

Cyflwynwyd yr ymateb i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#) ar [rhyddhau cleifion o ysbytai ac effaith hynny ar y llif cleifion drwy ysbytai](#)

This response was submitted to the [Health and Social Care Committee](#) consultation on [Hospital discharge and its impact on patient flow through hospitals](#)

HD 12

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



Stroke Association response to the Health and Social Care Committee call for evidence on hospital discharge and its impact on patient flow through hospitals

Summary

"Felt left to own devices after leaving with no advice on where to get any support physically, psychologically."
Stroke survivor, Neath Port Talbot

Hospital discharge problems in Wales are currently impacting on those affected by stroke in a variety of different ways:

- Stroke survivors are being discharged from hospital without information about their stroke and the support available, and this is impacting on their recovery.
- Not all stroke survivors receive the services they need after being discharged from hospital, with many feeling they 'fall of a cliff' after being discharged. Six month reviews are not routinely carried out.
- A lack of early supported discharge - particularly in north and west Wales.
- Delayed transfers of care are causing a number of problems in emergency care for stroke patients, with long waits for patients to access stroke units and poor ambulance response times.

We note the forthcoming review of hospital patient flows for stroke care being undertaken by Healthcare Inspectorate Wales. We hope this will provide a detailed picture of how patient flow and discharge impact on stroke care. We would be glad to update the Committee on this subject once HIWs review has been completed in 2022.

Quotes provided from stroke survivors and carers are taken from a survey we carried out in November 2021 to gather evidence for this response.

Hospital discharge information and stroke

Stroke changes life in an instant. As a result, many stroke survivors in hospital are learning about stroke, its effects, their recovery and what it means to their lives for the first time. Access to the right information while in hospital and on discharge is therefore essential to enabling people to understand what has happened and what it means for the individual and their family.

Unfortunately, all too often stroke survivors leave hospital without the information they need, leading to them feeling abandoned, confused, and not knowing what will happen next or who to contact.

"I would have liked something to enable myself and family what to do next and where you go for information."

Stroke survivor, Caerphilly

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 stroke and recovery when they left hospital. No-one told us they had too much information.

We asked those completing the survey what information they did not have on discharge which they wished they had received:

Information they wished to receive	Percentage who wanted it
How to prevent another stroke	52%
Who to contact if they have questions	62%
Information on how their stroke might affect them	69%
Details on how to get further support, such as social services	66%
Details on how to contact charities, such as the Stroke Association	41%
Information on the medicine they've been prescribed	52%
Information on the treatment they've received	45%
Explanation of what may have contributed to their stroke	52%
Next steps and who might be in contact with me	62%
I would not want any of this information	0%
I received all the information I needed	10%
Other	10%

The responses show that there are a number of pieces of information those affected by stroke want when they leave hospital which they are not currently receiving, and only a small amount agree they are receiving all the information they require.

"Information felt rather irrelevant, after two months in hospital, coming home was a huge shock very difficult to cope with and not at all what I had been wishing for."

Stroke survivor, Cardiff

We asked respondents how the lack of information made them feel about leaving hospital. Several mentioned that they felt nervous leaving hospital, and that they had received no information, or that the information did not feel relevant.

Our lottery-funded Community Steps project is working 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 between the group, with the majority having had a negative experience of discharge during their own recovery.

Our campaigners felt bombarded with information during the early stages of their initial diagnosis with stroke, with no ability to capture or revisit it. Other pieces of information were not provided at all. 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, the 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.

Our campaigners are calling on local health boards to fully implement the personalised stroke record, by ensuring every stroke patient leaves with a completed version. This will help ensure all those affected by stroke have access to the vital information they need to make the best possible recovery.

Feeling abandoned when leaving hospital

<p>"On discharge G had a social worker, district nurse team, care team and OA's. He had weekly physio, speech and language and is starting hydrotherapy next month. I found if you don't speak up your discharged and left." Carer for a stroke survivor, Wrexham</p>

Stroke survivors frequently tell us they feel like they fall off a cliff when they leave hospital. Many services which had been provided at a stroke unit cease, and community services may not be available straight away. The Covid-19 pandemic has

made this even more acute, with 65% saying they received less care and support when surveyed in the early stages of the pandemic¹.

Even prior to the pandemic, people told us they did not receive the services they need. In 2018 21% of stroke survivors told us they did not receive enough support after a stroke².

Just over half of those we surveyed (52%) said they felt ready to leave hospital. However some we surveyed felt unsure whether they were ready to leave, and were concerned about what it would mean for the support they were currently receiving.

"Felt we were just left to it. Not helped by being new to the area."
Carer for a stroke survivor, Pembrokeshire

The majority (59%) of those we spoke to did not have the right care and support set up for when they left hospital. Those who responded highlighted a number of different services which they felt were not in place at the time of their discharge, including physiotherapy, speech and language therapy, social services and psychological support.

Several of those we surveyed said the only support they received was from their partner or family member, and that there was a lack of information or support available for those providing care. One mentioned that they were not even asked about their home circumstances prior to discharge.

We want to see better communication between stroke teams in hospital and the community, as well as the stroke survivors they work with, to ensure people are discharged with the right support in their recovery. This should also include support available for those who provide care for stroke survivors.

"I just want to say that I was discharged from hospital I knew that I had speech therapy set up and that the speech therapy was great. And that the stroke Group was amazing."
Stroke survivor, Monmouthshire

Clinical guidance recommends that stroke survivors receive a review of their needs six months and annually post-stroke³. This is also endorsed by the Welsh

¹ 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

² Stroke Association, *Lived Experience of Stroke - Chapter 4 Rebuilding lives after stroke*, 2018. Available: https://www.stroke.org.uk/sites/default/files/leos_one_pager_wales_chapter_4.pdf

³ Royal College of Physicians, *National clinical guideline for stroke: 5th 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)

Government's Stroke Delivery Plan⁴. These can be vital in identifying unmet needs of stroke survivors post-discharge, but are not currently routinely undertaken. Figures show only 39% of stroke survivors currently receive a six month review⁵.

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 guidance⁶. We hope this recommendation will be implemented as part of the Welsh Government's forthcoming delivery plan under the Quality Statement on Stroke.

Lack of early supported discharge

"The early discharge team physio visits were far too few, so help with mobility issues soon disappeared. the clinical psychologist was absolutely no help at all and couldn't wait to discharge me off her list and it was very much sink or swim."
Stroke survivor, Cardiff

Early supported discharge (ESD) is an approach which enables stroke survivors to leave home and receive their rehabilitation services within the community. Clinical guidance states that "hospital in-patients with stroke who have mild to moderate disability should be offered early supported discharge, with treatment at home beginning within 24 hours of discharge."⁷ An early supported discharge team should consist of a range of professionals organised as a single multi-disciplinary team, including nursing, physiotherapy, speech and language therapy, occupational therapy and psychology, with access to other professionals such as social work, dietetics and pharmacy⁸. Prior to discharge with ESD, family and carers should be involved in planning for the transfer of care and an occupational therapist should assess the home⁹.

"Was happy to leave after nearly 6 months in hospital but then felt I was left with no direction of what to do next."

⁴ 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>

⁵ Sentinel Stroke National Audit Programme, *SSNAP Portfolio for April - June 2021 admissions and discharges: Country results portfolio*. Available:

<https://www.strokeaudit.org/Documents/National/Clinical/AprJun2021/AprJun2021-CountryResultsPortfolio.aspx>

⁶ The Cross Party Group on Stroke, *The Future of Stroke Care in Wales - Report of the inquiry into the implementation of the Welsh Government's Stroke Delivery Plan*, March 2020. Available:

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

⁷ *National clinical guideline for stroke: 5th Edition*

⁸ Ibid.

⁹ Ibid.

Stroke survivor, Neath Port Talbot

While ESD is used routinely in many areas, with almost 60% of stroke survivors receiving ESD across England, Wales and Northern Ireland, use of ESD remains limited in Wales, and availability varies dependent on location¹⁰.

In Hywel Dda Health Board and Betsi Cadwaladr Health Board rates of ESD are very low. One exception to this is Wityhush Hospital, which has recently launched a pilot ESD scheme. At Prince Charles over half of stroke survivors receive ESD, while no patients at Princess of Wales receive it - despite being in the same health board. Rates of ESD in Wales are below¹¹:

Hospital	April – June 2021	Hospital	April – June 2021
Grange	10.7%	Princess of Wales	0%
Glan Clwyd	1%	Bronglais	4%
Wrexham Maelor	2.9%	Prince Phillip	0%
Ysbyty Gwynedd	0%	Glangwili	0%
UHW	65.7%	Wityhush	48.8%
Prince Charles	57.4%	Morriston	51.1%
SSNAP average	59.3%	Wales average	26%

Patients who do receive ESD may face a delay before the service starts. In the recent SSNAP post-acute audit, of the 4 providers included in the audit, 3 did not meet the audit standard of ESD being provided within 24 hours¹².

There is a need for further development of ESD services in Wales, to ensure all those who are suitable for this approach are able to receive it. This will be beneficial for stroke survivors, enabling them to return home and receive services in a familiar location, but also enable more bed spaces in stroke units to be freed up and improve the flow of patients through the health system.

¹⁰ SSNAP Portfolio for April - June 2021 admissions and discharges: Country results portfolio

¹¹ Ibid.

¹² Sentinel Stroke National Audit Programme, SSNAP Post-acute Organisational Audit 2021 - Named service results. Available:

<https://www.strokeaudit.org/Documents/National/PostAcuteOrg/2021/2021-PAOrgPortfolio.aspx>

We note the commitment to ESD within the new Welsh Government Quality Statement on Stroke¹³ as part of a new model of stroke services. While we agree with the new approach envisaged by the Statement, we would urge local health boards not to wait for wider reconfiguration proposals to be finalised before introducing ESD.

Impact of delayed transfers of care

"The discharge was dreadful he came home at 11 o'clock at night, he was very agitated and distressed, ambulance initially took to wrong address."
Carer for a stroke survivor, Flintshire

This winter the pressure on the NHS in Wales has been well-publicised. There is no doubt that this includes an impact on stroke patients.

We are gravely concerned about the current ambulance response times for the amber category, which includes stroke. In the most recent figures, 82.1% of amber category ambulances took over 30 minutes to respond¹⁴. The Welsh Ambulance Service have informed us that during one week in October the average waiting time reached 3 hours.

Several treatments for stroke are time limited, including thrombolysis and thrombectomy. According to clinical guidance, thrombolysis should be started within 4.5 hours of the onset of a stroke¹⁵. Treatments are also more effective the sooner they can be administered. Ambulance delays can therefore prevent those affected by stroke being able to receive treatments which can save lives and reduce post-stroke disability.

In the most recent SSNAP stats, which cover April to June 2021 (and therefore do not account for winter pressures) the average time between the onset of a stroke and arrival at hospital in Wales was of 5hrs42, compared to 3hrs22 in England and 3hrs5 in Northern Ireland¹⁶. 47% of patients who do not receive thrombolysis in Wales are due to being outside of the time window, compared to 36% in England and 41% in Northern Ireland¹⁷; suggesting patients are missing out on vital treatment due to the time it takes to get to hospital. While it is not possible to know

¹³ Welsh Government, *The Quality Statement for Stroke*, 22 September 2021. Available: <https://gov.wales/quality-statement-stroke-html>

¹⁴ StatsWales, *Emergency responses: minute-by-minute performance for amber calls, by Local Health Board and month*. Available: <https://statswales.gov.wales/Catalogue/Health-and-Social-Care/NHS-Performance/Ambulance-Services/emergencyresponsesminutebyminuteperformanceambercalls-by-localhealthboard-month>

¹⁵ *National clinical guideline for stroke: 5th Edition*

¹⁶ SSNAP.

¹⁷ Ibid.

whether the longer waiting time is due to ambulance waiting times, we know response times in Wales are slower and this will be at least part of this picture.

The Welsh Ambulance Service have told us that at times of severe pressure this year there have been times when stroke patients have been asked whether it is possible to make their own way to hospital, and admit that avoidable harm to stroke patients has occurred. We welcome the candidness the Welsh Ambulance Service have brought to recent conversations with us.

The explanation we have received from the Welsh Ambulance Service is that delays to response times are caused by ambulances facing delays in unloading patients (which are mostly non-stroke patients) at emergency units. This reduces the number of ambulances available to respond to other incidents, including stroke. The delays at emergency units a consequence of how full these units are, with patients unable to be moved to other appropriate wards in hospitals due to a lack of available beds caused by delayed transfers of care. This means the impact of problems with discharging patients from hospitals in Wales is impacting on the entire system, including emergency care for stroke patients.

Action needs to be taken by Welsh Government and the NHS to address these problems, to prevent further avoidable harm to those affected by stroke from occurring.

We have also seen an impact on the time it takes for stroke patients to be admitted to stroke units once they are at hospital. The average time between arrival at a hospital and admission to a stroke unit in Wales is 7 hours 23 minutes, compared to 3 hours 48 minutes in England¹⁸. Conversations we have had with health boards indicate part of the problem is an overflow of medical patients into beds which are intended for stroke patients.

"I only spent a week in hospital, but that week was so bad, I would do anything to get out of there. My recovery started the day after I left the hospital."
Stroke survivor, Blaenau Gwent

We have also recently seen requests from two health boards in Wales (Hywel Dda and Swansea Bay) for families to take medically fit patients home if they are able to do so, regardless of whether an appropriate care package is in place.

We are concerned stroke patients may be exactly the type of patient who may be within the scope of such requests. The sudden nature of stroke may mean stroke survivors who are previously able-bodied may now have impairments which may mean they require additional care and support from a system which they and their family may have no experience of. Anecdotally we have heard from our own co-

¹⁸ Ibid.

ordinators that families are agreeing to care for their loved ones without being able to visit them themselves due to Covid-19, and may not have a full understanding of what they are agreeing to.

We do not believe it is appropriate to discharge stroke patients without adequate care and support being available to them when they get home. Any requests to families to take stroke survivors home should be based on full and informed consent, with clear timelines when support will be available and any interim provision made available.

Steps must be taken by Welsh Government and the NHS to ensure these problems do not re-occur post winter pressure. This should include the full implementation of the new Quality Statement on Stroke, to build more resilient pathways and services

Greater use of ESD would also enable more patients to leave stroke wards promptly, freeing up bed spaces and improving the flow of patients through the system.

"Both of my strokes were at weekends, and I was kept in for longer than necessary by a day or two."

Stroke survivor, Denbighshire