healthwatch Surrey

What we're hearing from Stroke survivors and carers

March 2023

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About Healthwatch Surrey

Healthwatch Surrey is an independent health and care champion, empowering the residents of Surrey to have their voices heard. We seek out people's experiences of health and care services and share these with service providers and decision-makers, to support services to improve and tackle health inequalities. We believe that health and social care providers can best improve services by listening to people's experiences.

We also provide advice and signposting to help the people of Surrey find the care that best suits their needs. Any urgent or concerning experiences within this report have been escalated to the appropriate teams. All appropriate information and advice and signposting to complaints processes has already been given.

About this report

This report has been designed to be shared with the Integrated Stroke Delivery Network to help inform them of the experiences of people who have survived a stroke and their carers. The comments within this report were gathered at community engagement events throughout 2022.
In addition to speaking to people at these events, people have also shared their experiences of health and social care services through our Helpdesk, Independent Health Complaints Advocacy service, 'Giving Carers a Voice' engagement, online Feedback Centre and postal submissions.

This report is not designed to be representative of all services.

What people have shared

Positive experiences

People have told us about the help and support they've received while recovering and adjusting to life after stroke. This illustrates the importance of community groups and the positive impact good support has.

> I'm here at the Stroke Group. I come here once a week and it gives my wife a bit of a break, and I get a hot lunch, she drops me off here… When I became ill the only genuine help I

> got was from the Parachute Regiment and they came along and visited me regularly as I am a veteran. **181108, October 2022**

People have also shared their praise for other services:

> I've actually moved but [kept] my GP… they are excellent. We've moved house because of the stroke, and we have moved … to a flat, as it was easier to cope with. The GP let me stay on with them and have been really supportive. The doctor has given me her email address and I can contact her directly. I had a stroke seven years ago and they have been supporting me ever since. **181108 October 2022**

> I had a brain tumour in 2005, had a stroke as a result of the operation, and I am now wheelchair bound. Moved to a flat and registered with a new GP who have been excellent. When registered, my wife was able to go to the surgery and pick up all the forms. Transfer of records worked well - anytime she rang up the GP for anything, we would get a call. We have felt very supported during the last two years. Frimley hospital have given me regular check-ups there, last appointment I mentioned eye sight deteriorating. I had a scan but was referred for an MRI. I have been waiting four weeks now, thought it would be quicker given my history. **160426, January 2022**

> I suffered a stroke 12 years ago which has left me with mobility issues and memory problems… I go to physio [every week], which is really helpful. My wife drives me there and to [a] community lunch and social stuff. I can walk with my support dog. **182788 November 2022**

> I had a stroke while on holiday 5 years ago and been living with the after affects. But, had a TIA [Transient ischaemic attack] 5 weeks ago and I can't really read or talk properly since. I had a lot of rehab via [my local community] hospital and they were good. **182774 November 2022**

Accessibility of services following a stroke

One stroke survivor has told us about physical accessibility of health appointments:

> I have an electric chair since I suffered badly with a stroke. My surgery is only just about accessible, it is tight. I have told them at the surgery. **182790, November 2022**

We have also heard about the effect of cognitive impairments on accessing services following a stroke:

> Getting access to my GP now is a real problem. I can't ring up – my mind goes blank. I can't go online either as I can't read very well at the moment. So, I have to drive and especially go in. The receptionist is so unfriendly. The surgery doesn't allow for my condition. I can't text either. Home visit would be nice. **182774 November 2022**

Initially positive but lacking carer support

We have also heard concerns from carers about the support they and those they are caring for receive:

> My wife had a stroke in August this year. She was in Hospital for a week and then was discharged. She then had Physio, SALT [speech and language therapy] and OT [occupational therapy] for 6 weeks but it stopped after 5 weeks as they were so pleased with the progress she was making. But now I can see that progress has slowed and she's not improving. In fact, she is getting worse, (it's now November). Her memory is really bad now. I have to supervise everything she does – cooking, washing, washing for herself, cleaning. She has trouble identifying things. I have gone back to the GP. I'm having a tough time at the moment. I can only leave her for a couple of hours but then she gets agitated and upset. **183082 November 2022**

I experienced symptoms of a TIA (transient ischaemia attack or mini stroke) late one Monday afternoon - visual disturbance, loss of movement in right arm and leg, inability to speak. The symptoms passed quickly, but I knew were serious enough to seek medical advice I called 111 who suspected a TIA or a hemiplegic migraine and reported the episode to my GP with the recommendation that I should be referred to be seen by a TIA clinic within 24 hours. My GP called me within an hour, recorded symptoms and referred me immediately to [the] TIA Clinic
23 hours later I had heard nothing so I called (Tuesday). They told me I live outside their area and would pass the referral to [another hospital], but that their head of department had seen my notes and was confident my symptoms had been due to a migraine.

I wanted the reassurance of appropriate tests rather than a diagnosis based on second-hand notes from a telephone consultation, so I then called [that hospital]. They also told me I live outside their area, and that I should be referred to [a third hospital]. Another day passed, so I contacted my GP again (on Wednesday) who told me that Stroke Unit had closed and all their referrals therefore now go to [the first hospital] - I still don't know whether this is correct, but neither, it seems, does anyone else! - and that they would follow it up.

Late on Wednesday, [the first] TIA Clinic called to invite me for a consultation and tests on Thursday morning, saying “we hear that [the 2nd hospital] won't see you.” There was no apology for turning me away and no acceptance that I should be seen at [their clinic] two days earlier. It felt the appointment was offered grudgingly and was somehow a massive favour to me for which I should be grateful (I was of course!)

> On arrival, the TIA Clinic nurse said "you shouldn't really be here, you are out of our area, you should be at [the 2nd hospital]."
>
> The 'mechanics' of my appointment ran very well - all tests and moving between different departments were quick and efficient
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> The conclusion of my appointment was I had suffered a TIA, and an MRI scan revealed that I had also suffered a previous 'silent' stroke. As the consultant was delivering this concerning news, he was also telling me "but you shouldn't be here, you live out of our area." Being told repeatedly that I was in the wrong place was stressful - it felt insensitive, unhelpful, and a bit like victim-blaming. Today, ten days later, [the 2nd hospital] called me to see whether I had been seen at the [3rd]…
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> There is clearly an issue with the patient's pathway from GP to hospital - all medical services should be clear on their geographical responsibility. Patients with potentially life-threatening symptoms should not have appointments delayed by 48 hours. There is also an issue with communication - it should not be up to that patient to have to chase their referral round numerous hospitals in an effort to be seen, especially at a time when they should be avoiding stress. There should also be no element of victim-blaming - I was made to feel uncomfortable, unimportant and inconvenient. **164439, July 2022**

Further support needed for life after stroke

Carers have been telling us their experiences of trying to get additional support for those they care for:

> I am extremely unhappy with [the wheelchair service]… My nan had a major stroke in 2013, which left her completely paralysed on her left side and cruelly led to the onset of vascular dementia… Following the stroke, her husband, my

grandad passed away. The toll of her demanding needs became too much, and his own health deteriorated greatly. So, my nan moved in with me and my family where my mum and I cared for her. Whilst she lived with us, she was able to access [a different] wheelchair service which funded a wheelchair which was moulded into her body shape (as the stroke left her legs and neck contorted). Acquiring this was life changing for her and us as a family as we were able to take her around the house and to take her on trips outside, allowing her to experience life again on a similar scale… The wheelchair is no longer fit for purpose as her body shape has changed along with her weight. This has dramatically changed her quality of life. The criteria from [this] wheelchair service that you must be able to self-propel in order to qualify for a wheelchair is inherently unfair and quite frankly I would argue, discriminatory. **174745 August 2022**

[At the end of] 2021, my husband suffered a catastrophic brain injury (a stroke). He was [previously] fit and healthy. He now has many complex needs, including being doubly incontinent. We live in a typical 3 bed terraced house. The bathroom is upstairs. [In mid 2021], this year an OT came to assess our house for suitability to be cared for at home. She said our back room would be suitable for a micro live in- he would need to have a hospital bed/hoist/wet room and car package. I'd need a special washing machine and a sluice in the kitchen. They want to send him home to live in one room. He won't be able to get out and about as a wheelchair can't fit in our house; the doors aren't wide enough. My husband has said that he wants to go home only if and when the house has a shower and a toilet downstairs. [2 months later] we had a meeting with [Adult Social Care] Locality Team… [My husband] told them that he wants to go home when it is adapted, is ready with a shower, and wet room. [It was] suggested that 2 carers came in twice a week into the house and then take him out to shower him. We made it very clear that was unacceptable, and he wouldn't be coming home with these provisions. The care

> package would go out for brokerage and providers would bid for it. If I don’t like the first one I have to take the second one even if I don’t like it. [Months of protracted communication followed with Adult Social Care over the type of care needed. The OT carried out a second assessment and deemed the home was not suitable for discharge and he was found a permanent placement in a care home]. **180595 December 2022**

Virtual wards

Stroke survivors have also been telling us how they would feel about using virtual wards:

> I have no anxiety about going into hospital. Would prefer it to being monitored at home. But I could ask my carer to support me, and if she would, then I could try it. **182790 November 2022**

Further details of our conversations with residents in East Surrey about the development of virtual wards in the area can be found here. We have also been speaking to residents in North West Surrey and will publish findings on our website soon.

Cost of care

People have also shared that a lack of finances impacts on the support they receive:

> I had a stroke back in 2012 and received very good care from [the hospital] at the time. More recently I had a fall and went into [hospital] when I had a visit from Social Services. When I was discharged, Social Services arranged for carers to come in a few weeks. I ended up stopping them coming… I had been given a financial assessment after the few initial weeks of the carers coming to see if I could contribute to the care. They deemed I could afford £16 per week. But then all of a sudden it went up to £85 per week. I think they discovered my friend was living with me. I don't know how that would make a difference. After that, the bills went up,

but no letter to explain why. My son contacted them on my behalf, he called and emailed but they didn't' get in touch… I decided I would cancel the carers as financially I could not afford them… They said I couldn't do that, and they needed Social Services to instruct them… In the end someone else called me, I felt this person was more of a decision maker, he emailed my son and asked if he could call him. He was very understanding, and, in the end, he agreed to send an email to stop the care. **181105 October 2022**

I was advised to apply for PIP, but I didn't apply first time, so I have applied again. The decision is pending. They have now asked to see our passports. I don't know why. We have supplied all the information that was required. They say if they don't receive them in a month, then we will have to submit the PIP all over again… So, I'm stuck until I get this PIP decision. I would love to pay a cleaner and someone to help around the house for a few hours. This would really help me as I do everything at the moment. I'm 70 and it's very tiring and stressful. I can't afford this without the PIP payment.
183082 November 2022

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