

# Stroke Services Snapshot Report A Patient & Carer Perspective

Spring/Summer 2022



# Accessible Formats

This report is also available in Welsh.

If you would like this publication in an alternative format and/or language, please contact us.

You can download an electronic copy from our website:

<https://swanseabaychc.nhs.wales/>

Or ask for a copy by contacting our office. Contact details can be found on page 42.

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# About Swansea Bay Community Health Council (CHC)

Swansea Bay CHC is the independent watchdog of the National Health Service (NHS) within Neath Port Talbot and Swansea. We encourage and support people to have a voice in the design and delivery of healthcare for their families and local communities.

Swansea Bay CHC works with the NHS, inspection, and regulatory bodies. We provide an important link between those who plan and deliver NHS services, those who inspect and regulate them and those who use them.

We hear from the public in many ways. Before the coronavirus pandemic, we regularly visited NHS services to hear from patients while they were receiving care and treatment. We spoke to their families and carers too. We also heard from people at local community events and by talking to community representatives and groups.

We had to change our ways of hearing from people because of the coronavirus pandemic. We did this by using surveys, social media and using videoconferencing apps such as Zoom, Teams and Skype. These apps have made it possible to attend virtual engagement events too. We continue to hear from people through enquiries and our complaints advocacy service.

Swansea Bay CHC represents the "patient and public" voice in Neath Port Talbot and Swansea.

# Background and Introduction

Strokes are a major health concern in the UK, with over 100,000 people having a stroke each year and around 95,000 people admitted to hospital with an acute stroke. In the UK, strokes are the fourth largest cause of death, with around 1.3 million people living with a lifelong disability having survived a stroke<sup>1</sup>.

Nationally, it is estimated that 7,400 people have a stroke each year in Wales<sup>2</sup>. Statistics by Stats Wales estimate there to be around 8,758 stroke survivors living in the Swansea Bay area and around 69,000 in Wales<sup>3</sup>.

## Current Picture within Swansea Bay

Swansea Bay University Health Board attended Swansea Bay Community Health Council's Scrutiny Sub Committee meeting in December 2021, to provide an update on current stroke services in Swansea Bay.

The Health Board confirmed the total number of stroke beds within Swansea Bay is 49, with stroke services currently being delivered across the 3 main hospitals:

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<sup>1</sup> <https://www.stroke.org.uk/what-is-stroke/stroke-statistics>

<sup>2</sup> 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>

<sup>3</sup> Stats Wales, Patients on Quality and Outcomes Framework (QOF) disease registers by local health board, 2018-19. Available: < <https://statswales.gov.wales/Catalogue/Health-and-Social-Care/NHS-Primary-and-Community-Activity/GMS-Contract/quality-and-outcomes-framework/patientsonqualityandoutcomesframework-by-localhealthboard-diseaseregister>>

- ⌚ Acute stroke unit (ASU) in Morriston
- ⌚ Rehabilitation beds on Ward C, Neath Port Talbot
- ⌚ Rehabilitation beds on Ward 4, Singleton hospital

## **Current Challenges**

The Health Board shared some of the challenges stroke services were up against:

- ⌚ A lack of 'ring fenced' beds for stroke patients. This means that the wards have a mixture of medical beds and are not used exclusively for stroke patients
  - These beds are shared in location with other services, such as ortho-geriatrics<sup>4</sup>, general rehabilitation and discharge planning beds
- ⌚ Limited bed capacity due to the pressures of unscheduled care<sup>5</sup>
  - this impacts on the specialist 24-hour stroke care and can lead to delays in admission to the ward

## **Proposals to create a Hyper Acute Stroke Unit - HASU**

The Health Board plans to create a single specialist centre, the new HASU unit. They believe this is the best way to provide excellent care and deliver best outcomes for stroke patients. Its creation would see individuals with suspected stroke avoiding the emergency department

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<sup>4</sup> Orthogeriatrics is the care of elderly orthopaedic inpatients, most commonly following a fractured hip.

<sup>5</sup> Unscheduled Care is medical help that is not expected. It includes emergency care.

and being triaged instead, in a stroke specific area within Morriston Hospital's Enfys Ward (Acute Medical Assessment Unit (AMAU)). This would create a specialist area for suspected strokes to be diagnosed without increasing demand within the Emergency Department. Enfys (AMAU) is planned to have an appropriate ambulance bay for all medical patients.

Whilst the initial plans for the HASU are to only cover the Swansea Bay area, the Stroke Association's understanding is that the footprint of the unit may be increased in the future, to include Hywel Dda stroke patients.

We heard how the Health Board does not expect there to be an increase in patients attending Morriston Hospital for services such as cardiology<sup>6</sup> or vascular<sup>7</sup> services. However, there may be an increase in demand for radiology<sup>8</sup> due to an increase in stroke consultants. A move towards a mechanical thrombectomy service will also require more computed tomography angiography (CTAs)<sup>9</sup> scanners.

### **What is Mechanical Thrombectomy?**

Thrombectomy or mechanical thrombectomy is a procedure used to treat some ischaemic stroke<sup>10</sup> patients. Currently, Mechanical thrombectomy for stroke is not available in Swansea hospitals. Swansea Bay University Health Board has a contract through Welsh

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<sup>6</sup> A branch of medicine that specialises in diagnosing and treating diseases of the heart, blood vessels, and circulatory system

<sup>7</sup> diagnosing and managing conditions affecting the circulation, including disease of the arteries and veins.

<sup>8</sup> A branch of medicine that uses imaging technology to diagnose and treat disease.

<sup>9</sup> Sometimes these scans will involve an injection to highlight the arteries of the neck and brain more clearly, known as computed tomography angiography (CTA)

<sup>10</sup> An ischaemic stroke happens when a blockage cuts off the blood supply to the brain.

Health Specialised Services Committee (WHSSC) to provide mechanical thrombectomy services in Bristol 7 days a week.

Currently, less than 1% of stroke patients benefit from this service. We heard how there were on-going discussions within Wales about developing a more local pathway, however there would be challenges in relation to specialist recruitment. SB UHB told us that the vision is to provide a more local approach to mechanical thrombectomy, with the aim of 10% of stroke patients receiving this intervention.

## What we did

A mixed method approach was used to obtain a range of stroke survivor perspectives on care within the NHS, including emergency care, diagnosis, treatment and rehabilitation.

### Survey

In an effort to reach as many people as possible, we shared our survey's promotional messages on social media platforms, including Instagram, Twitter, and Facebook and by email with various stakeholders and local groups, including:

- ☺ Council for Voluntary Service (Neath Port Talbot & Swansea)
- ☺ Local Area Coordinators
- ☺ Stroke Association
- ☺ Local stroke groups
- ☺ Swansea Bay University Health Board
- ☺ Local community groups, including Covid-19 support groups



- ⌚ Seldom heard groups
- ⌚ Local and national charities

We offered alternatives to the online survey, with people invited to contact us by post, phone, email and through our website.

The covid measures in place in hospitals, stopped us from engaging face-to-face with patients, their families and carers.

### **Virtual engagement talks**

We held virtual engagement talks to engage with patients, carers and families about their experiences of stroke care in the NHS. Talks took place in June 2021 with the Stroke Association's Working Age Stroke group, which we attended jointly with Hywel Dda CHC. 15 members were present, the majority suffering a stroke within the last 12 months.

Conversations took place around SB CHC's stroke services survey, to gather the views of patients' experiences of services across their stroke care journey. Topics included:

- ⌚ Emergency treatment and care
- ⌚ Care in hospital
- ⌚ Discharge from hospital and return home
- ⌚ Therapies
- ⌚ Impact of the Coronavirus pandemic on stroke services
- ⌚ The future of stroke services

## **Using our Scrutiny Sub-Committee Meeting (SSC)**

In December 2021 we invited Swansea Bay Health Board to attend our SSC meeting to provide an update on stroke services and the Health Boards' future plans for stroke services (please see update above, at page 5)

In February 2022, the Stroke Association presented at our Scrutiny Sub Committee Meeting, providing their own perspective on the current performance of Swansea Bay stroke services and their views on the Health Board's HASU proposal. (Update can be found on page 35)

## **Patient Story**

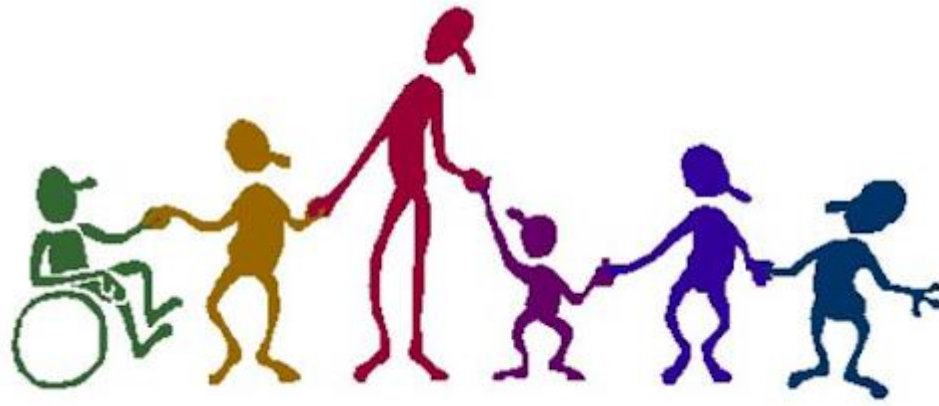
Attending alongside the Stroke Association at the CHC Scrutiny meeting, a stroke survivor presented their story to the group, highlighting patient experience across a stroke survivors' journey in the NHS.

We also collected feedback in other ways, e.g., through our enquiries and complaints advocacy service, local community networks, community representatives and groups, and monitoring of health board activities, including feedback and complaints.

# Who we are hearing from

Page 9 provides a snapshot of the people who shared their views and experiences with us through our local survey.

You can find out from our [Equality Plan](#) what we are doing to hear from different groups of people so that we can better represent the diversity of the communities we serve. You can find our Equality Plan on our website: <https://swanseabaychc.nhs.wales/about-us/our-governance/governance-documents/equality-plan-2021-2022-pdf/>



Everyone shared their views and experiences in English although our survey was also available in Welsh and Easy Read.

Of those people that answered our monitoring equalities questions:

71% were male, 29% female

96% told us they were White (Welsh, English, Scottish, Northern Irish, British)

70% told us they were Christian (including Church of England, Catholic, Protestant, and other Christian denominations)

Age range categories:

Almost 24% were aged 45 – 60 years old

Around 53% were aged 60 – 75 years old

Almost 24% were aged 75+

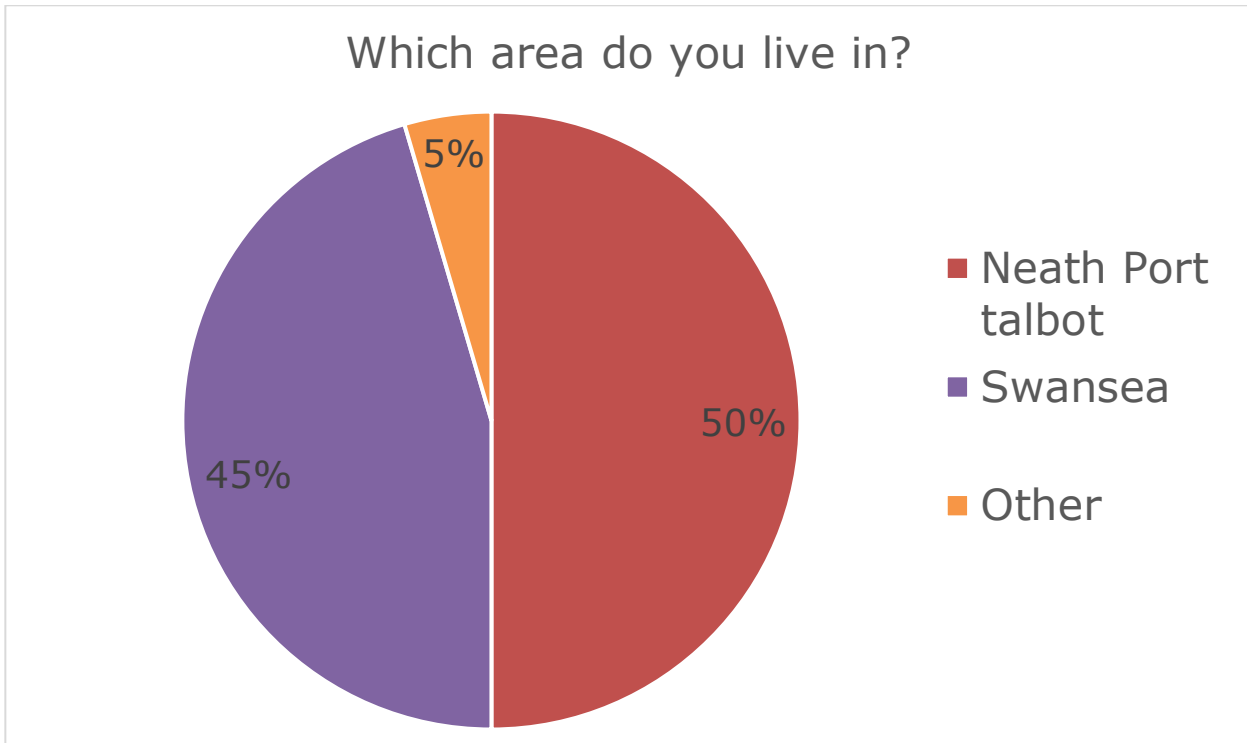
Around 86% identified as heterosexual

16 people told us they had a long-standing condition, such as:

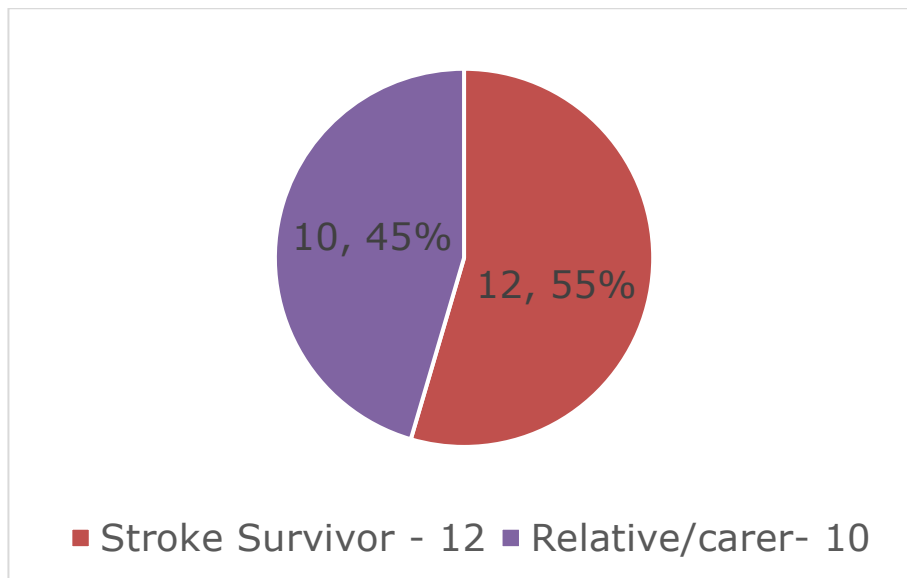
- A physical condition – 6%
- A long-standing illness – 25%
- Deaf or a severe hearing impairment – 6%
- Blind or partially sighted – 6%

# What we heard

22 people shared their experience with us. 10 people were from the Swansea area and 11 from Neath and Port Talbot. 1 person told us they lived in another Health Board area.



12 people shared their own personal experience while 10 people responded on behalf of the stroke survivor, as a family member and/or carer.



1 person told us they had a stroke in 2022 with the majority (11) in 2021; 1 in 2020, and 5 told us they experienced a stroke in 2019. 4 people experienced their stroke prior to 2019.

### **Emergency Treatment and Care**

The majority (10) told us that when they became ill, they attended Accident and Emergency. 8 were taken to hospital by ambulance.

More than half (63%) told us they were satisfied with the care and support they received from ambulance staff. Positive experiences included the ambulance arriving quickly and the care provided by the crew.

“Turned up very quickly were very efficient and reassuring”

“I had a mini stroke on Easter Monday, April 2021. The ambulance crew said they’d come from Brecon which is about an hours’ drive away. They arrived at my home well within the hour. They were excellent and looked after me”

6 people told us they experienced delays getting to hospital by ambulance.

"Absolutely horrific. Fall and stroke. 94-year-old man fell down 3 stairs and landed at the bottom. Ambulance called at 8pm. This was cancelled by them at 1am as they didn't have any ambulances. Rang for an ambulance the following morning as he was still unwell, rang at 10.30am and ambulance arrived at 8pm!"

"Had to wait 3 hours for the ambulance. 999 staff kept in touch with us by telephone, but the wait was frightening"

"Following stroke my husband had heart attack. Spent 4 hours and 30 minutes on Tesco floor before first responder came. Another 30 minutes for Code Red Ambulance..."

"Husband collapsed at 6:45. I knew straight away it was a stroke. Rang ambulance and was told it was not a priority, husband was still able to talk although he couldn't move, he was stuck in the bathroom. Rang again at 7:40 was told again that he was not a priority. By 8:00, husband was losing consciousness. I rang again and they said an ambulance would be dispatched as soon as possible. 9:55 they finally arrived and stated they couldn't move my hubby" as he was in a confined space and was a large man. My son in-laws took him down the stairs and then the team took over. He finally got to hospital at 10:35, totally unconscious"

## Identifying a stroke

We heard how some medical professionals were not always identifying the early warning signs of a stroke.

### 111 service

1 person felt let down by the 111 service for their failure to identify the symptoms of a stroke.

"I phoned 111 and was told that the nurse would phone me back within 30 minutes, which she did. She referred me to the Doctor, who would phone me back within 4 hours. He phoned about 4 hours later. He told me to go to my GP because he thought I was having a bad attack of shingles. This was about 5 hours after I initially phoned. I spoke with my GP who told me to get someone to drive me to Murrumbidgee because I had all the symptoms of a stroke. I was badly let down by 111. Care in the hospital was exemplary"

One relative felt that ambulance staff on the day did not recognise signs of a suspected stroke, delaying her mother's care.

"Ambulance crew refused to take Mum to hospital as her symptoms were not worsening. She couldn't walk, had slurred speech and left-sided weakness. They advised us to see GP next day or attend A&E if worried. My husband carried her to the car and took her to A&E. The ambulance was parked outside the house with crew watching us struggle. This delayed her care"



The long waits for an ambulance to arrive led to some people deciding to drive their loved ones to hospital instead.

"Waiting time too long hence taken by car"

"Rang for an ambulance, was told it could be up to 2 hours.

Managed to get my husband in the car and I drove him to A&E"

"Ambulance was called but couldn't attend for hours, so my daughter's friend who is a paramedic came with me & my husband to A&E"

### **Unable to offload**

Once outside the hospital, we heard how patients were kept on the back of an ambulance for hours, delaying their care further.

"...Ambulance arrived at 8pm. He then sat in said ambulance until 11.45am THE FOLLOWING day!"

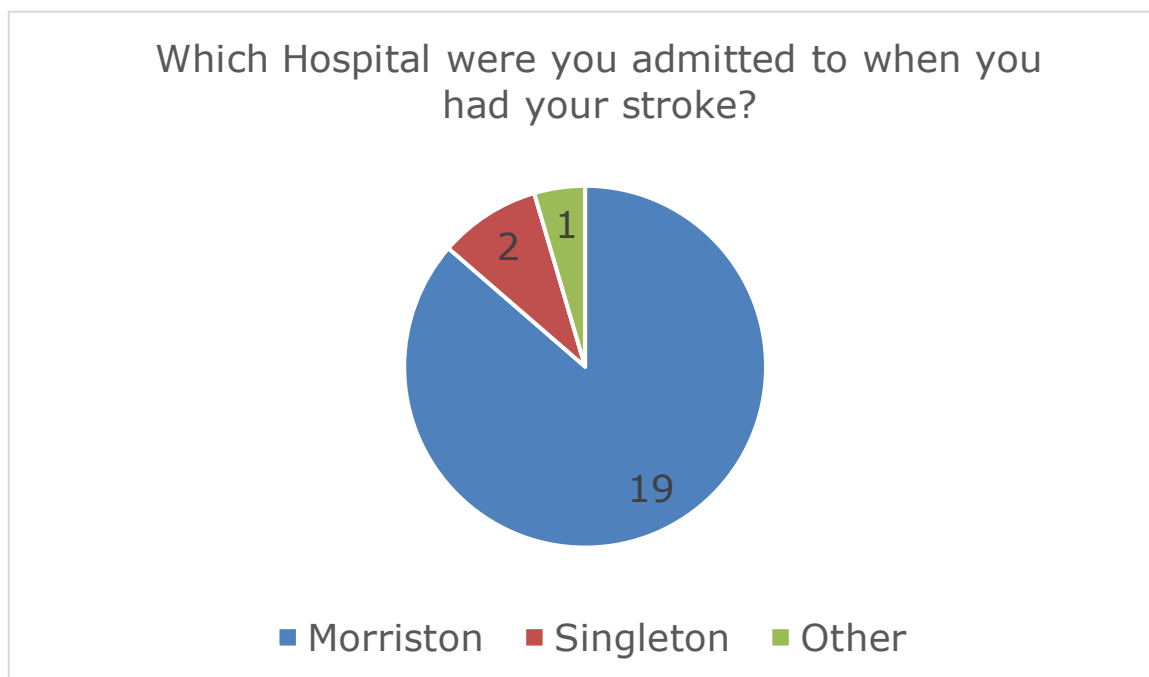
"12 hours on the back of 3 different ambulances outside Morriston A&E"

"15-hour wait in the ambulance as there were no beds"

"We had to wait in the ambulance as A&E was full - finally got into the department 5 hours after arriving"

## Arrival at Hospital

The majority of people (19) told us they were admitted to Morriston Hospital when they had their stroke. 2 told us they were admitted to Singleton while another was admitted to Glangwilli Hospital in Hywel Dda health Board area.



## Assessment & Diagnosis

14 people told us they received prompt assessment and diagnosis on admission to hospital. Other positive experiences included being taken directly to a stroke ward and the quality of care provided by staff.

“Was assessed straight away by specialist team and sent for scans. Treatment and the team were amazing”

“Husband taken for CT scan, diagnosed and moved to stroke ward within the hour”

## Clot-busting treatments

Out of the 22 people who completed the survey, 59% told us they did not receive thrombolysis. 86% told us they did not receive thrombectomy treatment.

Some people told us about delays receiving 'time-critical' treatment.

"On arrival at A&E the stroke call was put out and mum rushed into resus. Due to delay with ambulance refusing to admit mum, the window of opportunity for thrombolysis treatment was narrowed. The registrar on call also deliberated whether to administer the drug"

"Fell on Monday and fractured cheekbone. Dealt with Minor Injury Unit in Port Talbot. Sent me to be assessed at A & E. Sent home after quick check. On Thursday, fell again and suffering pins and needles in arm. Sent for x-ray. Finally, consultant sent me for CAT scan. They admitted that since I'd been sat in A&E for 9 hours, it was too late to give me clot busting injection"

## Care Whilst in Hospital

### Stroke Ward

13 people told us they were admitted to a ward for stroke patients.

"Ward F were amazing, my husband was there for 4 months, they were fantastic with not just him but the family also"

However, a number of people told us they were kept on A&E or put elsewhere.

"Put into a physio training room at 11:00pm after more than 12 hours at the hospital"

"Ward 12 I believe"

"A and E assessment ward"

"Remained in A and E until discharged"

"Left in A&E"

A&E was felt not to be the best place for some suspected stroke patients.

"A&E was frightening and uncomfortable for an 86-year-old"

"A&E was awful not enough staff and chaotic"

### **Information, Support and understanding**

Whilst the table on page 20 highlights that the majority of people were satisfied they had received respect from staff and enough information, support and understanding about what was happening to them,

"When my husband was admitted to Ward F the staff were all great. He was kept up to date with all that was happening even though it was really busy"

Other people told us they did not feel the same way.

“No real support as so busy”

<b>Did you receive.....?</b>			
	<b>Yes</b>	<b>No</b>	<b>Not Enough</b>
Information about the illness	76%	5%	19%
Information about the potential long term effects of stroke	50%	28%	22%
Discussion about your treatment	73%	11%	16%
Support & understanding	74%	21%	5%
Respect from all staff	90%	10%	
Information in a way you could understand	77%	12%	12%

## **Emotional Support in hospital**

A number of people (15) told us they either did not receive enough support or received no support at all, to help deal with any emotional issues they may have been experiencing at the time of diagnosis, such as confusion, depression or crying.

## **What is happening to me?**

Whilst some stroke survivors felt that hospital staff gave them enough support about what was happening to them and what they should expect next, 10 people felt they only partly received support and 3 told us they did not feel supported at all.

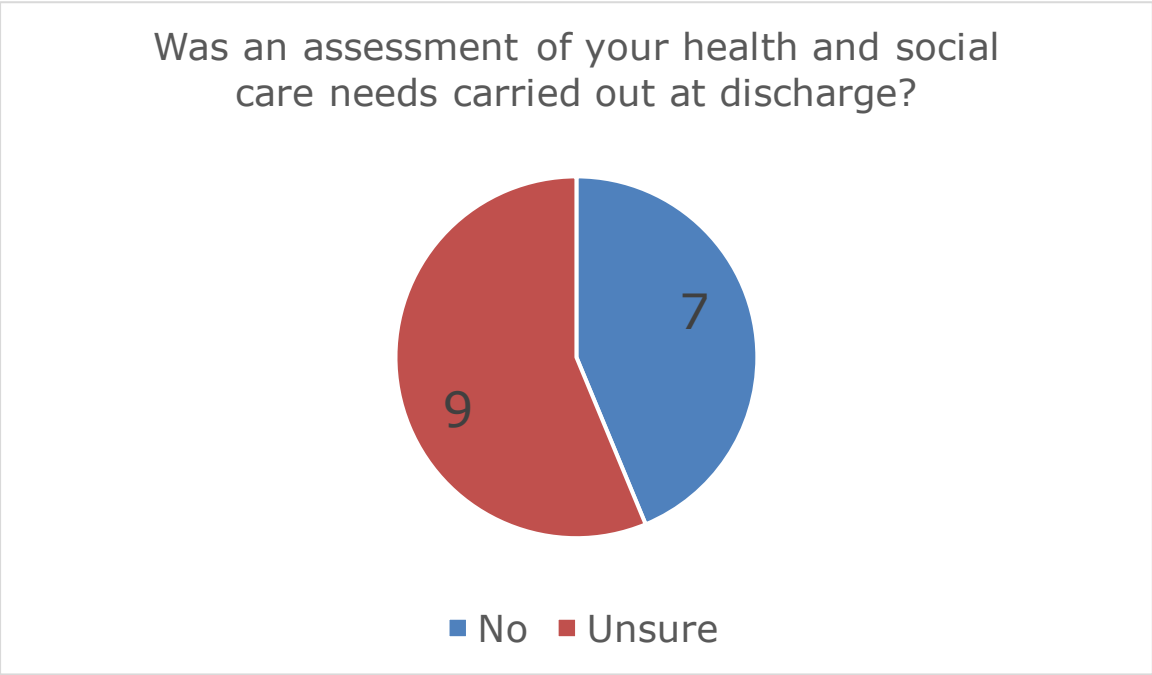
## **Support for others**

12 people told us they did not feel that hospital staff provided families, carers or the person with them with enough support about what was happening to the patient and what they could expect next. 5 people told us they did not receive any support at all.

"No offer of support for family"

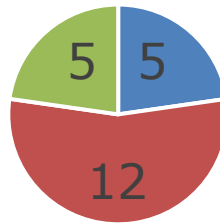
We invited people to tell us more about their care whilst in hospital. 16 people shared their views, with common themes including the following

### Discharge from Hospital



“On the 8th day I got to speak to a nurse who informed me she would be ready in 30 minutes to come home. No assessment and we were really concerned as we didn’t know her capabilities”

Did you receive a care plan or other document setting out what would happen next and where you could get advice before you were discharged home?



■ Yes ■ No ■ Unsure

5 people told us they received a care plan or other document before they were discharged home. People appreciated the information provided to them.

“Yes, it was good to know as much as possible”

“The paperwork given to me had various telephone numbers of related clinics etc”

However, there were clear inconsistencies between patients, with 12 people telling us they did not receive a care plan at all. One person felt that the discharge sheet was unclear.

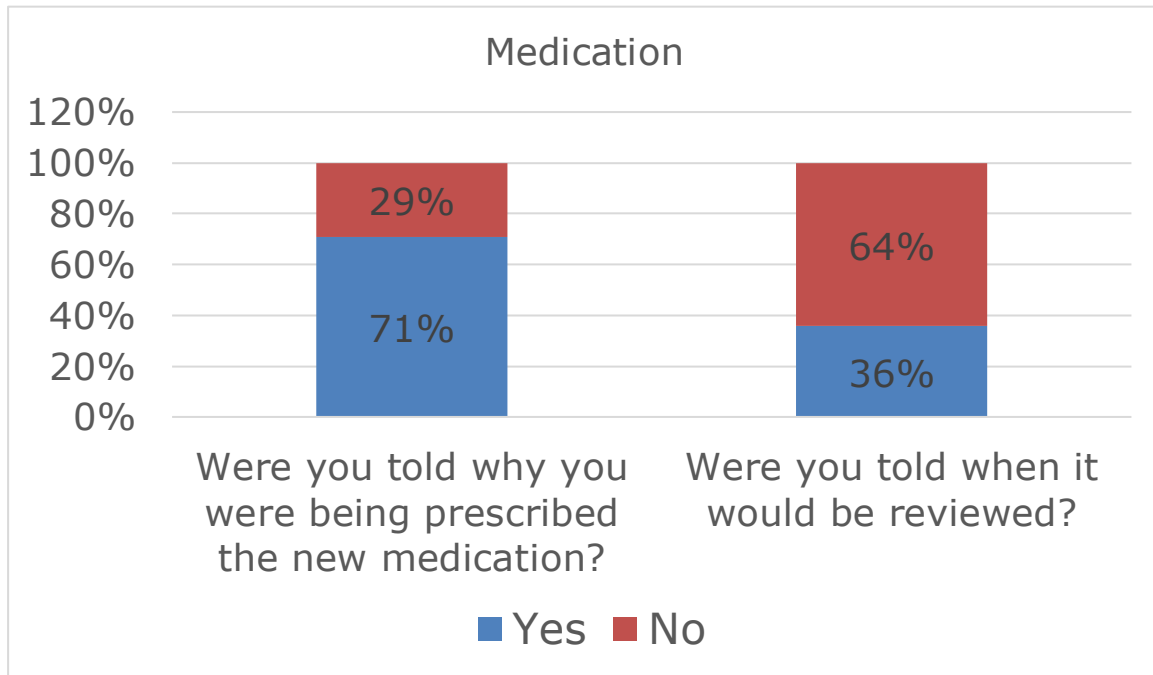
“Husband was sent home without a care package”

“The booklet gave details of contacts, but the discharge sheet was ambiguous”



## New medication

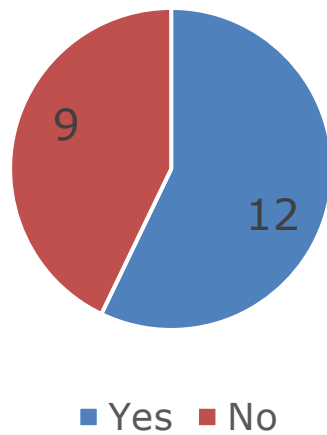
Before leaving hospital, 29% told us they were not told why they were being prescribed any new medication. 64% told us they were not told when their medication would be reviewed.



"I was just given the medication and I was left with no other communication from a member of staff"

"Not being able to get a clear dialogue with doctors and consultants about side effects of medication, and taking that forward has been distressing for a month and still unresolved"

Were you given any information about other organisations that may be able to help with advice or support such as the voluntary sector?



9 people told us they were not given information about other organisations that may be able to help with advice or support, such as the voluntary sector.

### **Emotional support**

A significant number of people (16, 73%) told us they were not offered any emotional support in hospital such as counselling, to help with their mental well-being following their stroke.

## Discharge from hospital

Several issues were experienced at the time of discharge, including delays waiting for medication and people feeling the process was “rushed”

“It was unrealistically slow waiting for medication. Which was frustrating”

“Very busy so quickly discharged as needed bed for other patients”

“Rushed”

“Awful. A very limited assessment done and then an extremely unprofessional phone call made to his elderly wife where they asked loads of questions in order to cover themselves in sending him home. Absolutely disgusting. A formal complaint has been processed”

“No real support as so busy. Just discharged as quick as possible with no follow up support offered to husband or family”

After leaving hospital, stroke patients will often need further rehabilitation and care to help with their recovery at home. A team of different specialists may help with recovery, including physiotherapists, psychologists, occupational therapists, speech and language therapists.

## Rehabilitation assessments

14 people (64%) told us they did not receive a rehabilitation assessment.

16 people (73%) told us their expectations were not discussed with them.

## Rehabilitation treatment

While some patients received rehabilitation in hospital or at home, 14 people said they did not receive any form of rehabilitation treatment. People told us they received some of the following: physiotherapy, occupational therapy, speech and language therapy, psychological services, ophthalmology services and social care assessments.

Some people told us they were not satisfied with the rehabilitation, feeling that the rehabilitation available to them was either limited, needed to be repeatedly chased for or was not provided.

“Other than physiotherapy, none offered”

“Was not given any. Just sent home and forgotten about”

“Rehabilitation is poor and have to ask for everything constantly”

## Follow-up appointments

Whilst some people told us that that received follow up appointments, 7 people told us they have not had a review at all.

“NO follow up appointments or reviews, no medical intervention other than our GP for 17 months”

11 people told us there were services they would have liked but did not receive, to help with their recovery. We heard how psychological support was particularly important to patients and their families/carers.

"Psychological support Emotional support/adjustment"

"More psychological support as it was probably the hardest thing had to deal with as a family"

"Help & understanding about the condition & what happened, for myself and family"

"Support, advice and counselling"

"Follow up"

"Physio, counselling"

"Support at home following discharge"

People reminded us that those close to patients needed to be supported too.

"Physiotherapy, Counselling for not just husband, as it has been a massive life change. Help with medications. JUST help really x

## Feeling forgotten

We heard how some stroke survivors and caregivers felt abandoned by health services.

"No follow up, no support"

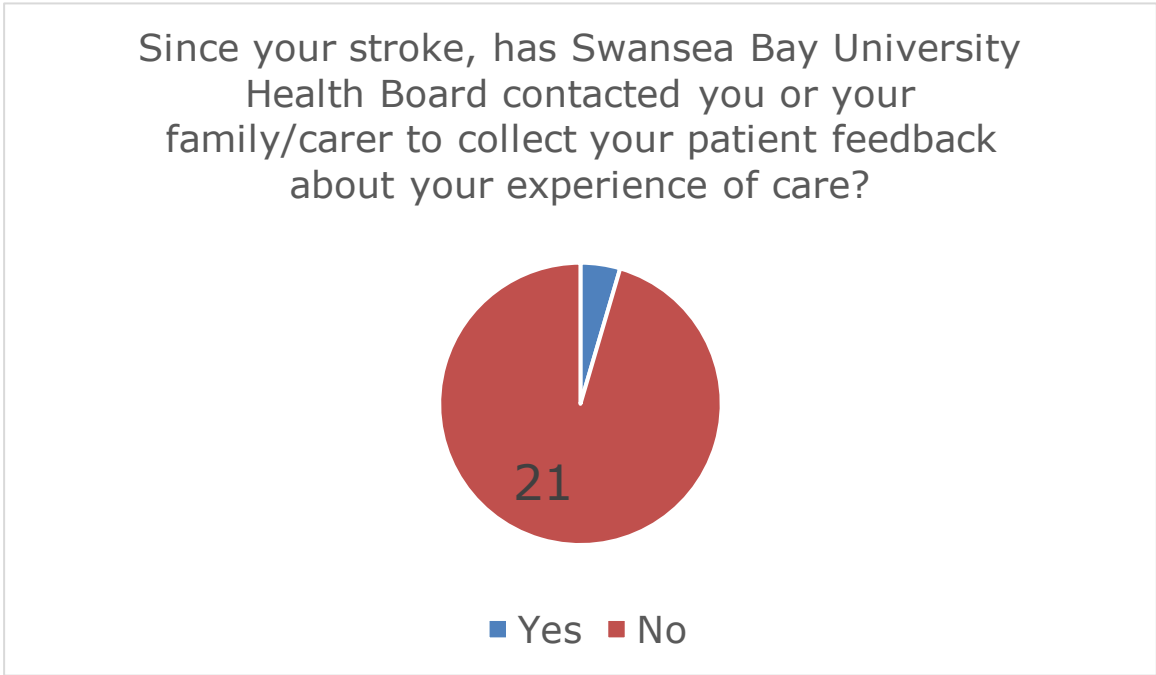
"Left to go home and forgotten about. Very, very poor after care service"

## Covid-19

We heard the different ways Covid restrictions affected stroke patients, through cancelled therapy and visitor restrictions on wards.

"My physio ended with COVID. No one has been in touch to say if it will be starting up again and my physical condition has deteriorated since"

"Isolation from the family. It was the first time in her life my mum had been admitted to hospital and she found it very frightening. Contact and visits from family for reassurance would have helped"



Out of the 22 people who took part in the survey, 21 told us Swansea Bay Health Board has not invited them to share their patient experience.

## Overall experience of stroke care in the NHS

Half of the people we spoke to (11, 50%) rated their experience of NHS stroke care as 'good, very good or excellent', with 6 patients (27%) rating their experience as 'fair'. 5 people (23%) rated their overall experience as 'poor' or 'very poor'.



## Post-stroke Support Services

### Stroke Association

We heard how the Stroke Association has provided valuable support services to some patients and their carers.

"The only advice we received was from Stephanie at the Stroke Clinic who contacted me, with sound advice and guidance. Also, from Amanda at the Stroke Association. Both of whom responded to my wife and myself with empathy"

Emailing Amanda and Stephanie [Stroke Association] has been a lifeline. I am not sure we would have known what to do or expect without their input"

### People's suggestions for improving stroke services for patients, their families and carers

People made various suggestions to improve stroke services, including:

#### Providing skilled staff

People want a skilled, multidisciplinary workforce, capable of meeting the needs of stroke patients.

"A specific ward with trained staff and doctors, instead of seeing a range of doctors, as it was only the stroke doctor who made any sense of any of it. Not generic nurses or doctors who have no idea what is going on and keep referring you on or telling you something will happen, and it never does"



## Identifying suspected stroke

Findings highlighted the need for earlier and better diagnosis of stroke. People suggested reviewing the NHS 111 telephone system and further training for ambulance crew.

“The algorithm used by 111 needs urgent review, or the staff need to be trained”

“Ambulance crew need to have further training in diagnosis of stroke and to be made aware of the importance of timely treatment”

## Improved communication & information

People want to see better communication between services, patients, families and caregivers, to help reassure people. Those caring for patients at home also want to feel supported and be given or signposted to further information and advice.

“Stroke service was great but more communication with family would have been wonderful during such a difficult time”

Everybody needs to know what each other is doing and where people can find more help”

“More information and support for patients and care givers on discharge”

## **Information about lifestyle Changes**

Some people feel an element of fear following a stroke. Stroke survivors would like to receive advice about making lifestyle changes, to reduce their future risk of stroke.

“More information & support with life changing factors & fear”

“More advice and guidance on what to expect and how to plan new goals, i.e., driving, decision making, fatigue, moving forward with fitness and wellbeing”

## **Better access to therapy**

Many feel that stroke rehabilitation needs radical overhaul.

“More information, rehabilitation support”

“The NHS needs to address the lack of physiotherapy available to stroke patients desperately”

## The Creation of a Hyper Acute Stroke Unit (HASU)

We asked people to tell what they thought about Swansea Bay Health Boards' proposals to create a HASU.

Overall, the people we heard from in the survey, were supportive of the Health Board's proposals. They could see the benefit of developing a centre of excellence, staffed by specialists, and which would be located near Morriston Hospital's Accident and Emergency department.

"Sound good let's hope they can be delivered"

"It is a good idea as having a stroke unit available in the same hospital a major A&E is essential, as time is essential in dealing with stroke victims"

"Specialist units are the way forward, with fully trained staff with defined care appropriate to the unit"

One person shared a few ideas for the Health Board to consider when implementing changes to stroke services, one of which is for the Health Board to be “more proactive”.

“A digital approach has to be introduced to stop the level of writing and duplicating. This can be done by hand-held devices that show the patient to the member of staff accurately and in the optimum time. Bearing in mind the level of some people’s abilities, this could be linked to hospital and GP records. Staff deal with the presenting need, but rarely look beyond that and see the person within. If the NHS is going to improve health, it needs to be more proactive. A scared person not knowing what is happening to them remains scared, so more reassurance by working cohesively as a team needs to be addressed. Dignity and discretion, care, empathy and understanding are just a few words that could form the foundation of on-going assessment and training, so it becomes the core of them. And finally tidy wards, make for tidy minds, staff and patients. The several wards I had to endure were scruffy, untidy and dirty, the food trolleys were filthy”

## Stroke Associations Views on the HASU

At our CHC Scrutiny meeting in February 2022, The Stroke Association told us that whilst they welcome the proposals for the development of a HASU at Morriston Hospital, they have concerns over practicalities, including:

- Shortage of stroke skilled staff across the current stroke pathway – HASU requires more staff
- Having a HASU in Morriston, along with 3 stroke units in West Wales, creates additional staffing demand
- Need for modelling<sup>11</sup> to look at potential impact
- Early Supported Discharge (ESD) provision needs to be improved
- Rationalising<sup>12</sup> rehabilitation sites could have potential benefit
- Mental health services also need to be addressed

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<sup>11</sup> The activity of using mathematical models, to make calculations or predict what might happen:

<sup>12</sup> To concentrate expertise in fewer number of locations

# Learning from what we heard

Feedback received was mixed across each stage of the stroke pathway and echoed much of that in our 2017 report. Whilst we heard examples of some excellent feedback along a patient's stroke care journey, we also heard some very poor feedback.

People were generally positive about ambulance crews, describing them as "efficient and "reassuring". There were also positive stories relating to a prompt response from the service.

Negativity about emergency services was mostly attributed to lengthy waiting times for an ambulance to arrive and patients waiting hours outside a hospital in the back of an ambulance. Feeling that they had waited too long, a few individuals opted to transport their loved ones to hospital instead.

Some people reported concerns with some medical professionals' ability to identify the early warning signs of a stroke, suggesting that paramedics need to receive more training on how to recognise and manage strokes while others suggested a review of the 111 system.

Once inside the hospital, we heard instances of suspected stroke patients being left to wait in Accident and Emergency for an extended period or being taken to general wards. People lucky enough to be admitted to a specialist stroke ward, mostly described positive patient experiences.

Whilst many patients told us they received prompt assessment and diagnosis on admission to hospital, patient experience is inconsistent.

Several people experienced delays receiving 'time-critical' clot-busting drugs, resulting in a negative impact on the subsequent outcome for the patient.

Less positive experiences across the patient stroke pathway were also consistent with our earlier report findings, relating mostly to discharge from hospital, rehabilitation and aftercare.

Comments on discharge painted a picture of some people feeling "rushed" and pressured to leave too soon.

Others continue to tell us that they were discharged home without a care package in place. The feedback also suggests that there is confusion over what people understand to be the 'care plan'.

Deficiencies in rehabilitation provision was another cause of criticism, in terms of the quality, quantity and range of support services. These covered a wide range of specific issues including a reported under provision of therapies such as physiotherapy and gaps in the provision of emotional support for patients, carers and family members.

People reminded us how stroke can be a life changing event which can be difficult for the patient and their families to deal with. It was felt that there was a need to ensure greater consideration for the emotional impact of stroke and that people have access to the appropriate levels of emotional support and advice.

Some people told us they experienced fear and anxiety following their stroke and were not clear about what they could do to prevent future strokes.

A number of people were not told about the support the voluntary and community sector could provide and would appreciate more information being provided to patients and their families / carers.

Of those that were aware of the support available, people told us they found the services provided by their local Stroke Association, to be particularly valuable in a person's recovery from stroke and in supporting carers.

Overall, it is clear from the feedback that patients are not getting equitable access to the specialist staff, tests, equipment, procedures, rehabilitation, and aftercare support they need in a timely manner.

### **Reaction to HASU proposals**

The CHC, Stroke Association and patient/carer feedback in our report, supports the concept of bringing local stroke services together in a single location in Swansea Bay, through the HASU and improving outcomes for patients. However, there is scepticism about Swansea Bay University Health Boards' ability to create a centralised stroke unit that will guarantee better service. We share key concerns with practicalities identified by the Stroke Association. Please see page 33 for details.

This view is based on the evidence available to us, the personal experience of patients and their families/carers and the Stroke Association, relating to the shortages of experienced staff and other shortcomings in service delivery described in our report.



# Suggestions & Recommendations

This report has provided a snapshot of the views of some people across Swansea Bay, with experience of local stroke services.

Whilst there were a lot of positive comments on all parts of the stroke pathway, we did identify some inconsistencies and gaps in the care and services that Swansea Bay Health Board patients are receiving.

In March 2022, we wrote to the Health Board setting out our concerns arising from presentations delivered at our Scrutiny Meeting, over the current performance and future of stroke services. We asked the Health Board for a copy of their Equality Impact Assessment for the HASU proposals, determining the potential impact of stroke services redesign on the following: travel and access, health and equality.

Whilst the CHC acknowledges and accepts the Health Boards' case for change and the benefits of centralising specialist hyper acute care, it is important to ensure that the proposed changes to stroke services are equitable across the Swansea Bay population.

We reiterate many of the recommendations in our 2017 report, a copy of which is available on request.

## New for our March 2022 report:

- Strive to provide stroke services that meet RCP<sup>13</sup> and NICE<sup>14</sup> standards of best practice
- Carry out periodic reviews of the discharge process to check the patient experience and identify areas in need of review or change
- Ensure that emotional support is offered along with treatments such as physiotherapy and speech and language therapy
- There should be clear and simple literature giving patients, families, and carers information about the support available locally: This should include:
  - emotional/mental well-being and
  - practical support to carers and family members
- Ensure that all stroke patients are given advice from appropriately trained practitioners about healthy lifestyles and what preventative measures they can introduce into their daily living
- Care needs to be consistent for every patient. The experience of stroke survivors and their families was not defined by their hospital care alone. Plans to develop the HASU should also consider:

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<sup>13</sup> The Royal College of Physicians (RCP) guidelines - This guideline sets out how stroke care should be provided, covering the whole pathway from pre-hospital care to long-term management.

<sup>14</sup> National Institute for Health and Care Excellence (NICE) - the quality standard covers diagnosing and managing stroke in adults (over 16). It includes diagnosis, initial management, acute-phase care, rehabilitation, and long-term support for people with stroke. Quality standards help Health Boards improve the quality of care they provide or commission.

- how these wider issues impact on patient outcomes, including rehabilitation support, and
- how they plan to be addressed

We urge the Health Board to consider the key concerns identified in this report and in our letter to the Health Board, dated 18 March 2022, when finalising proposals to improve local stroke services.

We welcome further discussions with the Health Board along its journey, to develop the HASU to improve patient outcomes.

## What next?

Our report will be shared with Swansea Bay University Health Board, to support them in the development of proposals for the future of stroke services in Swansea Bay.

We will continue to represent the CHC at the Health Board's Stroke Delivery Group Board Meeting and to oversee the Health Board's plans, to establish a Hyper-Acute Stroke Unit in Swansea Bay.

# Thank you








We thank everyone who took the time to share their views and experiences with us about their experiences of NHS stroke services. We also thank the Stroke Association and local stroke groups for helping to facilitate virtual talks with stroke survivor groups and promote our survey.

## Feedback

Swansea Bay CHC would love to hear what you think about this publication, and any suggestions about how we could have improved it, so we can use this to make our future work better.



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If you write to us in Welsh, we will answer in Welsh. This will not lead to a delay in responding to your correspondence.

We welcome telephone calls in Welsh.

**Swansea Bay  
Community Health Council**