

How Covid-19 has impacted people affected by stroke and what that means for stroke policy & support services

SAFE Life After Stroke Forum Webinar, 12th March 2021

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Content

- Lived Experience of Stroke Survey (2018)
 - A brief reminder of how things were before the pandemic
- What we did when Covid-19 struck
 - Approach to gathering insight
 - Key Findings from the “Stroke Recoveries at Risk” research
- Implications & Recommendations

Lived Experience of Stroke Survey: Life for stroke affected people pre-pandemic

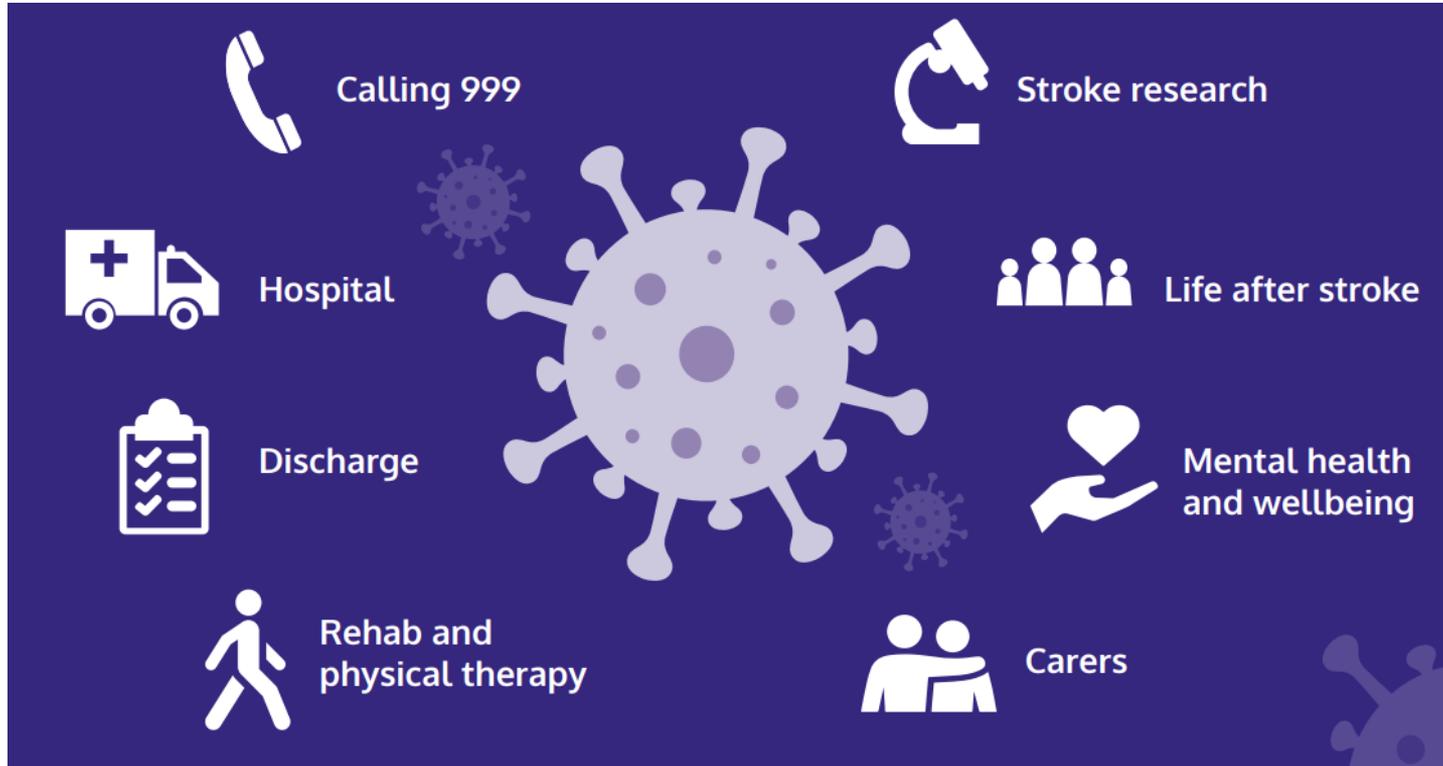
- Often the worst effects of stroke are the ones which others cannot easily see
- Carers bear a significant and ongoing burden
- There is much still to be done to improve stroke support & rehabilitation
- Younger survivors (of working age) are hit particularly hard by the ramifications of their stroke – many experiencing financial difficulties and unable to return to work

**11,000+ responses makes this the largest ever survey
of stroke affected people worldwide**

What we did when Covid struck

- Spring 2020 – gathered insight around the dramatic decline in 999 calls/stroke admissions to hospital
- May 2020 – surveyed our Research Award holders to understand the impact of the pandemic on stroke research
- June 2020 – surveyed 1, 949 people affected by stroke to build a clear picture of how the pandemic has affected the care stroke survivors received, as well as their lives and recoveries
- Strong response rate from each of the four nations across the UK
 - 1,546 (79%) stroke survivors
 - 403 (21%) carers and family members
 - 110 people who had their stroke this year, and 69 people whose stroke has happened during the Covid-19 pandemic (since March 2020)

Almost all aspects of stroke treatment & care have been impacted by the pandemic



Problems accessing rehabilitation & support



Around half of stroke survivors have had therapy appointments or home care visits cancelled or postponed



56% have not felt safe to go to scheduled appointments a demonstration of the significant disruption to rehabilitation and support caused by Covid-19.

39%



of stroke survivors who had a stroke this year said they had not received enough rehabilitation therapies

34%



of those who had their strokes in 2019 or before said the support they received from health and care services had been worse than before the pandemic.

Felt like I had fallen off the health care system a little bit, all appointments cancelled and local GP not able to see me even though I was sure I had a mini stroke since being in lockdown.

My mum has severe dysphasia and with no speech therapy for 5 weeks while with me, and limited speech therapy while in hospital, her progress is not what it should be. This is severely impacting on her recovery and wellbeing.

I think lockdown has made a massive impact on my recovery. I've had no physiotherapy at all since. In fact, it may be September when I can start again.

Telehealth works for some, but not all

I have had appointments related to my stroke online or over the phone



I have had therapy (including physiotherapy, occupational therapy and speech and language therapy) online or over the phone



Where telemedicine has been provided there was a high level of satisfaction

■ 61% satisfaction
 ■ 30% dissatisfaction



BASE: 242 people

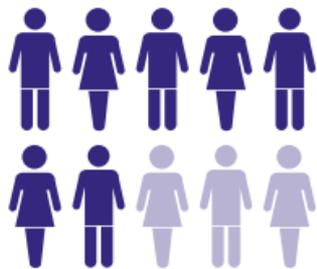
I have telephone anxiety due to history of stroke. When I'm stressed or tired, I suffer with aphasia more and I can't speak properly, which makes me feel stupid and treated differently. So to do telephone consultations, adds anxiety to my life. Where usually, I shy away from using the phone, I have been forced to give it a go more

I find telephone conversations very difficult, therefore haven't had any support full stop during this pandemic

My physio sessions have temporarily moved to FaceTime and it is going ok. We know each other very well and I am three years in my recovery so able to use my experience and knowledge to help it work.

Declining mental health and wellbeing:

The pandemic and lockdown have taken their toll on stroke survivors' mental health



7 in 10 (69%)

of stroke survivors have felt more anxious and depressed lately

68%



saying they feel more worried about their health

69%



more worried about what the future holds.

I go days without talking to or seeing anyone. I find myself sometimes crying for no reason

I have been feeling very depressed and unable to do things in the house as I get tired very quickly. It's been extremely lonely not seeing anyone very much. It's isolating. I worry that it might cause another stroke.

I've been worrying a lot. I'm scared of having another stroke. I'm 100% more scared of having another stroke than catching coronavirus

Caring during lockdown:

The pandemic has had a stark mental health impact on informal carers



77% of carers and family members

have been providing more care during lockdown

56%



of carers feel overwhelmed and unable to cope

72%



of those caring for someone who had a stroke this year feel overwhelmed and unable to cope

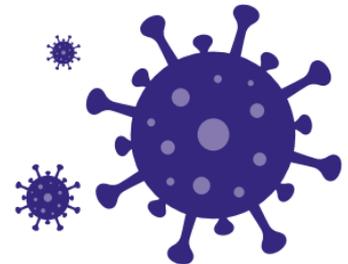
I have often felt overwhelmed with the responsibilities of looking after my husband after his stroke at the end of February.....I have had such a sense of being trapped at home.....He seems to be happy enough but I just want to run away.

We have been more isolated from family and friends during this time when their support would have made life much better. I have had no respite from the stroke survivor, which would have helped my mental health

I have needed to be physio, psychologist, friend, communicator, carer, motivator and much more

Key recommendations

- Health and care systems should **evaluate all changes to the stroke pathway in response to Covid-19.**
- Stroke teams should **follow up with all stroke survivors who had a stroke this year** to review their needs.
- Health and care systems and local authorities should **prioritise increasing mental health provision.**
- All stroke **rehabilitation must meet national clinical guideline leve**



How the findings are being used



1. We have adapted and developed our services

- Here for You
- Stroke Association Connect



2. We have put pressure on system decision makers both locally and nationally to prioritise stroke

- Public Health England has since committed to running the Act FAST campaign in March, as recommended by us
- We have fed in our insights around digital care and virtual stroke rehab into NHS England and the National Stroke Programme
- Findings shared with the Committee of Best Practice in Wales and debated in the Scottish Parliament



3. We have raised public awareness of stroke and the need for better stroke support both during and after the Covid pandemic via widespread media coverage

- TV, radio, print & online including Sky News, The Guardian & the Daily Mail

Where to find out more

- Stroke Recoveries at Risk report:

https://www.stroke.org.uk/sites/default/files/campaigning/jn_2021-121.1_-_covid_report_final.pdf

- Lived Experience of Stroke report:

<https://www.stroke.org.uk/lived-experience-of-stroke-report>

