means a system that was already struggling will be under even more pressure.

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"I have no confidence. I feel every day is a struggle to find any improvement."

**Stroke survivor, Tredegar**

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**The pandemic has had a clear negative impact on the mental health of those affected by stroke.** Over two thirds (68%) of stroke survivors reported feeling more anxious or depressed during the pandemic, with only 16% disagreeing. A staggering 72% have worried more about their health, and 72% have worried more about what the future holds. Almost half of respondents (49%) have felt less able to cope with the impacts of stroke, higher than the figure for the whole of the UK (where 45% felt less able to cope). While **37% of stroke survivors felt abandoned during lockdown**, 32% said they didn't feel abandoned, and 27% said neither.

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"I miss the day-to-day contact of people and a place to have a coffee and chat"

**Stroke survivor, Welshpool**

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Prior to the pandemic, stroke survivors were already struggling to have psychological support in Wales. Six-month reviews are not always routinely undertaken by health boards. Our research shows further evidence of the need to improve access to psychological support and reviews for stroke survivors.

Local health boards should follow-up with everyone who has had a stroke during 2020, to review and address their recovery needs, to make sure there isn't a 'forgotten' cohort of patients. As we move out of the pandemic, local health boards should also ensure all stroke survivors receive six-month reviews as standard. This should be committed to by Welsh Government as part of a new national plan for stroke.

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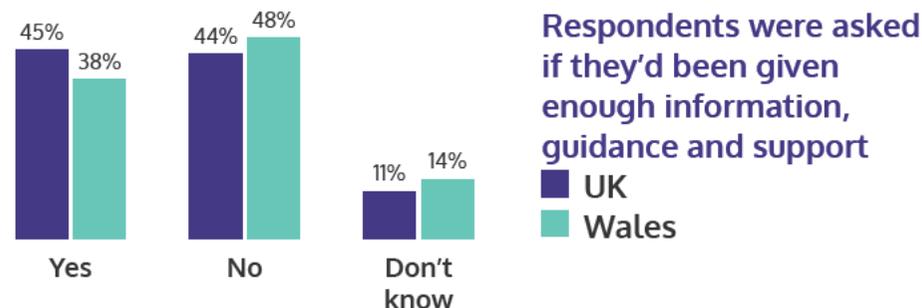
"Increased caring responsibilities whilst maintaining full-time employment. The person I care for has become agitated, stressed and tearful."

**Carer for a stroke survivor, Maesteg**

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Carers of stroke survivors in Wales **have felt the impact of additional pressures** during lockdown, with over half (57%) saying they feel overwhelmed and unable to cope, while only 28% said they were not. 68% said they were carrying out more caring duties during lockdown, however this was less than the figure for the whole of the UK (77%). 20% said they are not. 89% said they are finding it more difficult to carry out practical tasks such as shopping for food or picking up prescriptions.

55% of carers did feel that they had received enough information, guidance and support. This was the highest figure of the four countries of the UK. However, 26% disagreed with this statement.



We asked stroke survivors in Wales about **staying safe during lockdown**, and if the government had advised them that they were in the shielding category. Only 14% reported that they believed they were in the shielding category, a far smaller proportion than across the whole of the UK. However, 46% (compared to 37% across the whole of the UK) had chosen to follow shielding guidance themselves anyway. Almost half of stroke survivors felt that they had not been given enough information, guidance and support with 49% feeling they had not had enough information compared to 38% who felt they had. This compared to 45% feeling they had enough information in the whole of the UK.

The majority of Welsh stroke survivors surveyed, did not feel safe to go to appointments. 26% said they felt safe, compared to 34% across the UK. 64% said they did not feel safe, compared to 57% across the UK.

If further lockdowns and shielding are required, the Welsh Government must ensure clear and accessible information is communicated to stroke survivors and carers about how they are best able to look after themselves.



## My mental health has suffered immensely”



Peter, 60 from Risca, had a stroke in 2017. He received six weeks of mental health therapy following his stroke, but says he was “dropped” by the system and has been in a deep depression ever since. Like many others, Peter has particularly struggled with his mental health during the Covid-19 pandemic.

“The pandemic has affected me massively. I lost staff at my business which has meant I’ve had to work more hours myself leading to extreme fatigue. This makes everything worse.

“Even though I have been busy with work I feel very isolated. My mental health has suffered immensely and the stress related to Covid-19 has made it worse. Any progression I had made has been halted. I think another lockdown is inevitable and regardless of whether there is, I think it will be a long time until things are normal. The thought of that makes me even more depressed as I miss the contact with other stroke survivors.”

## Our recommendations for Wales

In addition to the UK-wide recommendations in 'Recoveries at Risk', we recommend that:

- The pandemic has highlighted the continued need to improve stroke services in Wales. **The Welsh Government should replace the Stroke Delivery Plan when it expires with a new national plan for stroke**, with hyperacute stroke units as its priority, in order to drive improvement across the stroke pathway.
- Local health board stroke teams should **follow up with all stroke survivors** who had a stroke this year, to review and address their recovery needs, to avoid a 'forgotten' cohort of patients caused by the pandemic. Local health boards should ensure six-month reviews are provided as standard.
- 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 for stroke survivors. Local health boards should also ensure they have short- and medium-term plans for improving rehabilitation services in their local area while reconfiguration is ongoing.
- **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, exacerbated by Covid-19.
- **Local authorities must provide adequate support to carers** are able to cope with the additional pressures of Covid-19, supporting them to take regular breaks and maintain their wellbeing.
- **The Welsh Government must commit to investing in Act FAST public health messaging**, given its success as a behaviour change intervention and particularly in preparation for any future Covid-19 waves.
- In the event of further Covid-19 waves, Welsh Government should adopt a **clear, comprehensive and reassuring communications** strategy to stroke survivors, engaging people affected and the voluntary sector in development.

When stroke strikes, part of your brain shuts down. And so does a part of you. Life changes instantly and recovery is tough. But the brain can adapt. Our specialist support, research and campaigning are only possible with the courage and determination of the stroke community. With more donations and support from you, we can rebuild even more lives.

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