

# Stroke Recoveries at risk

How the Covid-19 pandemic has  
affected stroke survivors' lives  
and recoveries

September 2020

Rebuilding lives after stroke

**Stroke**  
Association

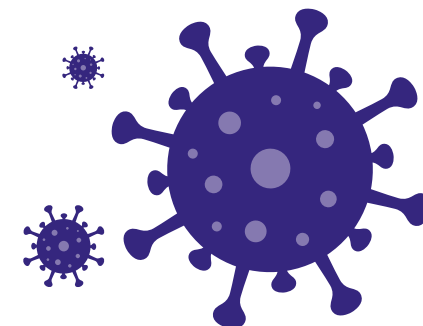
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"The care I received while in hospital has been fantastic! Sadly, in the outside world, it's nothing but Covid-19, all else has been ignored."

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# Forewords

"Covid-19 has turned all of our lives upside down this year. What used to feel safe and secure is now unpredictable. Everyday tasks require planning. Communicating with loved ones is different. New technology has to be embraced. Isolation and loneliness can loom large.

For stroke survivors, these sorts of challenges are nothing new. When stroke strikes, part of your brain shuts down. And so does a part of you. It's closer than you think – around 100,000 people will have a stroke in the UK this year.

Stroke is a sudden brain attack and the leading cause of adult disability in the UK. Almost two thirds of survivors leave hospital with a disability, and many will experience depression and anxiety as they adjust to life after stroke. To be a stroke survivor during a pandemic, whether the stroke happened years ago or more recently, intensifies existing challenges, and creates significant new ones.

This timely report is based on the experiences of nearly 2,000 people affected by stroke, who have shared their experiences of the pandemic and lockdown with us. You'll read about some of them in greater detail on the coming pages. Thank you very much to everyone who took the time to share their story, and to the researchers and stroke professionals whose insights we've drawn upon too. The views of people affected by stroke and the stroke clinical community inform not only this report, but everything we do.

One of the best parts of my job is seeing the remarkable recoveries that many stroke survivors achieve, due in large part to the ongoing care and support they receive. I am sure you will be deeply concerned to read of so many recoveries being put at risk due to Covid-19, despite the outstanding efforts of healthcare professionals. If people continue to miss out on the physiotherapy they need, or suddenly find themselves isolated with nobody to talk to, there is a very real danger that the impact of Covid-19 on stroke survivors and their carers will remain unchecked for years to come. Many could lose out on the opportunity to make their best possible recovery.

You may also be concerned to read of the damaging impact that pandemic has had on stroke research, and the growing evidence of a possible link between Covid-19 and strokes. In light of this, it's vital that stroke research is restarted and appropriately funded as soon as possible.

We have a chance to get stroke treatment, care and recoveries back on track, but only if we act quickly and with genuine commitment. This report offers clear, achievable recommendations for policy makers across the UK. If you feel you can help implement them, I urge you to get in touch – **we'd love to work with you.**"



**Juliet Bouverie OBE**  
Chief Executive  
Stroke Association



Rod is a Sky Sports Darts Commentator. He is 52 and from Halifax.  
Rod had a stroke in May 2020, during the UK lockdown.

"I was out in the garden in May this year, when I started to feel uncomfortable, woozy and unwell. My face and mouth were drooping. My wife, Louise, immediately knew I was having a stroke.

Louise followed the FAST advice and dialled 999 immediately. The ambulance came in 15 minutes, and I was taken to Calderdale Royal Infirmary. I feel lucky – I could have been on a long walk in the middle of nowhere and not got to hospital as quickly.

The care I received during my five weeks at the Calderdale Royal stroke unit was simply magnificent. I have nothing but praise for the NHS nurses, doctors and physiotherapists that helped me when I needed them most. I've had to learn to walk again and I received physio and occupational therapy every day. I should have had a face-to-face appointment with the Stroke Association whilst I was in hospital, but that couldn't happen because of Covid-19 restrictions.

I'm continuing with regular physio now - some provided by the NHS and some that I'm able to pay for privately. It's exhausting, but I am determined to keep giving 100%, because I know that will help my recovery. I am proof of the difference that intense and personalised rehabilitation can make. My stroke affected my speech, but I'm making real progress which is great! Being a Darts Commentator, speech is vital to my career and I'm hoping to get back behind the mic in time for the World Championship in December.

This report shows the variety of ways that the pandemic has affected stroke survivors and those around them. Seeing what others have been through during lockdown, I feel fortunate about the treatment and care I received, and I have had great support from Louise. I hope that decision-makers make sure that all those affected by stroke get the support they need to rebuild their lives."

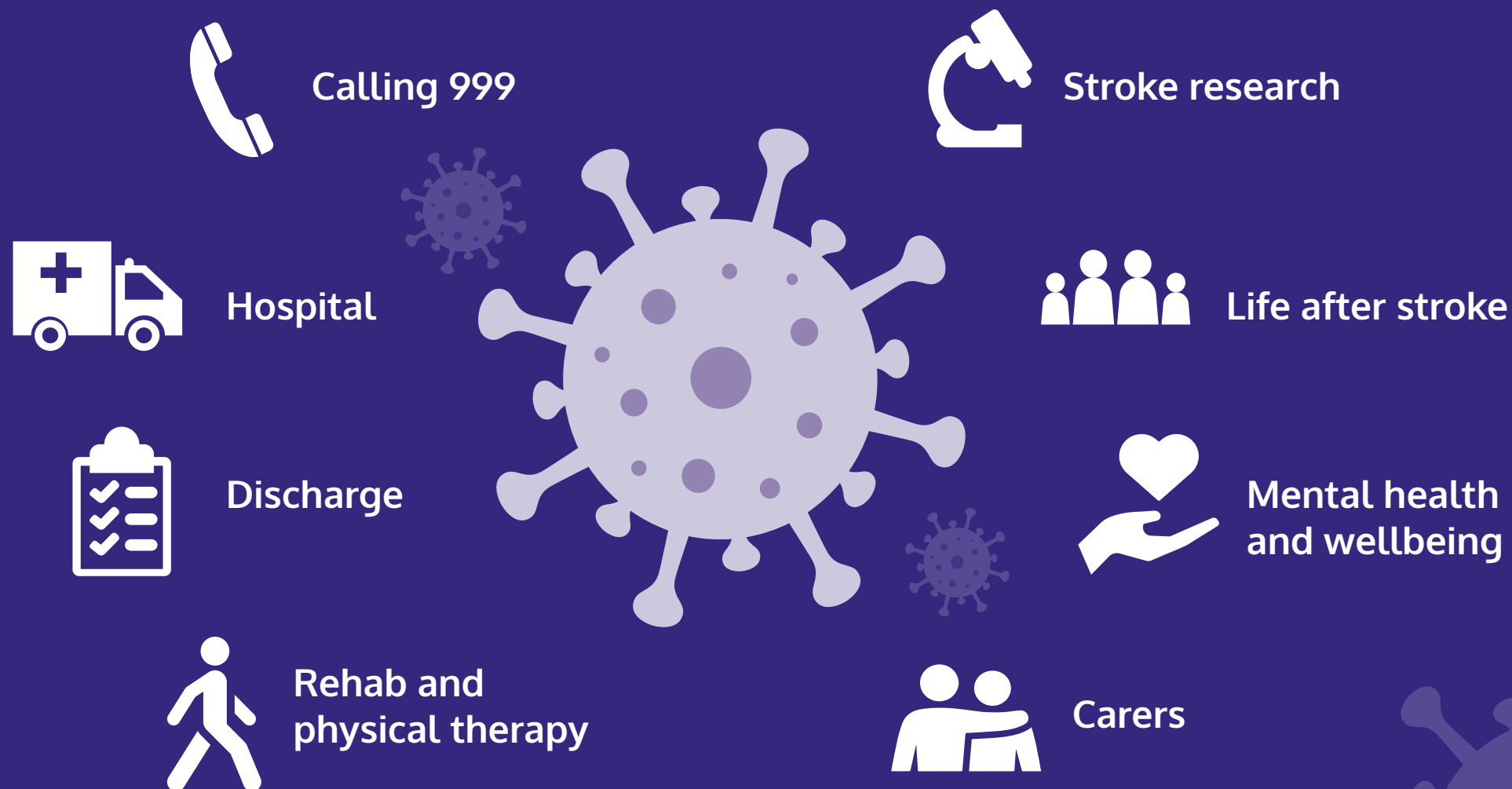


**Rod Studd**  
Darts Commentator  
Sky Sports



# Executive summary

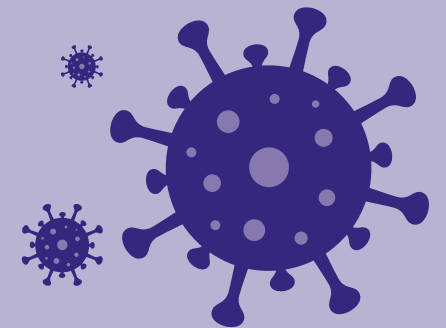
Almost all aspects of stroke treatment and care have been impacted by the pandemic.







Our survey of almost 2000 stroke survivors and their carers across the UK found that the Covid-19 pandemic has affected every aspect of stroke treatment and care. This includes delays to calling 999 and going to hospital with stroke symptoms and hospital care and discharge. It's also impacted access to rehabilitation and ongoing support, causing significant challenges for stroke survivors trying to rebuilding their lives, no matter when they had their stroke. Unsurprisingly, survey respondents have also reported feeling more anxious and concerned about the future, and carers have felt the significant pressures of lockdown.





# Key findings and impacts

## National stroke initiatives

### Delaying stroke commitments -

The disruption to health and care services caused by Covid-19 meant national stroke initiatives across the UK were paused or slowed. This is putting the progress made in stroke care over recent years at significant risk.

## Treatment

### Delays accessing stroke treatment –

30% of those who had a stroke during the pandemic delayed seeking emergency medical attention due to Covid-19. In England, Wales and Northern Ireland the number of stroke admissions fell by around 13% in April, with fewer people experiencing milder stroke presenting at hospital.<sup>1</sup> In England and Wales, stroke deaths in private homes were 52% higher than usual during the Covid-19 surge.<sup>2</sup>

**Treating strokes in hospital** - 76% of stroke survivors who had a stroke this year felt satisfied with the care they received in hospital, and stroke professionals reported innovations and improvements to stroke care. However, only 20% of surveyed stroke physicians reported no impact on stroke care in April, with the majority saying thrombolysis and thrombectomy treatments were affected.<sup>3</sup> In April, the overall risk of stroke patients dying in hospital increased by 12%, with Covid-positive stroke patients especially at risk (41%).<sup>4</sup>

**Being discharged from hospital** - 69% of people who had a stroke during the pandemic were satisfied with their discharge from hospital, but 21% were dissatisfied. Around 1 in 3 people (38%) also felt they hadn't received enough support from health and care services since leaving hospital.

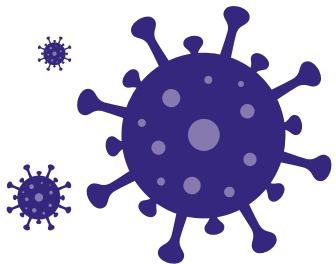




## Rehabilitation

**Problems accessing rehabilitation and support** - 39% of stroke survivors who had a stroke this year felt they had not received enough rehabilitation therapies, including physiotherapy. 34% of those who had their stroke in 2019 or before said the support they received from health and care services had been worse than before the pandemic. Around half of all stroke survivors had therapy appointments cancelled or postponed, and 56% have not felt safe to go to scheduled appointments - demonstrating the significant disruption to rehabilitation and support that Covid-19 has caused.

**Using virtual rehab and healthcare** - Some stroke survivors have had appointments (45%) and therapy (28%) online or over the phone, but many others have gone without their usual rehabilitation and support. This could be because they were not offered virtual appointments, or didn't accept them. Satisfaction with telehealth was high among 52% of stroke survivors. Yet 17% reported negatively on the experience, and virtual appointments are clearly not suitable for everyone.



39%



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

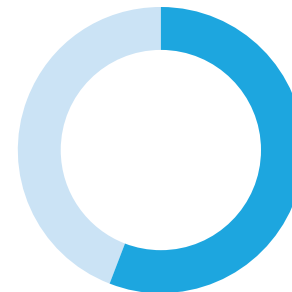
34%



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.



**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.

## Life after stroke

**Declining mental health and wellbeing** – The pandemic and lockdown have taken their toll on stroke survivors' mental health, exacerbating a significant and pre-existing unmet need. 7 in 10 (69%) stroke survivors have felt more anxious and depressed lately, with 68% saying they feel more worried about their health and 69% more worried about what the future holds.



**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.

**Caring during lockdown** - The pandemic has had a stark mental health impact on informal carers, many of whom say they need more wellbeing support and respite care. 77% of carers and family members have been providing more care during lockdown. Worriingly, over half (56%) feel overwhelmed and unable to cope, particularly those caring for someone who had a stroke this year (72%).



**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





**Finances and employment** – 4 in 10 (41%) stroke survivors have worried more about their finances and employment during the pandemic, particularly those of working age. The Stroke Association has awarded more hardship grants than usual, as individuals turn to our charity to fund vital home or personal equipment to cope with the effects of their stroke.

**Staying safe during lockdown** - Nearly one fifth of stroke survivors (20%) were advised by the NHS or government that they were in the shielding category. Over a third (37%) followed shielding guidance by choice, despite not being officially advised to shield. Stroke survivors reported uncertainty and confusion over whether they were more at risk if they contracted Covid-19, which increased their levels of anxiety.

## Stroke research

**Impacting stroke research** – The majority of stroke research stopped completely due to Covid-19. 3 in 4 Stroke Association funded researchers have had their research paused. Although some studies have restarted, including recruitment, it may take substantial resource to restart or replan others. Stroke research is historically underfunded, and Covid-19 threatens the funding available to drive much needed improvements in stroke care and treatment.

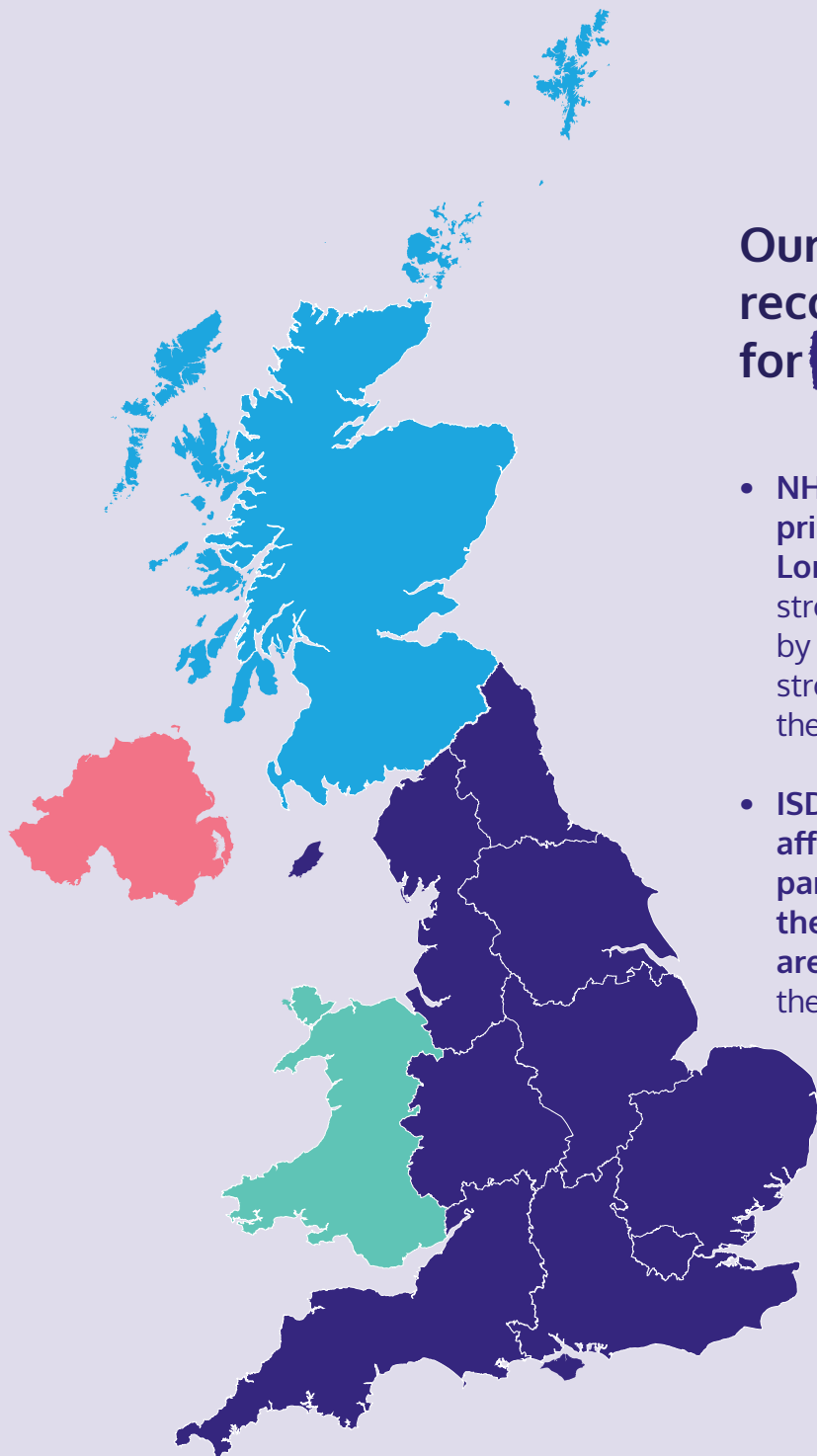


## Our recommendations

1. **All UK governments must urgently progress - or commit to - national stroke initiatives, and deliver commitments made prior to the pandemic**, acknowledging that stroke is one of the biggest health challenges of our time, and the damaging effects of the pandemic on stroke survivors.
2. **All stroke rehabilitation must meet national clinical guideline levels**, to mitigate the disruption to recoveries caused by the pandemic, addressing the individual needs of stroke survivors and maximising their potential for recovery.
3. **Stroke teams should follow up with all stroke survivors who had a stroke this year to review and address their rehabilitation needs**, to avoid a 'forgotten' cohort of patients caused by the pandemic.
4. **Health and care systems should involve stroke survivors and professionals in evaluating all changes to the stroke pathway in response to Covid-19**, using the pandemic as a catalyst for positive change and mitigating any negative impact on people affected by stroke.
5. **Health and care systems 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.
6. **Governments and local authorities must provide adequate support to carers** to help them to cope with the additional pressures of Covid-19, supporting them to take regular breaks and maintain their wellbeing.
7. **Stroke must be prioritised when research is restarted**. Non-Covid-19 stroke studies should be at level two in the National Institute for Health Research's Restart Framework, defined as studies providing access to life-preserving or life-extending treatment. Future research should also explore the possible link between Covid-19 and stroke.
8. **All UK governments should commit to investing in Act FAST public health messaging**, given its success as a behaviour change intervention and particularly in preparation for any future surge in Covid-19 cases.







## Our additional recommendations for **England**

- NHS England and Improvement must prioritise stroke commitments in the **Long Term Plan**, to mitigate against stroke survivors being further impacted by the pandemic and to make sure that stroke care in England continues to make the progress it needs to.
- ISDNs should work with people affected by stroke and other system partners to deliver on commitments in the **National Stroke Programme in local areas** and enable stroke services to meet the national clinical guidelines for stroke.

## Our additional recommendations for **Scotland**

- the Scottish Government must make urgent progress on its 2019-20 and 2020-21 Programme for Government stroke commitments:
  - Define [and implement] a progressive stroke service, covering the full pathway, including rehabilitation and long-term support.
  - Improve stroke care bundle performance in hospitals. Increase awareness of the signs of stroke, and stroke prevention.
  - Make thrombectomy available for everyone who needs it by 2023.
- the Scottish Government should establish a regular reporting mechanism for the Programme for Government stroke commitments to Parliament, to track progress on commitments, ensuring transparency and accountability.

## Our additional recommendations for Northern Ireland

The Department of Health and Northern Ireland Executive should stand by commitments they made before the pandemic and urgently:

- **Roll-out a new, regional long-term support pathway, which is appropriately funded to meet the needs of people affected by stroke.** In particular, the new pathway should address the following issues which have been exacerbated by the pandemic:
  1. The provision of the right rehabilitation support for people when and where they need it and for as long as they need it.
  2. Increased investment in psychological and emotional support services for people affected by stroke.
  3. Enhanced support for carers to take regular breaks and maintain their wellbeing, as well as a legal recognition of the vital role they play in our health and social care system.
- **Progress with the planned reform of stroke services to create a sustainable and high-quality service for everyone affected by stroke in Northern Ireland.**

## Our additional recommendations for 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.
- 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.





# About us

The Stroke Association is the UK's leading stroke charity. We're here to support people to rebuild their lives, because we believe everyone deserves to live the best life they can after stroke. We provide specialist support, fund critical research and campaign to make sure people affected by stroke get the very best care and support.

The Stroke Association is committed to working with decision-makers and system partners to act on the recommendations in this report. Across the UK, we're supporting progress on national and local stroke initiatives, drawing on stroke survivors' insights and our expertise as delivery partners, and bringing people together to improve the lives of stroke survivors. To find out more, email [campaigns@stroke.org.uk](mailto:campaigns@stroke.org.uk).

In response to the pandemic, we have rapidly developed new support services and innovations to help meet the most pressing needs of stroke survivors. These include Stroke Connect, a partnership with the NHS and Stroke Association that provides stroke survivors with personal, specialised support, information and reassurance in the early days following hospital discharge, and Here for You, a volunteer-run telephone support service to help stroke survivors who are feeling lonely or isolated.

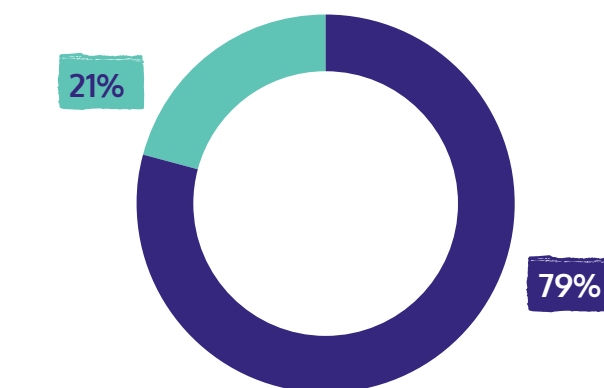


# Methodology

We surveyed 1,949 people affected by stroke in June 2020, to build a clear picture of how the Covid-19 pandemic has affected the care they received, as well as their lives and recoveries.

This research is the most comprehensive survey of the stroke community since the pandemic began. We had a strong response rate from each of the four nations across the UK. We received responses from 1,546 (79%) stroke survivors and 403 (21%) carers and family members. This includes 110 people who had their stroke this year, and 69 people whose stroke has happened during the Covid-19 pandemic (since March 2020).

We received responses from

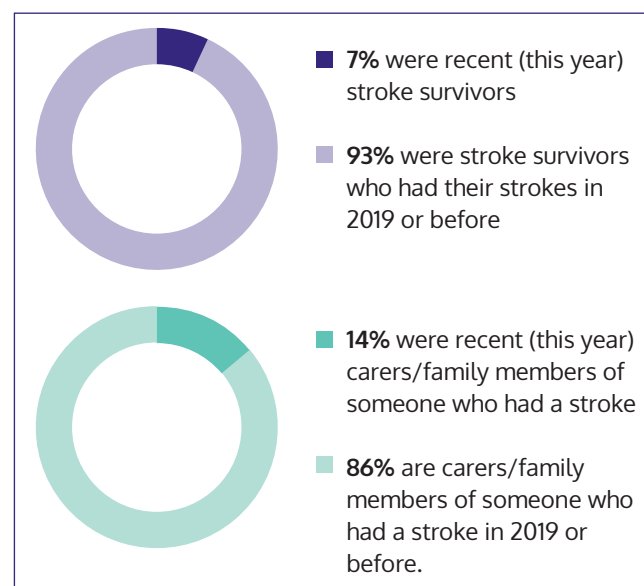


- Stroke survivors (79%)
- Carers or family members (21%)

When stroke survivors had their strokes



- During the pandemic (5.49%)
- January or February 2020 (3.08%)
- 2019 (15.19%)
- 2018 or before (74.76%)
- Don't know (1.49%)



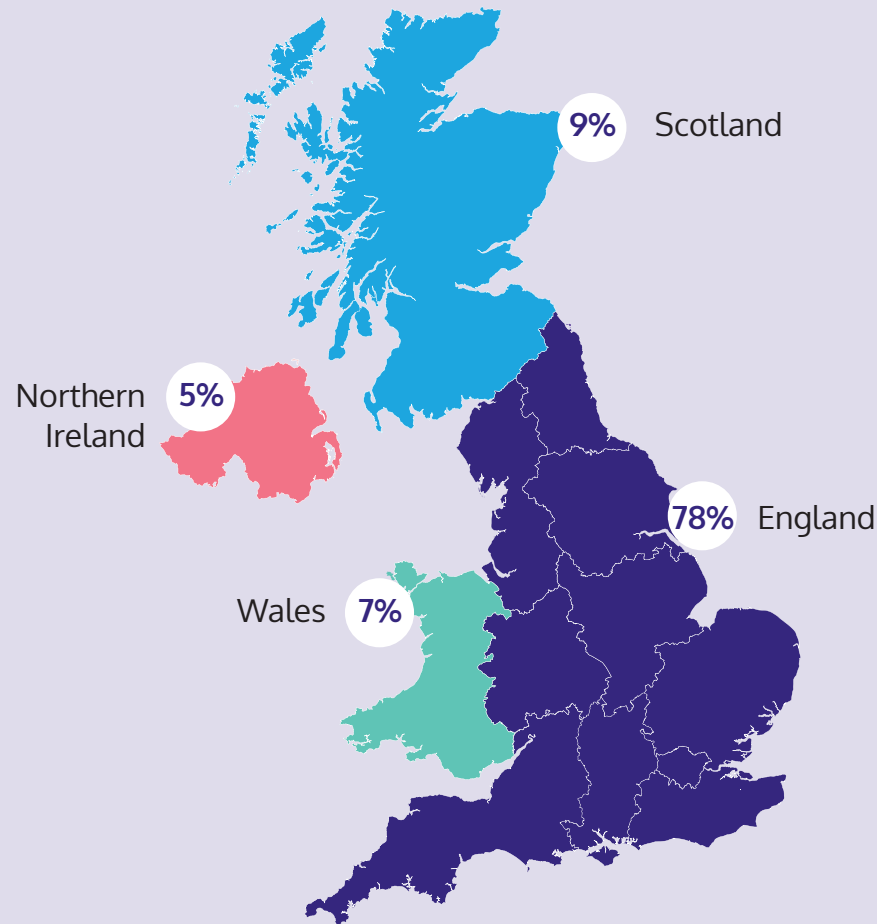
Age ranges:

- Under 18 (0.1%)
- 8-24 (0.36%)
- 25-34 (1.59%)
- 35-44 (4.21%)
- 45-54 (14.47%)
- 55-64 (22.57%)
- 65+ (34.33%)
- Not provided (22.37%)





## Nations representation



Stroke survivors, their carers and family members shared their views with us by completing an online survey, answering questions and leaving free-text comments about how the Covid-19 pandemic had affected their experiences of treatment and care, and impacted different aspects of their lives.<sup>5</sup>

We are aware of the limitations of our survey results. Compared to the general population, we received an overrepresentation of survey responses from those aged 65 and over, and an overrepresentation from those whose ethnicity is White British. We mainly heard from people who are already in touch with our organisation, often because they've accessed our stroke support services. This could mean the findings in this report overrepresent those who have received more support than the general stroke population.

We've also used evidence gathered by the wider stroke community to increase our understanding and build a comprehensive picture of how Covid-19 has affected all aspects of stroke treatment and care. We conducted a survey of our Stroke Association Research Award holders about the impact on the research community, asked stroke professionals their views through our Professional's Network in June, and commissioned Eden Stanley market research data in May, to explore the drop in stroke patients in emergency departments. We have also featured the findings from the British Association of Stroke Physicians (BASP) Covid-19 members' survey, and drawn upon national stroke clinical guidance in response to Covid-19 and Office of National Statistics data on non-Covid-19 deaths.

# Delaying national progress

Before the pandemic began, most stroke survivors received less than half the amount of rehabilitation recommended by national guidelines, and many reported feeling 'abandoned' after leaving hospital. Across the UK, access to high quality stroke care and life-saving treatments has been variable. Now, the pandemic has served to magnify the challenges that stroke survivors already faced, particularly when accessing rehabilitation after hospital, and getting support to address their mental health needs.

The pandemic has had a positive effect in some cases. Rapidly produced national stroke guidance helped to maintain standards of stroke care,<sup>6</sup> as have the tireless efforts of stroke clinicians. We have also seen some brilliant innovations in stroke care over the past months, as health systems adapted in response to the virus. Virtual appointments and phone consultations have broadened access to stroke care, and stroke teams have quickly adopted pre-hospital assessments and remote working that may have actually improved care in places.

Yet it's vital governments and health systems do not overlook their existing commitments and proven interventions - such as hyperacute stroke care, thrombectomy treatment and Early Supported Discharge - which save lives and reduce disability. Now is also the time to embed networked approaches to stroke care, so that systems can collaborate and pool resources and expertise to create the best stroke pathways for local residents.





And national programmes must recognise stroke prevention as a cost-effective investment. 9 in 10 strokes can be preventable. In the midst of this pandemic, decision-makers cannot overlook the huge potential to save lives, and lessen pressures on the health system in coming years, with the right investment in stroke prevention programmes now.

Governments and health and care systems across the UK must take urgent action to deliver on the stroke ambitions they had already committed to before the pandemic took hold. With strong national and local leadership, and stroke priority programmes, we must overcome the significant recent disruption to stroke treatment and support. Addressing the problems highlighted in this report will allow future policy and practice to truly support stroke survivors to rebuild their lives.

The pandemic has also brought existing health inequalities into sharp focus. Like Covid-19, the impact of stroke is disproportionate in some communities. Strokes are more likely to happen to those from socially deprived areas, and these are often more severe. People from black and South Asian communities are more likely to have a stroke than white people. Risk factors such as high blood pressure and diabetes also disproportionately affect these communities, contributing to their risk of stroke.

In light of the pandemic, and the structural disadvantages it has brought to the fore, understanding health inequalities must be a priority for all aspects of stroke prevention, treatment and post-hospital care. The Stroke Association has already embarked on developing its own strategy to highlight, challenge and address or tackle health inequalities that exist in stroke health.

## Our recommendations

The Covid-19 pandemic cannot jeopardise the lives and recoveries of those affected by stroke any more than our findings show it already has. We recommend that:

- **All UK governments must urgently progress - or commit to - national stroke initiatives and deliver commitments made prior to the pandemic**, acknowledging that stroke is one of the biggest health challenges of our time, and the damaging effects of the pandemic on stroke survivors. National initiatives should consider the full pathway, from prevention through to life after stroke.
- All national stroke initiatives should consider how to reduce health inequalities as a key focus of their activity, and this should also be a priority for future research.

# Treatment

We received responses from 110 stroke survivors who had their stroke this year, including 69 whose stroke happened during the Covid-19 pandemic (since March 2020), to understand more about their stroke, hospital and discharge experiences. We also received responses from 57 carers or family members of those who had a stroke this year.

## Delays accessing stroke treatment

Stroke is a medical emergency. The sooner somebody receives a brain scan to diagnose their stroke, the quicker they will receive appropriate treatment and the more likely they are to survive and make a good recovery.<sup>7</sup> At the start of the pandemic, hospitals across the UK saw a significant drop in stroke patient admissions, and many stroke patients presented to hospital later than usual,<sup>8</sup> reflecting wider trends in non-Covid use of A&E departments across the UK.<sup>9 10 11</sup>

29% of the 69 survey respondents who had their stroke since March 2020 agreed that they had delayed seeking emergency medical attention because of coronavirus. This supports market research we commissioned in May, which found that 68% of the public were less likely to contact emergency services if ill with non-Covid-19 symptoms due to the pandemic.<sup>12</sup> 42% hadn't wanted to burden emergency services, while 34% were afraid of catching Covid-19 in hospital.<sup>13</sup> National stroke audit data from April shows that stroke admissions fell by 13% in England, Wales and Northern Ireland.<sup>14</sup> In a British Association of Stroke Physicians members survey, 42% of stroke physicians reported reduced activity at TIA and stroke clinics in April.<sup>15</sup>



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"I waited longer to report [my stroke] in the first place as I dreaded going to the hospital as I and my daughter had been isolating ourselves since 9 February. My most recent stroke was about mid-April and eventually I went to hospital mid-May as I had started having fits and paralysis down my left side, which were symptoms I had not experienced before... I feel that it will now take me longer to recover than it did before."

**Stroke survivor who had their stroke since March 2020**

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"Fewer strokes presenting at hospital as people are scared of catching the virus, so they are staying home and their symptoms are worsening."

**Stroke professional**

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"We do not know where new patients with stroke have gone! The stroke unit is low on numbers and anecdotally General Practice staff locally do not report seeing people with stroke or TIA."

**Stroke Association funded researcher**

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This has sadly resulted in more people dying from stroke in care homes and private homes during recent months - a wider effect of the virus. ONS data shows that stroke deaths in care homes were 39% higher than the five-year average in England and Wales, and stroke deaths in private homes 52% higher, during the Covid-19 surge from mid-March until May (68% and 57% for April alone).<sup>16</sup> As the pandemic has continued, the number of stroke presentations has gradually returned to normal levels.



**29% of people who had their stroke during the pandemic (since March 2020 onwards) delayed seeking emergency medical attention due to the coronavirus pandemic.**



Worryingly, some stroke survivors told us they felt that their stroke was not seen as a priority by NHS staff, or reported issues getting their stroke diagnosed. We also heard from people who had received conflicting advice, and cases where healthcare professionals had advised patients experiencing stroke symptoms not to visit hospital because of the virus. This culmination of delays to stroke treatment may have created a cohort of stroke survivors whose rehabilitation and recovery needs are greater and more complex as a result.

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"It's frightening, because stroke was not seen as a priority to A&E. The most important thing in the world was Covid-19. It might have been to them but, to me, I was having a stroke, and that's what I needed help with at that time. They couldn't scan me, and the stroke unit would not see me, and they chose not to admit me "because we couldn't examine you properly anyway" because of social distancing and no scans taking place at the moment. Is it ok that people die with stroke just as long as they don't die from Covid-19? I live alone and I was sent home still unable to move, dribbling, dropping mouth, and not being able to walk properly. There was no follow up at all. I live alone and I have been left with no advice and no concern that what happened might happen for a third time."

**Stroke survivor who had their stroke since March 2020**

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"I should have gone into hospital for an extra brain scan due to headaches but it was deemed more dangerous to have one during the height of the pandemic. Extra worry as it was suggested that I caught a bus to A&E if headache got really bad."

**Stroke survivor who had their stroke since March 2020**

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## Our recommendation

To avoid excess stroke deaths and disability as the pandemic continues, it's vital that both the public and health professionals continue treating stroke as a medical emergency. We also recommend that:

- **All UK governments should commit to continued investment in Act FAST public health messaging**, given its success as a behaviour change intervention and particularly in preparation for any future surge in Covid-19 cases.



## Treating strokes in hospital

Covid-19 prompted inevitable changes to the care delivered in hospitals, as health systems responded to the virus surge. 70% of those who had a stroke during the pandemic were satisfied with the care they received in hospital while only 12% reported feeling dissatisfied, in line with similar survey findings from before the pandemic. Evidence suggests that the pandemic impacted stroke care in hospital, in both positive and negative ways.



**70% of stroke survivors** felt satisfied with the care they received in hospital, while only



**12% of stroke survivors** reported feeling dissatisfied.



**72%** understood the hospital treatment they received when they had their stroke, while



**7%** disagreed with this statement.

The majority of survey respondents (72%) said they understood the hospital treatment they received when they had their stroke (7% disagreed). However, worryingly less than half (45%) felt that they were involved in decisions about plans for their recovery (28% disagreed) during this time, suggesting a lack of personalised care that is vital for recovery. The main issues cited by those who'd had a negative experience in hospital were feeling like their stroke care was compromised, and feeling that their stroke was not seen as a priority by staff.

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"Having a (second) stroke in lockdown has been a nightmare. I got to hospital after my stroke and a clinician told me they could not confirm stroke because all scans are on hold and not currently being carried out. They said they would "ordinarily" admit me to the stroke unit, but they felt it was "too risky". The A&E clinician said they would get a stroke doctor to come down to A&E to see me instead, but they never did. I couldn't speak properly or walk properly or stand well on my own, and they told me to go home. They didn't even tell me how I should get home. I couldn't feel half of my body."

**Stroke survivor who had their stroke since March 2020**

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Encouragingly, recent interim audit data from England, Wales and NI shows that key stroke care indicators were largely maintained in April, May and June 2020, if not slightly improved. This includes the time taken to carry out a brain scan, to admit to a dedicated stroke unit and the number of patients who received thrombolysis (clot-busting drugs) treatments<sup>17</sup>. These achievements, however, are balanced against the reduced number of stroke admissions seen in the same period.

Positively, many stroke professionals have also reported innovations and improvements in stroke hospital care and team working during the pandemic. These include pre-hospital triage services, telephone consultations and more use of Early Supported Discharge. We praise the dedicated and hard work of stroke clinicians throughout the pandemic so far, and welcome any effective innovations that can demonstrate improvements to patient care. It's vital that recent changes to stroke care in hospital are evaluated, to identify sustainable and long-term improvements that can be embedded across the UK.

Although most stroke units have been able to submit data during the pandemic, the true impact on stroke care, including the delivery of thrombolysis and thrombectomy, remains an incomplete picture. In the British Association of Stroke Physicians members' survey, for example, only 20% of physicians reported no impact on stroke unit care in April. 59% and 75% of members also reported an impact on the provision of life-changing thrombolysis and thrombectomy (surgical clot removal) treatments in the same month.<sup>18</sup>

Thrombectomy is a game-changing procedure that is suitable for around 10% of all stroke patients. Before the pandemic, access to thrombectomy was already variable across the UK, and there has been no thrombectomy service in Scotland since summer 2018. It is concerning to hear anecdotally that thrombectomy services have been affected by the pandemic, given the existing challenges and delays to rolling out the procedure more widely. It is now paramount that national and local decision-makers prioritise broadening access to thrombectomy to all that would benefit as soon as possible.

## Our recommendations

Timely and high-quality hospital stroke care is essential to maximise the number of people who survive their stroke, and begin a good recovery journey. We recommend that:

- **Health and care systems should involve stroke survivors and professionals in evaluating all changes to the stroke pathway in response to Covid-19**, using the pandemic as a catalyst for positive change and mitigating any negative impact on people affected by stroke.
- Stroke services should renew their focus on implementing mechanical thrombectomy, committing to ambitious targets to increase provision to all patients who would benefit.







## Being discharged from hospital

**Discharge from hospital to home is a key point of transition in a stroke survivor's recovery. It requires the support of both health and social care services, working together in a joined up way to ensure that patients return home safely, with all the support they need in place. We'd previously heard about some of the issues people face when being discharged from hospital in our 2016 New Era for Stroke report. Then, 30% of people told us they felt unprepared when it was time to go home, and 45% felt abandoned once they'd left hospital.<sup>19</sup>**

Our recent survey findings present a mixed picture of discharge during Covid-19, with the majority of stroke survivors who had a stroke this year saying that the discharge process itself worked well, but reporting issues accessing care and support once home. Overall, 69% of stroke survivors who had their stroke during the pandemic were satisfied with their discharge from hospital, while 21% were dissatisfied.

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"I've had all of my therapy and stroke nurse visits at home weekly since my discharge from hospital in April, I've just had one phone consultation up to now, I have been most fortunate considering because of the Covid-19 outbreak."

**Stroke survivor who had their stroke since March 2020**

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Many then commented on issues they had with lack of support once they reached home, highlighting the problems with joined up care between hospital and community settings in some cases. Less than half (49%) felt they had received enough support from health and care services since leaving hospital, with over a third (38%) saying they hadn't. Key themes from respondents' comments included a rushed discharge process, poor communication from stroke services and too little support to help them rebuild their lives at home.

Respondents highlighted issues caused by a lack of communication between hospitals and local authorities, such as not being provided with home assessments or adaptations. Carers also mentioned a lack of information around what should happen next, including details of what the stroke survivor in their care could safely eat and drink, contributed to ongoing health worries.





I felt satisfied with the way I was discharged from hospital



69% agree



8% neither agree not disagree



21% disagree



2% don't know

I felt I received enough support from health and care services since leaving hospital



49% agree



10% neither agree not disagree



38% disagree



3% don't know

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"Discharge from hospital was rushed and we had no home assessment. I had to pay my neighbour to fit a stair rail."

**Carer of a stroke survivor who had their stroke Jan/Feb 2020**

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"In some ways it has helped as he wouldn't have come out of hospital so quickly and I have no doubt that being at home has helped with his recovery, but we do feel like we're in limbo now... communication hasn't been great."

**Carer of a stroke survivor who had their stroke since March 2020**

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"The care I received while in hospital has been fantastic! Ambulance crew, doctors and nurses, all wonderful! Sadly, in the outside world, it's nothing but Covid-19, all else has been ignored."

**Stroke survivor who had their stroke since March 2020**

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## "If my wife hadn't been there, I would have struggled"



David, 59 from Leeds, had his stroke at the end of February 2020, just a few weeks before lockdown.

"I was driving on the motorway when I starting feeling woozy. I couldn't really see properly, but fortunately managed to get home. I just thought I was feeling a bit fluey but my wife recognised it was a stroke and dialled 999. I was talking and thought I was fine, but she said I wasn't making any sense. I'm in a wheelchair from a previous illness, but I was leaning and started to slide over. My face had also dropped.

"Luckily the ambulance arrived within 10 minutes. I went to Pinderfields Hospital – I live in the middle of Leeds and Wakefield so they gave me the choice of where to go. I didn't go to A&E but was taken straight to the stroke ward, where they did a CT scan and put me on me a drip over night to clear any blood clots.

David talks of the impact of his stroke and how Covid-19 has meant he has received less care and support with his recovery than he would have liked.

"The whole of my right side has been affected, and also my speech. I could walk a little before my stroke with crutches but now I can't walk at all without my frame. The movement in my arm is coming back but I still can't write or pick up a cup. Mentally, I get very emotional and very, very tired. Not being able to see my kids and grandkids when I was feeling down really got to me.

"I've had physiotherapy and occupational therapy. But they didn't come out [to my house] as much as I would have liked, and a lot was over the phone or by video.

"I had carers come to visit me for the first few weeks to help me because I couldn't get dressed or do anything myself and my wife Lee was at work. Unfortunately, they had to stop because of Covid-19 and had to focus on other cases who needed the support more – they were short staffed. My wife was put on furlough and she could then support me. If Lee hadn't been there, I would have struggled."

Our findings show the pandemic had more of an adverse effect for those who had a stroke in January or February this year, than those who had a stroke during the pandemic. Those who had their stroke in January or February reported higher levels of dissatisfaction with discharge (32% vs 19%) and more uncertainty over when their care plans would next be reviewed (34% vs 25%).

Medical professionals have also highlighted their concerns about stroke patient discharge during the pandemic. In their comments to us, some noted that the discharge process was rushed and, as a result, stroke survivors received much less support and rehabilitation than they usually would in hospital settings. Some stroke professionals were also concerned about patients returning to unsuitable home environments with little support and rehabilitation in the community to help them rebuild their lives.





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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. It is not unusual for the team at hospital to identify issues through discussion with patients/ families / social workers etc - I worry that people may be being sent back to environments where support (practical / emotional....) has not been implemented."

**Stroke professional**

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"All existing Early Supported Discharge patients had to be referred on to the community stroke team (prematurely) and as a consequence some of them are still waiting to be seen 10 weeks later."

**Stroke professional**

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However, other professionals reported improvements to patient discharge. For example, the British Association of Stroke Physicians' survey found that 32% of members reported an increased use of Early Supported Discharge (ESD) services.<sup>20</sup> ESD services are recommended in Royal College of Physicians clinical guidance and play a vital role in joining up care as stroke survivors make the crucial adjustment from hospital and home.<sup>21</sup> It shortens the length of time patients spend in hospital, making sure they receive the same levels of appropriate support in their own home instead. A well-functioning ESD service improves patient outcomes and reduces disability. However, it is essential that the service is properly implemented as the pandemic continues, and that stroke survivors receive the full ESD package recommended in guidance.

## Our recommendations

As health and care systems evaluate all changes made to the stroke pathway, including to hospital discharge, we recommend that:

- **Stroke teams should proactively follow up with all stroke survivors who had a stroke this year, to review and address their rehabilitation needs,** to avoid a 'forgotten' backlog of patients caused by the pandemic. Appropriate and additional support should be provided, as well as additional mechanisms to re-refer to the system.
- Stroke services should ensure that Early Supported Discharge services are properly established during and beyond the pandemic, and that all eligible stroke survivors receive the full ESD package recommended in guidance to improve outcomes and reduce disability.

# Rehabilitation

The consequences of stroke are life changing and often devastating - two thirds of survivors have disabilities caused by stroke.<sup>22</sup> With effective rehabilitation and support, the first few weeks and months after leaving hospital offer a particular window of opportunity, in which stroke survivors can often make significant strides towards recovery. Yet we know that long-term personalised support is also essential, and stroke survivors can still benefit from therapy and interventions years after their stroke.

We asked all 1,546 stroke survivors who took part in our survey about their experiences of stroke support and their ability to recover during the pandemic. This is because the majority of stroke survivors experience long-term impacts on their daily lives, and many still benefit from rehabilitation therapies years later. We also asked the 403 carers or family members about the support and rehabilitation they and their loved ones had received.

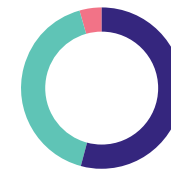


## Accessing rehabilitation and support

Our findings suggest that access to rehabilitation services has significantly deteriorated since the Covid-19 pandemic, and is threatening to put stroke recoveries at risk. 39% of stroke survivors who had a stroke this year said they had not received enough rehabilitation therapies, including physiotherapy, occupational therapy and speech and language therapy. This figure is even higher (56%) for those who had their stroke just before the pandemic (in January or February), further suggestion of a 'forgotten' cohort of stroke survivors in the rush to respond to Covid-19. These individuals are now at risk of experiencing more long-term and complex disabilities than they otherwise would have – impacts that are devastating for the stroke survivors themselves and also more costly to the health and social care system.

34% of those who had their strokes in 2019 or before said the support they received from health and care services had been worse or much worse since the UK was affected by coronavirus. 55% said it had been the same, and 8% said it had been better or much better. Reduced access to community rehabilitation has had a negative affect even for those who started their recovery journey long before the pandemic.

Some respondents highlighted long-term issues they still required support with, such as swallowing problems, memory issues and anxiety. Their comments show that the pandemic has caused recoveries to stall, or in some cases actually contribute to making the effects of their stroke - including fatigue, decreased mobility and anxiety – worse or more difficult to deal with. A large proportion report that the pandemic has had a negative effect on their progress, and that it will subsequently take longer for them to recover.



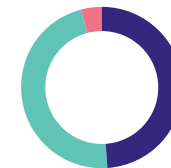
Have had appointments related to stroke cancelled or postponed

55% Yes 4% Don't know  
41% No



Have had therapy cancelled or postponed

54% Yes 3% Don't know  
43% No



Have had some or all home care visits cancelled or postponed

49% Yes 4% Don't know  
47% No

How has support received from health and care services been since the UK was affected by coronavirus



3% Much better



5% Better



55% Neither better or worse



20% Worse



13% Much worse



3% Don't know



Comments show that the pandemic has caused their recoveries to stall, or in some cases the effects of their stroke - including fatigue, decreased mobility and anxiety – to worsen. A large proportion report that the pandemic has had a negative effect on their progress, and that it will subsequently take longer for them to recover.

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We feel that my father's care, follow up and any further rehabilitation has been zero since discharge. We feel we are not being given information regarding his prognosis or future. We feel he has been pretty much left to lie in bed with 4 x daily carers (fantastic carers). He feels he has been left to die."

**Carer of a stroke survivor who had their stroke in January or February 2020**

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"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."

**Carer of a stroke survivor who had their stroke in January or February 2020**

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"I have felt my mobility worsen as my usual exercise activities were not available (swimming, guided seated yoga). Walking is not as good activity for me and some days I cannot manage a walk."

**Stroke survivor who had their stroke 2018 or before**

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## "Everything was cancelled due to Covid-19 and lockdown. It all fell apart"



Colyn, 76 from the Lake District, had a stroke in 2019 while he was on holidays in the Scottish Highlands. A former teacher and professional mountaineering instructor, Colyn was left with one-sided weakness and fatigue following his stroke. He received occupational therapy and physiotherapy while in hospital. While this should

have continued at home, the Covid-19 pandemic prevented this from happening.

"I didn't have my first physiotherapy session until the end of January [2020]. The physiotherapist then went off sick so it wasn't until February that I started properly with two brilliant physiotherapy sessions. I asked to use the gym equipment and managed to use the rowing machine, static bike and the cross trainer. I'm a hard task master for myself and was determined to get better. Then everything was cancelled due to Covid-19 and lockdown. It all fell apart.

"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. I live in the middle of the Lake District. The nearest swimming pool is Kendal and I don't drive at the moment, which means I have to get a bus which takes hours there and back. I've done some exercises but it doesn't have the same effect as being there with the physiotherapist.

"I'm 76 now and have always been fit. I played football and basketball, went fell running, I climbed all manner of mountains for years, and used to cycle. But I can't do any of that now. The government has failed vulnerable people in lockdown."



53% of all stroke survivors who responded to the survey also had therapy (including physiotherapy, occupational therapy and speech and language therapy) cancelled or postponed, and nearly half (49%) have also had some or all home care visits cancelled or postponed. These could have been cancelled by health professionals or stroke survivors themselves - as 56% have not felt safe to go to scheduled appointments and 41% have not wanted health and care workers to visit at home due to fear of the virus. Accessing health services during the pandemic has caused anxiety and stress for many stroke survivors.

Stroke professionals also highlighted their concerns with rehabilitation during the pandemic. 33% of British Association of Stroke Physicians' survey respondents reported reduced activity in rehabilitation services in April, with 30% reporting reduced quality, mainly due to less opportunity for rehabilitation in hospital and reduced community rehabilitation.<sup>23</sup> Our own survey of stroke professionals highlighted these issues too. Stroke professionals raised concerns that key opportunities to restore independence and improve quality of life through rehabilitation were being missed. Some said their patients had reported feeling abandoned once in community settings.

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"Reduced space and personnel available for rehabilitation; pressure to discharge patients too early, losing opportunity for restoration of independence."

**Stroke professional**

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"The vast majority of moderate to severe have received no rehab. Window of opportunity for max benefit missed (...) There is no point saving lives if we can't provide rehabilitation to optimise the quality of that life."

**Stroke professional**

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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**

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"Significant impact on rehab in community as not able to provide face-to-face contact ( ...) Community patients have reported feeling "abandoned" [and it] has put pressure on family dynamics as families having to provide more support."

**Stroke professional**

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## Our Stroke Helpline is a place for information and support.



### Our Helpline Manager explains how the pandemic has affected the calls our Helpline receives:

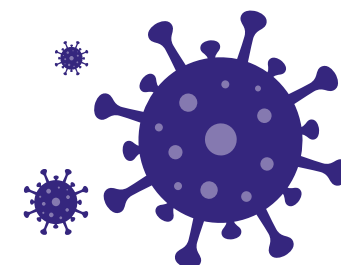
"Access to rehabilitation after discharge is a concern that many people have when they call us on the Helpline. During the pandemic these concerns and the uncertainty felt by

stroke survivors has increased significantly. Many hospitals are discharging patients more quickly which means that some stroke survivors are not getting the amount of intense in-patient therapy that they would normally receive. This can mean that their care needs on discharge are higher than they would normally be.

"We are also hearing from stroke survivors and their families that access to face-to-face physiotherapy and speech and language therapy when they return home from hospital is generally not happening, although this does vary from area to area. Some therapists are providing virtual therapy sessions and some are leaving exercise sheets for family members to practice. However, there's a real sense that people feel abandoned. I've also heard from other colleagues that some stroke survivors are fearful that they will be 'left behind or forgotten about when services resume' or that it will be 'too late' for their recoveries by the time much-needed therapy and support can be accessed."

These problems are not new - the pandemic has exacerbated existing problems accessing sufficient rehabilitation and support. Pre Covid-19, there were already significant shortfalls in the amount, duration and quality of rehabilitation stroke survivors received across the UK. National guidelines say that stroke survivors must have access to rehabilitation for as long as they show benefit, but adherence has been patchy. In our 2016 New Era for Stroke survey, 45% of stroke survivors said they felt abandoned once leaving hospital, commenting on a lack of joined up hospital and community care, too little support available once returning home and missed follow-up reviews.<sup>24</sup>

Our recent Covid-19 survey results also highlight general problems accessing routine healthcare during lockdown. A large proportion of stroke survivors told us that they were unable to, or did not want to, access GPs, pharmacies and other healthcare services to help them manage their condition. The majority of respondents also reported routine appointments and scans being delayed or cancelled.





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"Consultant said I need an ECG and yet my appointment isn't until September, which is a major concern."

**Stroke survivor who had their stroke since March 2020**

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"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."

**Stroke survivor who had their stroke since March 2020**

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"There has been very limited contact from any statutory services since then and no indication how or when he will be able to engage with services in the future."

**Carer of a Stroke survivor who had their stroke in 2019**

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While the Covid-19 surge necessitated changes to post-stroke care, it is now vital to fully restore and expand rehabilitation services to meet national guidelines. This is essential to avoid stroke recoveries stalling and prevent the problem getting worse. Failure to do so is likely to lead to increased needs and a rising tide of future demands on already stretched health and care systems.

Life after stroke support need not only be provided by health and care bodies. Voluntary sector organisations, including the Stroke Association, can help to provide the space and support necessary - through peer support groups, exercise classes and one-to-one engagement – to ensure that stroke survivors are able to access the support they need to continue their recoveries.

## Our recommendations

Going back to pre-pandemic levels of access to rehabilitation for stroke survivors is not enough. All stroke survivors across the UK should receive joined-up personalised care and rehabilitation to support their recoveries. We recommend that:

- **All stroke rehabilitation must meet national clinical guideline levels**, to mitigate the disruption to recoveries due to the pandemic, addressing the individual needs of stroke survivors and maximising their potential for recovery.
- Stroke services should complete a 6-month review for all stroke survivors, with particular attention paid to those who had a stroke recently who may have more pronounced unmet needs.

## Using virtual rehab and healthcare

**Embracing digital methods of service delivery - whether GP appointments, meetings with stroke consultants or therapy sessions - has been one of the most rapid and obvious changes to healthcare since lockdown began. Telehealth includes telephone, video conferencing and text messaging between professionals and patients. It has the potential to help manage wider pressures on the NHS, allowing people to access healthcare quickly and efficiently, but is not suitable for everyone.**

Our survey results show that 44% of stroke survivors have had appointments related to their stroke online or over the phone during the pandemic, and 28% have had therapy (including physiotherapy, occupational therapy and speech language therapy) online or over the phone. Unfortunately, virtual methods of healthcare have not been an option for everyone – the number of stroke survivors who had therapy cancelled or postponed is double the number who received therapy online or over the phone, showing that many have gone without their usual rehabilitation support.

For most stroke survivors who used it, telehealth was positive, or even preferable to face-to-face appointments, with 52% satisfied and only 17% dissatisfied with the appointments. Respondents generally told us it was a good use of time and resources, and that the appointments felt convenient and personal. Many cited safety as an important factor, with virtual appointments allaying anxieties about contracting Covid-19. Crucially, phone calls and online appointments have enabled many to continue their stroke recovery.



I have had appointments related to my stroke cancelled or postponed



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



I have had therapy (including physiotherapy, occupational therapy and speech & language therapy) cancelled or postponed

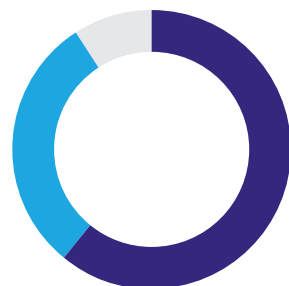


I have had therapy (including physiotherapy, occupational therapy and speech and language therapy) online or over the phone



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

■ 61% satisfaction  
■ 30% dissatisfaction



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"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."

**Stroke survivor who had their stroke 2018 or before**

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"Telephone consultation instead of attending outpatient appointment. Really good use of time/resources. Felt relaxed. Very efficient."

**Stroke survivor who had their stroke 2018 or before**

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"Had stroke 6 March stayed only one day as family were worried I would pick up virus. Was very lucky one or other family members stayed with me for four weeks and physiotherapy speech therapist and professionals came in for two weeks. After that telephone calls and lots of video exercises, which helped enormously. Care was excellent."

**Stroke survivor who had their stroke since March 2020**

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Yet virtual rehab is not suitable for all stroke survivors, especially those with communication difficulties or cognitive impairments, and those less digitally literate. Many told us that telehealth was challenging, and had negatively affected the care they received. Respondents who had difficulty communicating told us that the normal methods they might use to help them, such as body language and eye contact, weren't available when speaking to their doctors over the telephone or via video conference. Others with cognitive issues, or problems with their memory, told us that they would have liked time to prepare ahead of their appointments so they knew what they wanted to say, and questions they might like to ask.



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"My main problems post stroke are speech related and I find telephone conversation difficult. Also, I am not familiar with IT and can't get the hang of Zoom conversations!!"

**Stroke survivor who had their stroke 2019**

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

**Stroke survivor who had their stroke 2018 or before**

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"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."

**Stroke survivor who had their stroke 2018 or before**

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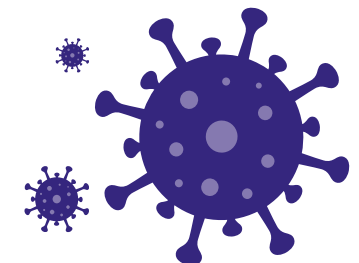
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"I understand fully the reason for a phone appointment (changed from face-to-face). I appreciate that it was changed to phone and not cancelled but I forgot what I wanted to say over the phone. I should've prepared for the appointment but didn't think to. Luckily my kids were in school at the time (just a few days before lockdown) I dread to think what a phone appointment would be like now with kids at home!" -

**Stroke survivor who had their stroke 2019**

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89% of stroke physicians surveyed by the British Association of Stroke Physicians had used telephone consultation and 36% used telemedicine in their practice, with the majority reporting positive experiences.<sup>25</sup> However, some said that teleclinics could be fatiguing to both professionals and patients, and we know anecdotally that virtual appointments can often take longer, using up more of a professional's time.



## Stroke Association Virtual Communication Plus Programme:



"In response to the pandemic in Northern Ireland, the Stroke Association Speech and Language Therapy team developed the Virtual Communication Plus Programme (VCCP). This is a six-week programme, delivered via Zoom, to stroke survivors living with aphasia. The programme aims to further develop communication skills within the group setting and provide an opportunity for social interaction and communication practice at a time of

social isolation. When developing the programme, it was really important for us to understand people's different experiences of using technology and being flexible in supporting people with aphasia to engage with the programme. Prior to the first session, each participant had a one-to-one session with a Speech and Language Therapist to enhance their confidence in getting online and to see what additional support may be needed from a family member or carer. The Stroke Association have also developed the Getting Online for People with Aphasia guide which has easy to follow information and guidance about getting online and accessing technology. Feedback has been really positive following the first six-week programme, with stroke survivors saying that it has increased their confidence and that it's very important to still be able to connect with others at this time. We're currently exploring how we can continue to provide online support for people with aphasia."

**Stroke Support Manager – Speech and Language Therapy**

"This has been the only contact I have had with people and I had lost my confidence that I had just started to build. Now my confidence has increased again".

**Stroke Survivor who completed the VCCP**

Developments in digital health care delivery during the pandemic have shown real potential to provide quick and efficient access to vital healthcare, in line with the ways we use technology in other parts of our lives. However, 'digital by default' also risks creating new barriers and inequities in stroke care access, or excluding those who are most vulnerable. Health and care systems need to assess and improve the feasibility and accessibility of remote consultations for stroke survivors, as they evaluate all of the rapid changes to care caused by Covid-19.

## Our recommendation

It's important that stroke survivors have choices about how they access services and support in the future, so that they can receive the personalised support most appropriate to them. We recommend that:

- Stroke services should evaluate and incorporate virtual models of stroke rehabilitation and support alongside face-to-face, offering people affected by stroke enhanced choice when accessing support. They should also engage with patients to make sure that no groups, including those with communication difficulties or those less digitally literate, are disadvantaged.

# Life after stroke

We asked all survey respondents about some of the common issues that stroke survivors face while rebuilding their lives after stroke, from mental health and wellbeing challenges, to impacts on their finances and employment, to help us understand the effects of the pandemic and resulting lockdown on these areas. Carers and family members also told us how lockdown has placed an increased strain on them, as they provide more care to loved ones.

## Declining mental health and wellbeing

**A stroke is a sudden life-altering brain attack that can have a profound effect on someone's mental health and emotions. Around three quarters of stroke survivors across the UK experience at least one mental health problem following a stroke.<sup>26</sup> These include a lack of confidence, depression, anxiety, mood swings and even suicidal thoughts. It is also common for stroke survivors to feel frightened, anxious, shocked or confused around the time of their stroke.<sup>27</sup>**

Although the pandemic and lockdown have affected us all, our survey shows that they have had a significant impact on the mental health and wellbeing of people affected by stroke. Most survey respondents have felt the emotional toll, while some report severely declining psychological health.

Over two thirds (69%) of stroke survivors told us they have felt more anxious and depressed lately. Lockdown has meant that many stroke survivors are unable to see family or friends, which has left them feeling isolated and lonely. However, some stroke survivors say they feel anxious about leaving the house, uncertain as to whether they are more vulnerable to Covid-19 because of their stroke. 68% of stroke survivors told us they now feel more worried about their health, while 69% worry about what the future holds for them and their loved ones.

For some, the additional stresses and concerns caused by the pandemic has left them worried that they will have another stroke. 45% of all stroke survivors now feel less able to cope with the impacts of their stroke, and over a third (37%) report feeling abandoned. Many told us they felt forgotten about by health and social care services.





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"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."

**Stroke survivor who had their stroke 2018 or before**

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

**Stroke survivor who had their stroke 2018 or before**

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"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"

**Stroke survivor who had their stroke in 2019**

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Over two thirds (69%) of stroke survivors said they have been feeling more anxious and depressed during the Covid-19 pandemic. (82% for people who had a stroke during the pandemic)

69%

82%

Around two thirds of stroke survivors say they are now more worried about their health (68%) and what the future holds (69%) for them and their families. The situation is even worse for those who have experienced a stroke during the pandemic with 88% saying they are more worried about their health while 81% are worried about what the future holds.

68%

69%

88%

81%

37% of all stroke survivors feel abandoned. (51% for those who had a stroke during the pandemic)

37%

51%

45% of all stroke survivors now feel less able to cope with the impacts of their stroke. (65% for those survivors who had a stroke during the pandemic)

45%

65%

The situation is worse for those 69 survivors who had their stroke during the pandemic. 82% say they feel more anxious and depressed, while 88% have worried more about their health. Half (51%) say they feel abandoned. This is particularly worrying as poor mental health can hinder survivors' recoveries.<sup>28</sup>

Those who are coping well emotionally with lockdown often say it is due to a strong network of family, friends and informal support. For those who are able to access online resources and forums, such as the Stroke Association's My Stroke Guide - a website for stroke support and advice - there is a strong online community.

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"Bizarrely, lockdown has meant there are always people at home with me, so I have been much less isolated and the quality of my life improved because of it."

**Stroke survivor how had their stroke 2018 or before**

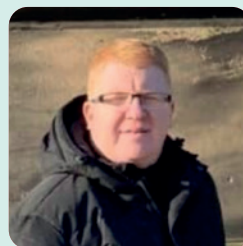
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"[My daughter] is very good at calming me down when I get panicky and things get on top of me. I couldn't have got through this without her."

**Stroke survivor who had their stroke 2018 or before**

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## Craig: "I feel so trapped"



Craig, 45 from Stoke-on-Trent, had a stroke caused by a major bleed on his brain in December 2018. Despite being told that he would be unable to walk, talk or even eat properly again, Craig has regained his speech while physiotherapy and sheer determination have allowed him to walk again. However, like many other stroke survivors across the UK trying to rebuild their lives, the Covid-19 pandemic has had a negative impact on Craig's recovery.

"All my physiotherapy for my legs has been cancelled and I've had no help at all. It used to be once a month and it really helped. Now I have no idea what to do next as I've got no access to the experts for more information. I've had to continue to do my exercises myself since my last appointment in January."

The pandemic and lockdown have also impacted Craig's emotional wellbeing.

"It's made me feel like I don't want to go out. I want to get out there and do exercise but I don't dare. People don't move out of your way when outside walking even though they can see there's problems with my walking.

"The emotions run wild. I feel depressed. I like being out, talking to people and raising awareness of what happened to me but now I feel so trapped."

Among stroke survivors who live alone or who are not able to access digital support, there is a growing sense of isolation, with many telling us they have felt lonely and abandoned during lockdown. Since March, our Stroke Helpline has seen the length of calls increase, as people affected by stroke seek emotional support and someone to talk to. Many stroke survivors and carers who call the Helpline now are more distressed than usual, struggling to cope with the impact of the pandemic and lockdown. For others, the pandemic and lockdown hasn't changed anything for them, as they felt isolated and abandoned already.

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"Because I live on my own, I feel really isolated and very alone...What if something was to happen to me, no one would know to be able to help me. By the time anyone would notice anything was wrong, it could just be too late."

**Stroke survivor who had their stroke 2018 or before**

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"My post stroke life and life since Covid have not been greatly different, especially the feeling of abandonment. The hard part will be after lockdown lifts and everyone else resumes their lives and I am just left abandoned as before."

**Stroke survivor who had their stroke 2018 or before**

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## Stroke professionals' views:

**Dr Terry Quinn, Stroke Association funded Clinical Lecturer:** "Telephone calls to complete a questionnaire for research often become long conversations with a stroke survivor who is shielding and has had no contact for weeks. This has been difficult for researchers and shows how little support stroke survivors receive."

**Stroke Association Support Coordinator in Northern Ireland:** "In the last few months, I have witnessed more anxiety and depression in the stroke survivors I have been working with than I would have seen before the pandemic and lockdown. Those living alone are particularly vulnerable and report loneliness and isolation. Being unable to access services and community support is also resulting in emotional distress and is impacting on stroke survivors' motivation and ability to set realistic goals for their rehabilitation".

**Marie Penney, Stroke Association Emotional Support Project Manager:**

"Stroke survivors are already experiencing isolation and fear due to having had a stroke. The pandemic has turned lives upside down and we're hearing every day how it affects people emotionally and psychologically. It is no surprise that we are seeing an increase in anxiety, depression, isolation and worry. Not being able to meet in person has been challenging but our ability to adapt has meant that we have been able to continuously provide emotional support remotely to those who have needed it during the pandemic".



The pandemic and resulting lockdown have increased the unmet mental health and wellbeing needs of stroke survivors, creating an urgent requirement for better emotional and psychological support provision.

## Our recommendation

Decision-makers should recognise the sudden life-changing impacts of stroke and the significant need for mental health support, which has been amplified by the pandemic. We recommend that:

- **Health and care systems 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.



## Caring during lockdown

More than 60% of stroke survivors rely on the help and support of an informal carer or family member to help them with day-to-day living – activities like getting dressed, making meals or going out to the shops.<sup>29</sup> Stroke impacts whole families, and being a carer can be very physically and emotionally demanding. Before the pandemic, many carers already reported feeling stressed, exhausted or anxious, with 85% saying they didn't always get the support and information they needed to help them in their caring role.<sup>30</sup>

The Covid-19 pandemic has placed even more of a strain on carers and family members of stroke survivors. 77% of the 403 who took part in this survey told us they have had to provide more care and support to loved ones during lockdown. In many cases, all other support and rehabilitation therapies for the stroke survivor stopped when lockdown began, and carers believe this has had a negative impact on their loved ones' recoveries.

Worryingly, over half (56%) of carers report feeling overwhelmed and unable to cope. This figure jumps to 78% among those caring for someone who had a stroke during the pandemic, showing the stark mental health impacts of this increased pressure on informal carers.



**Over half (56%)** of all carers who responded to our survey said they often feel overwhelmed and unable to cope.



**Over three quarters (77%)** of carers have had to provide more care and support during the pandemic.



**80% of carers** also told us they are finding it more difficult to carry out practical tasks, such as buying food or picking up prescriptions.



Despite this, only **43% of all carers** and **28% of recent carers** (those caring for someone who had a stroke this year) feel they have been given enough information, guidance and support over the past few months.

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"It feels like we are carers, occupational therapists and physios for my Mum as there is little the community teams can do although we are extremely grateful for the limited support they have been able to give. It feels lonely and overwhelming at times"

**Carer for a Stroke survivor who had their stroke since March 2020**

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

**Carer for a stroke survivor who had their stroke in 2019**

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"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."

**Carer for a Stroke survivor who had their stroke Jan/Feb 2020**

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Only 28% of those caring for someone who had a stroke during the pandemic feel that they have been given enough information, guidance and support. Many say they would have appreciated more advice and information from hospitals or community stroke teams about their loved ones' condition and how to properly care for someone who has had a stroke.

## A Stroke Support Coordinator's view:

**Our Stroke Support services are designed to provide the right support at the right time to ensure every stroke survivor makes the best possible recovery. Our Support Coordinators explain the impact of social distancing and the cancellation of visits to hospitals on carers and loved ones:**

The pandemic conditions have led to a lack of information being shared with family members and carers about the stroke survivor's condition and what to expect when they return home. This has led to many carers and families feeling overwhelmed, angry, frustrated, let-down and 'out of the loop'.

"I have had a couple of cases where family have felt overwhelmed as they were unable to visit their loved one in hospital to see for themselves how the stroke had impacted them or speak face-to-face with hospital staff. They felt 'out of the loop' as they were reliant on phone calls from the hospital for updates when of course, staff were very busy. A couple of family members I have supported have felt very challenged by this when trying to weigh up whether they could care for their loved one at home or whether they instead needed to be discharged from hospital into a care home. Family members felt very torn as they were unsure of the support their loved one would receive at home during lockdown but also knew that if the stroke survivor was discharged to a care home, they might not be able to visit them."

**(Stroke Support Coordinator)**





In response to our survey, many carers commented on the lack of communication they had with health and social care services, particularly while their loved one was still in hospital.

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"I am caring for my mum because of the lockdown situation. As I was unable to visit her in hospital I had no idea of the true extent of the impact of the stroke."

**Carer for a stroke survivor who had their stroke in January or February 2020**

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"The worst thing is not being able to see each other, I cannot sit and help with his recovery or give deeper insight to the person he was before the stroke and I feel that is a real disadvantage to his recovery."

**Carer for a stroke survivor who had their stroke since March 2020**

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Lockdown also made it more difficult for carers to undertake their caring role, with 80% telling us that it's harder for them to carry out practical tasks like buying food or picking up prescriptions. When asked what would help them in their caring role during the pandemic, the most common answers from carers and family members included support for their mental wellbeing and opportunities for respite.

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"As carers we had no information regarding Mum, her abilities or needs before she came home. There needs to be one point of contact for all her needs, a key worker. Her discharge was appalling."

**Carer for a Stroke survivor who had their stroke since March 2020**

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"If I could talk to someone about my anxieties and feelings without feeling guilty. My husband is suffering much worse than I am so I feel as though I shouldn't be thinking about myself."

**Carer for a stroke survivor who had their stroke since March 2020**

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"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"

**Carer for a Stroke survivor who had their stroke since March 2020**

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## Our recommendations

Decision-makers must recognise the increased strain on unpaid and informal carers during the pandemic, and should put appropriate care and support provision in place at the earliest opportunity. We recommend that:

- **Governments and local authorities should provide adequate support to carers** to cope with the additional pressures of lockdown, supporting them to take regular breaks and respite, and maintain their wellbeing.
- Stroke services should enable carers to access specialist information to support them in their caring role, signposting to voluntary sector services where appropriate.



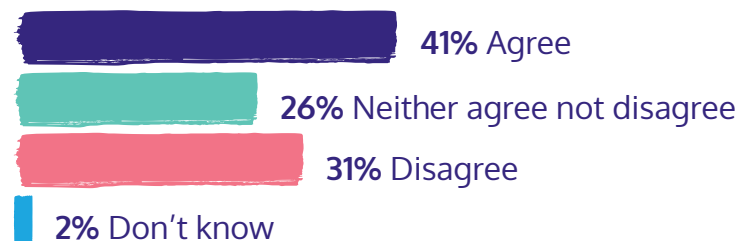
## Finances and employment

The financial impact of stroke, particularly among those of working age, is well documented. Our 2019 Lived Experience of Stroke report showed that a significant proportion of stroke survivors end up worse off, with 37% telling us they saw their income go down as a result on their stroke. Many face increased costs, and 1% reported having to sell their homes to cope financially.<sup>31</sup>

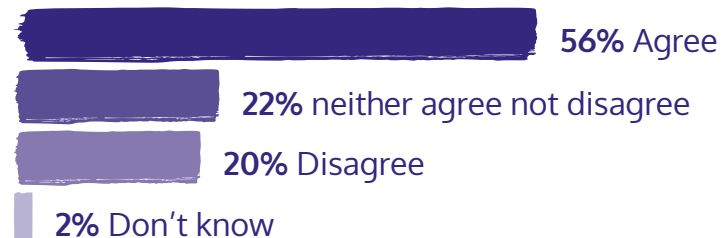
A concerning 41% of our recent survey respondents said they have worried more about their finances and employment during the pandemic. This is understandably more prevalent among those of working age (56%), as well as those who had their stroke in 2020 (57%). Similarly, three quarters (76%) of those aged 18-64 years are concerned about the future, compared to 20% and 62% of those aged 65 and over.

Key concerns for people included being furloughed or unable to return to work, not receiving enough support from their employer and increased worries about the economy and losing their job in the future. For some there was increased anxiety around accessing benefits, and many felt their shops were becoming more expensive due to there being less options available.

Breakdown of those who have worried more about their finances and employment during the pandemic.



Breakdown of those of working age and aged 65+ who are more worried about their finances and employment





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"We survive on benefits as I am unable to work and my wife cares for me, paying for food deliveries and the extra costs of having to buy dearer brands and not shop in the bargain stores has meant our money doesn't go as far, we are struggling."

**Stroke survivor who had their stroke in 2018 or before**

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"We cannot afford all our bills and are waiting for our council house to be taken away since we will have no money for rent soon."

**Stroke survivor who had their stroke in 2019**

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"We have now used up all our pension savings trying to keep up with mortgage payments and not get into debt."

**Stroke survivor who had their stroke in 2018 or before**

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At the Stroke Association, we have seen applications for hardship grants rise considerably during the pandemic. We have also awarded more hardship grants – 28 in April compared to an average of 17 per month in 2019 – as stroke survivors turn to charity support to fund vital home or personal equipment.

At the end of last year, the UK Government announced a National Strategy for Disabled People, with clear commitments to consider how the benefits system can best help disabled people, and to reduce the disability employment gap. Accounting for the understandable delay to this strategy due to Covid-19, it's vital that the National Disability Strategy is reprioritised at the earliest opportunity, given the economic impacts of stroke and the detrimental effects of the pandemic our survey results show.

## Our recommendation

It's clear that the coronavirus pandemic and current recession have reinforced existing financial and employment concerns for stroke survivors. We recommend that:

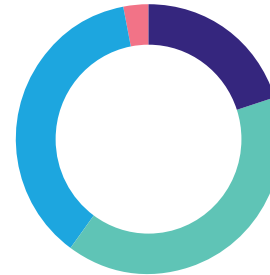
- The UK Government should prioritise its planned cross-government National Strategy for Disabled People, including the Green Paper on its benefits aspects, recognising the toll that the pandemic and lockdown has taken on stroke survivors.



## Staying safe during lockdown

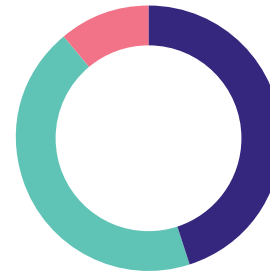
Strokes increase your risk of complications like pneumonia if you contract Covid-19.<sup>32</sup> Many stroke survivors also live with other health conditions that may make the effects of Covid-19 more severe. Yet, having a stroke doesn't always mean you are in the governments' shielding category, and many stroke survivors reported confusion and anxiety about their risk of Covid-19.

We found that nearly one fifth of stroke survivors (20%) were advised by NHS or the UK Government that they were in the shielding category, while two fifths (40%) were not shielding at all. Over a third of stroke survivors (37%) were following shielding guidance by choice, despite not having been told they were in the shielding category. Of these, over half (53%) said they didn't feel like they'd received enough appropriate information about how the government's lockdown guidance applied to them (39% said they had). This suggests that those shielding by choice were doing so for a variety of reasons, including confusion over advice, lack of trust or confidence in government guidance or wanting to exercise extra caution because of the virus.



**Have the NHS and UK Government advised you that you are in the 'shielding category'?**

- 20% Yes
- 40% No
- 37% No, but I am following shielding guidance by choice
- 3% Don't Know



**Do you feel you are receiving enough appropriate information about how the Government's lockdown guidance applies to you?**

- 45% Yes
- 44% No
- 11% Don't Know

Attitudes to whether governments provided enough information about how the lockdown guidance applied to them were very mixed, with 45% saying yes, 44% no and 11% not sure. In their comments, many stroke survivors told us that communication from government and health and care services could have been clearer, and many felt that they were unsure if the shielding guidance applied to them, highlighting a problem with official communications about lockdown instructions.

Survey comments show that uncertainty about whether stroke survivors are at greater risk of catching the virus, and worry about easing shielding advice, left many feeling stressed and anxious. However, 85% of carers and family said they understand how lockdown guidance applies to them and their loved one.

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"My family and I feel let down by the government with their contradictory advice. My parents were in self-enforced lockdown for three weeks prior to lockdown being enforced and I fear their health would have been compromised had they not taken these steps."

**Carer of a stroke survivor who had their stroke since March 2020**

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In their comments, some stroke survivors also highlighted their concerns about returning to work, and confusion over the conflicting advice given to them as lockdown eased. Our Stroke Helpline received more calls from carers and family members who were worried about returning to work and the risk they might then pose to clinically vulnerable family members.

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"My stroke nurse advised that I should be shielding but my work disagrees."

**Stroke survivor who had their stroke in 2019**

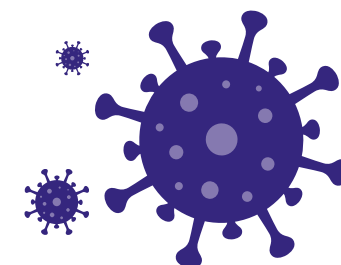
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"I feel the advice from the government and NHS is very confusing. My doctors surgery have told me I don't have to stay in as I'm not in the critical category but said that I still have to be 'very careful' - not very helpful if I am told to go back to work. They won't send me a letter to give to my employers if I need to and basically told me to use my common sense. This isn't helpful when there is immense pressure from the government to return to normal."

**Stroke survivor who had their stroke 2018 or before**

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## Our recommendations

A third of stroke survivors shielding by choice demonstrates the widespread concern and confusion over Covid-19 risk to those affected by stroke, and the guidance they received from government. We recommend that:

- In the event of further Covid-19 waves, governments and health systems should adopt a clear, comprehensive and reassuring communications strategy to stroke survivors, engaging people affected and the voluntary sector in development.
- Future guidance should include nuanced messaging for those at increased risk of Covid-19 complications who are not in the shielding category, and accessible information about using health services and manage existing conditions safely.

# Impacting stroke research

Stroke research is vitally important to drive improvements in care and treatment for those affected by stroke. Yet, it has been historically underfunded, receiving a fraction of the research investment of other comparable conditions. Research investment per stroke patient is only £48 in the UK per year, in comparison to £241 per cancer patient.<sup>33</sup> Now, Covid-19 risks reducing the pipeline of available funding for stroke research even further.

The pandemic has had a profound effect on stroke research funding and capability, causing the majority of non-Covid-19 research, including stroke research, to stop completely. In May, we surveyed 49 Stroke Association Research Award holders from 59 currently active awards, with a value of approximately £13m.<sup>34</sup> Three quarters of Stroke Association funded researchers have had their research paused, and only 4% of responders to a British Association of Stroke Physicians survey in April reported no impact to their research.<sup>35</sup>

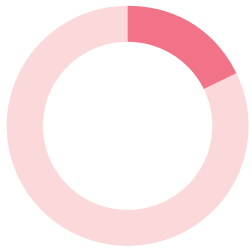
The Stroke Association has invested over £55m into stroke research since the early 1990s, with almost half focusing on stroke rehabilitation and recovery. Due to the substantial reduction in our fundraising income potential, our research budget has been cut significantly from £2.3m to £1.3m for 2020-21 and will continue to be reduced for the foreseeable future. Ongoing studies may now require costed extension, with a significant proportion of these funds required in the next three years.

Leveraging funding for research through organisational partnerships is a priority in our Research Strategy (2019-2024), but the pandemic has dramatically reduced income across the medical research sector. The Association of Medical Research Charities (AMRC) estimates it will take approximately 4.5 years for their medical research spend to recover to normal levels.<sup>36</sup>

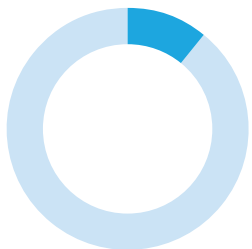




**Three quarters** of Stroke Association funded researchers have had their research paused



**18%** of Stroke Association researchers have taken on additional clinical work in response to the pandemic



**11%** of awards have accessed the Government Job Retention Scheme

The pandemic has also increased concerns about funding for stroke researchers, especially early-career researchers looking to establish careers after a PhD, and mid-career researchers who are dependent on their next grant to maintain their career. Some researchers told us their funding has already fallen through. Workforce pressures are another key concern, with almost one fifth of our researchers taking on additional clinical work in response to the pandemic and 11% of awards accessing the Government Job Retention Scheme.

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"Complete cessation of all research not related to Covid at my organisation has and will have a major impact on stroke research."  
**Stroke Association funded researcher**

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"The biggest issue is that my award doesn't financially support the project beyond my salary and other funders have halted their funding schemes."  
**Stroke Association funded researcher**

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## Dr Terry Quinn



Dr Terry Quinn, Stroke Association funded Clinical Lecturer, leads a team of researchers looking to improve stroke

care for cognitive effects. He says: "Stroke services are having to adapt to remote working and assessment, with little evidence base to inform the re-design of services. There is an important research question around how to offer remote stroke care. The effect of Covid-19 has (also) fallen disproportionately on early career researchers. There is a real danger that we lose a generation of future research leaders. Stroke research in the UK already has a major pipeline problem and we simply don't have the capacity to absorb such a loss."

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"There was a widespread shut down of all research activity, even if it did not have any potential to cause difficulty."  
**Stroke Association funded researcher**

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Most researchers told us they were not able to recruit or continue involving people affected by stroke in their projects, due to shielding advice for vulnerable groups and social distancing measures. The pandemic also severely restricted access to research resources and infrastructure, including Clinical Research Networks, university facilities, Clinical Trials Units and health records. This prevented research projects, even those not directly involving stroke survivors, from continuing and will challenge their restart.

## Professor Audrey Bowen case study



Professor Audrey Bowen, from the University of Manchester, is funded by the Stroke Association to carry out research into strategies

for coping with cognitive difficulties after stroke. Like many researchers across the UK, Professor Bowen's work has been affected by the pandemic.

"Our researchers had to stop visiting stroke survivors in their homes but have been able to conduct some research assessments by telephone or postal questionnaires. We also struggled to contact collaborating NHS therapists as they were pulled back to frontline duties and moved between NHS sites.

"Research is a collaborative exercise and so working separately from our homes for five months affects the teamwork necessary for a good study. However, we are communicating through Zoom group video calls, including with the stroke survivors who advise us on our studies. Some of our research team have

considerable caring responsibilities and have experienced illness. Things like this cost current research projects greatly in terms of time and outputs, and delays the development of future grant applications."

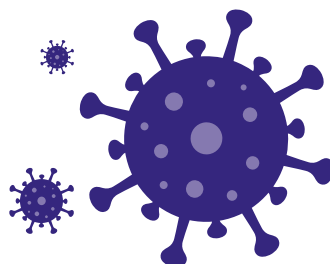
Professor Bowen is worried about the impact of the pandemic on the future of stroke research.

"Many stroke studies were paused or cancelled to prioritise research directly related to Covid-19. This is a huge set-back for stroke research. As many charities and other public research funders experience falls in income, there is even less money available for stroke research and for training future researchers. This endangers early career researchers the most as they are employed on fixed term contracts and require external funding. Furthermore, undergraduate students cannot conduct NHS stroke research projects this year due to national ethics restrictions. This reduces research awareness in future cohorts of health professionals and halts the flow of the next generation of stroke researchers."



There is growing evidence that Covid-19 may be linked to problems in the brain, including stroke in some people.<sup>37</sup> We urgently need more detailed research about large groups of stroke patients in order to understand any possible links between Covid-19 and risk of stroke.

Stroke research is more important than ever to understand any possible link between Covid-19 and stroke, and to evaluate the changes in acute care, rehabilitation and community stroke provision caused by Covid-19. Innovations in treatment and interventions are vital to support recovery and preserve quality of life for people affected by stroke. If this research is held back, it could result in thousands of people across the UK each year suffering worse effects of their stroke, and struggling more in their daily living. This in turn could increase the associated costs of the condition for both individuals and health and care services.



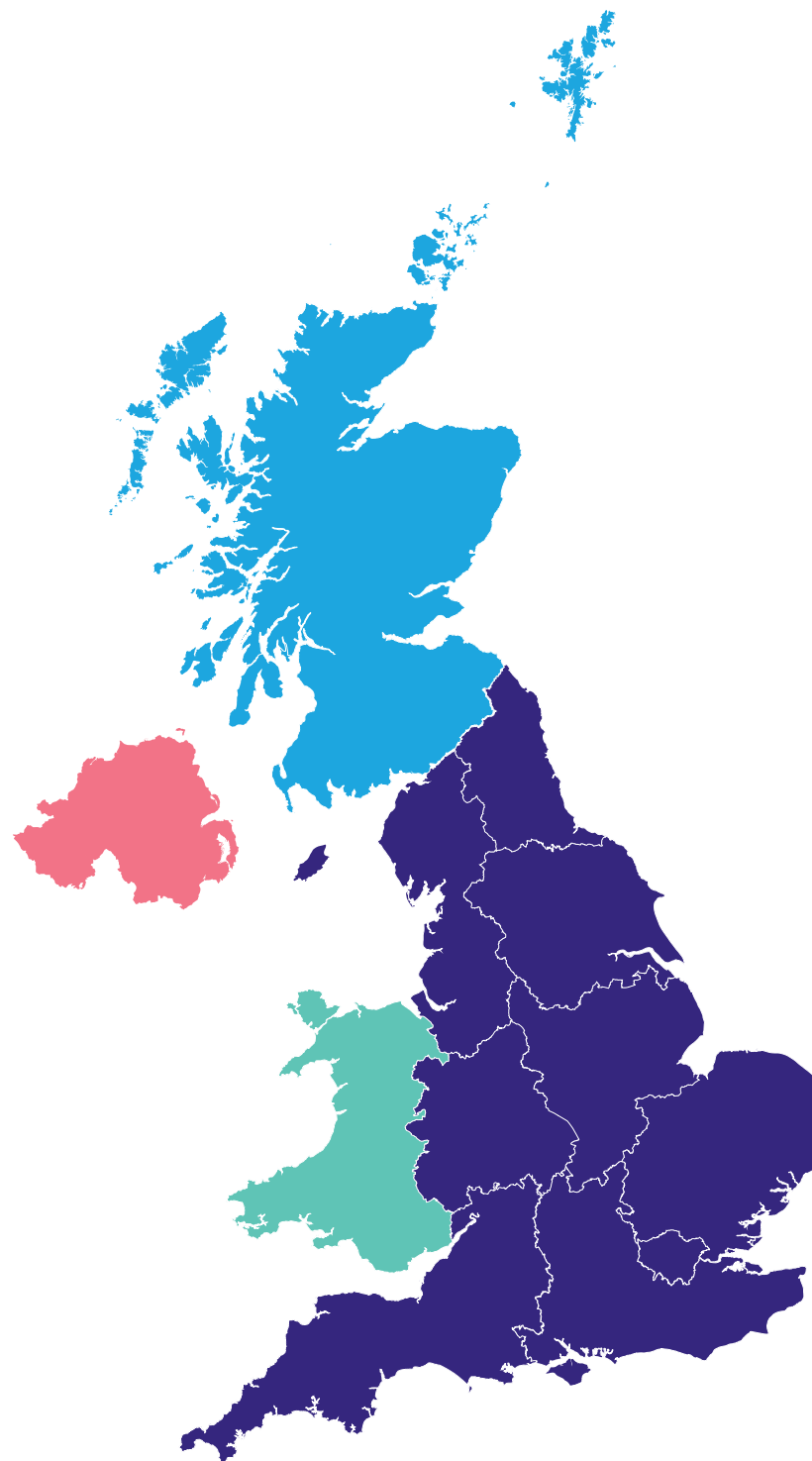
## Our recommendations

The UK Government and large public funders must take urgent action to lessen the lasting impact on health charity research. We recommend that:

- **Stroke research should be prioritised when research is restarted**, and non-Covid-19 stroke studies should be at level two in the National Institute for Health Research's Restart Framework, defined as studies providing access to life-preserving or life-extending treatment.
- Future research should explore any links between Covid-19 and risk of stroke, explore potential mechanisms, as well as seek to understand the impact of Covid-19 on the provision of stroke care and services in the short and longer term.
- UK Government should commit to a Life Sciences-Charity Partnership Fund for research, a co-investment scheme that would provide a level of match funding from government for future charity research. This would help to mitigate the significant challenges facing third sector research funders.
- Financial support and flexibility in use of existing grants for early and mid-career researchers should be available from funders, the NHS and universities. Employer's should appropriately consider the challenges caused by the pandemic and give researchers support in retention or promotion decisions.

# Stroke and Covid-19 across the UK

Many of the issues facing stroke survivors in this report were commonly reported across the UK. However, in some instances there were national variations, and these – along with the survey statistics for each devolved nation - are detailed in this section. As health is a devolved policy area, each UK nation has different structures and governance for stroke services, as well as different plans for delivering much-needed improvements. Here, we set out the stroke policy context and tailored recommendations for England, Scotland, Wales and Northern Ireland, to be considered in addition to the UK-wide recommendations.







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

Representing 78% of the total survey responses, the experiences of **1,218 stroke survivors (83 of which had their stroke during the pandemic)** and **308 carers or family members** in England show that the Covid-19 pandemic has had far-reaching negative consequences for those affected by stroke. This is putting stroke recoveries at risk, even for those who had their stroke a long time ago.

In 2019, the NHS Long Term Plan committed to advancing stroke care by introducing ambitious targets in key areas like access to thrombectomy, Early Supported Discharge and rehabilitation – as well as emotional wellbeing and life after stroke.<sup>38</sup> The plan also had prevention at its heart, and we welcomed the headline ambition to prevent 150,000 strokes, heart attacks and dementia cases over the next 10 years. New Integrated Stroke Delivery Networks (ISDNs) are being set up to deliver on these commitments, and to implement improvements across the pathway at a regional level.

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"I feel as though I have just been left to cope by my own devices  
it's all very new to me and very confusing"

**Stroke survivor, Manchester**

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The stark effects of the pandemic evidenced throughout this report show that stroke must remain a key clinical priority for NHS England and Improvement and Public Health England's successor, in the restoration and recovery phase and beyond. Any further delays to Long Term Plan stroke implementation risks placing a huge burden on health and care services in future. We urge that revised timescales for delivering Long Term Plan stroke targets are agreed as soon as reasonably possible, with action taken to address the concerns raised in this report.

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"Emergency care was fantastic from ambulance control, ambulance team to A&E. The care on the ward was also fantastic, it's just after discharge I feel has not gone so well"  
**Stroke survivor, Devon**

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"I've felt abandoned since I left hospital after I had my stroke 8 years ago so nothing has changed"  
**Stroke survivor, England**

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**68% of stroke survivors** have felt more anxious or depressed during the pandemic.



**78% of carers and family members** in England say they have been providing more care.



**6 in 10 (60%) stroke survivors** in England have received less support from health and care services than usual.



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

**Stroke survivor, Bexhill**

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"It feels like we are carers, occupational therapists and physios for my Mum (...) It feels lonely and overwhelming at times."

**Carer or family member, Cambridge**

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Whilst acute stroke care has steadily improved across England in recent years, rehabilitation and long-term support have long been the Cinderella service, lacking the data and investment needed to drive urgent improvements. Before the pandemic, access to rehabilitation was variable. Only 32% of patients benefitted from a six-month post-stroke review, meaning thousands didn't have their ongoing care needs identified and addressed.<sup>39</sup> Our survey findings show that the pandemic has only magnified this postcode lottery of stroke care. Many stroke survivors' recoveries are at risk unless vital improvements to rehabilitation and life after stroke support continue to be prioritised and delivered at pace through the National Stroke Programme for England.

The seismic challenge of responding to Covid-19 has inevitably and understandably slowed progress in delivering certain aspects of stroke reform in England. Yet, there is still a long way to go to realise the stroke ambitions in the Long Term Plan, and the effects of the pandemic have made them more important than ever. Covid-19 has sadly exacerbated many of the issues stroke survivors already experienced. Action to address these now will not only transform the lives of those affected by stroke, but also help the health and care system to cope with the growing burden of stroke in future. We are committed to working in partnership with NHS England and Improvement to deliver the ambitions of the Long Term Plan, offering strategic support to ISDNs and helping steer the National Stroke Programme in our role as co-chair.



## Our recommendations for England

In addition to the UK-wide recommendations in this report, we recommend that:

- **NHS England and Improvement must prioritise stroke commitments in the Long Term Plan**, to mitigate against stroke survivors being further impacted by the pandemic and to make sure that stroke care in England continues to make the progress it needs to.
- **ISDNs should work with people affected by stroke and other system partners to deliver on commitments in the National Stroke Programme in local areas** and enable stroke services to meet the national clinical guidelines for stroke.

# How has Covid-19 affected stroke survivors in Scotland?

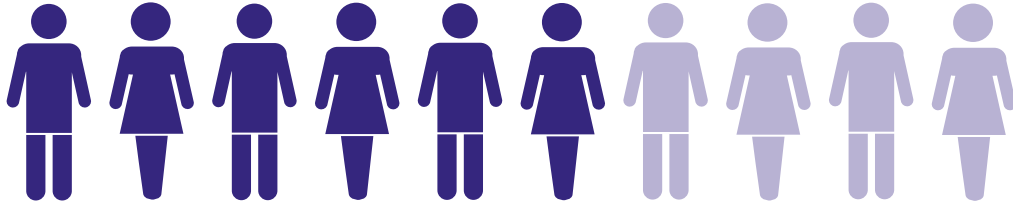
In Scotland, we heard from 139 stroke survivors, and 30 carers and family members of stroke survivors. Our results show that the Covid-19 pandemic is having a significant impact on the lives of stroke survivors and their families across all stages of their recovery. It's now vital that the Scottish Government's stroke commitments, outlined in their work plans for 2019-20<sup>40</sup> and 2020-21<sup>41</sup>, continue apace, and improvements are delivered across the stroke pathway in a new progressive stroke service.

Even prior to the pandemic, some basic stroke treatments and support have not been available uniformly across the country. Scotland needs a thrombectomy service. Scotland needs a supporting infrastructure for all stroke patients. And when they leave hospital, stroke survivors need a joined-up service that ensures they receive ongoing, personalised treatment, care and support to help them rebuild their lives.

Around 10% of stroke patients are suitable for thrombectomy treatment – mechanical blood clot removal. It is an extraordinary, highly specialised procedure that can save lives and reduce disability. It is also a cost effective treatment<sup>42</sup> and, on average, one thrombectomy patient saves the NHS an estimated £47,000 a year.<sup>43</sup>







**6 in 10 (59%) stroke survivors in Scotland say they have received less support from health and care services than usual**



**Almost half (48%) of stroke survivors have had appointments relating to their stroke online or over the phone**

There is currently no thrombectomy service in Scotland. Scotland would sit 44th and last among nations based on the European Stroke Organisation's 2019 survey.<sup>44</sup>

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**"My wellbeing has suffered and my recovery has also suffered."**  
**Stroke survivor, Carnoustie**

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After being delayed by Covid-19, an initial pilot thrombectomy service is due to launch this autumn in the North of Scotland, based at Ninewells hospital in Dundee. We are encouraged that the Cabinet Secretary for Health and Sport has announced similar services will be available for the two major population centres of Edinburgh and Glasgow in 2021 and 2022 respectively.<sup>45</sup> It is vital that stroke patients in Scotland can benefit from thrombectomy treatment as soon as possible, and any obstacles towards the Government's thrombectomy commitments must be addressed speedily and successfully.

For a national thrombectomy service to be viable, Scotland also needs a supporting framework for all stroke patients before and after their stroke. The latest Scottish Stroke Care Audit report<sup>46</sup> shows that stroke care bundle compliance – a group of four measures of basic care which every stroke patient should receive when they arrive in hospital – had only improved by 5% in 2019 from 59% to 64%. This means that more than a third of all stroke patients still do not receive timely, basic care. Not one of the 14 geographic Health Boards achieved the 80% standard for this measure. The same report also shows that door to needle times for thrombolysis is lagging in many areas. Urgent action must be taken to reduce the variation of stroke care, both regionally and between the 9-5 services and out of hours, including changing stroke pathways where needed.

Adjusting to life after stroke poses new challenges for many survivors, and our findings show that the pandemic has exacerbated many of these issues. We know that stroke survivors experienced difficulties **accessing rehabilitation and support** during the Covid-19 pandemic, putting many stroke recoveries at risk. 6 in 10 (59%) of stroke survivors in Scotland said they have received less support from health and care services than usual to help with their recovery, with 36% saying they hadn't. The majority of stroke survivors in Scotland reported that they'd had therapy cancelled or postponed (53%, compared to 48% in Wales and 50% in NI), showing that many have gone without the necessary rehabilitation and support needed to help their recovery.

Many stroke survivors in Scotland have been using **virtual rehab and healthcare** during the pandemic, having appointments relating to their stroke (48%) and therapy (30%) online or over the phone in recent months. Satisfaction with virtual or phone appointments was relatively high (58% felt satisfied, compared to the UK average of 52%), showing the potential for virtual methods of healthcare to complement face-to-face approaches.

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"I got some really good support/advice from a senior stroke nurse based at Edinburgh Royal Infirmary."

**Stroke survivor, Edinburgh**

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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 in Scotland report feeling more anxious or depressed during the pandemic. A staggering 70% have worried more about their health, and 72% have worried more about what the future holds, similar to figures from across the UK.

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"It makes his disability more problematic. Going to uni will need practical support – means not being able to socially distance. Makes making friends more difficult when not attending classes. Video calls with aphasia are more challenging. Can't learn to drive - lessons stopped. Restricts independence. And any support, while usually now fairly infrequent, has completely melted away. Uncertainty of future."

**Carer or family member, Edinburgh**

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**Over two thirds (68%) of stroke survivors report feeling more anxious or depressed during the pandemic**

**70%** have worried more about their health, and **72%** have worried more about what the future holds.

Those **caring during lockdown** in Scotland have told us their feelings of additional pressures, with just under half (46%) of all carers saying they feel overwhelmed and unable to cope. 25% say they are not, and 29% neither agree nor disagree. Over two thirds (67%) of carers are providing more care and support during lockdown (22% say they are not), and 68% say they are finding it more difficult to carry out practical tasks, such as buying food, picking up prescriptions or carrying out caring duties. Encouragingly, just over half (52%) of carers said that they had been given enough information, guidance and support during the pandemic, yet 24% disagree.

Regarding **staying safe during lockdown**, only 13% of stroke survivors in Scotland reported that they had been advised by the government that they were in the shielding category. This is a smaller proportion than across the rest of the UK (20%). A significant percentage were also following shielding guidance by choice, despite not being told they were in the shielding category. A higher percentage of stroke survivors in Scotland felt that they had been given enough information about how lockdown guidance applied to them than the rest of the UK (54% compared to the UK average of 45%).



The shortfalls in stroke treatment, care and support in Scotland, coupled with the profound effects of the pandemic on stroke survivors' lives, necessitate a sustained national focus on stroke. Now is the time to deliver stroke improvements, from prevention through to long-term support. Action now will transform the lives of stroke survivors in Scotland, and avoid the growing burden of stroke from overwhelming the health and care system in years to come.

## "I really struggle with the lack of routine"



Susan, from the Scottish Borders, had a haemorrhagic stroke caused by a bleed on the brain in May 2016. Following her stroke, Susan had problems with her speech, sight, hearing and mobility. Over time her speech and vision have improved, but Susan still struggles with walking. Susan has found lockdown really difficult.

"I really struggle with the lack of routine. Before lockdown, I went to the gym three times a week and had joined a walking group. However, my walking is hampered by drop foot, caused by my stroke. I'm waiting for an operation for this but it was cancelled due to Covid-19. I'm embarrassed about the way I walk."

Susan finds it frustrating not being able to go out and says she feels "trapped in the house".

"My sister used to take me to the hairdressers once a week, but we can't do that anymore. That's a big thing for me".

Like many other stroke survivors, Susan has felt the emotional impact of her stroke, particularly now during the pandemic and lockdown.

"I was emotionally crushed by the stroke. I was crying for hours and hours, days and days. I desperately needed counselling but none was available. I feel anxious and have lost my confidence".

Susan strongly believes that there should be more support available for stroke survivors after they are discharged from hospital.

"The best thing I did following my stroke was join a gym. Exercise not only helped me get stronger, it also improved my balance and helped my mental and emotional health.

"There needs to be more support out there for stroke survivors after they are discharged from hospital. Any help I have had, I have had to pay for it. Support should be available to all stroke survivors on the NHS."







## Our recommendations for Scotland

In addition to the UK-wide recommendations in this report, we recommend that:

- **the Scottish Government continues to make urgent progress on its Programme for Government stroke commitments:**
  - Define [and implement] a progressive stroke service, covering the full pathway, including rehabilitation and long-term support.
  - Improve stroke care bundle performance in hospitals.
  - Increase awareness of the signs of stroke, and stroke prevention.
  - Make thrombectomy available for everyone who needs it by 2023.
- **the Scottish Government should establish a regular reporting mechanism for the Programme for Government stroke commitments to Parliament, to track progress on commitments, ensuring transparency and accountability.**



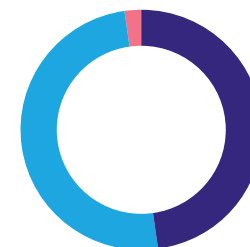
# How has Covid-19 affected stroke survivors in Wales?

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 reported number of stroke survivors with cancelled therapy appointments (48% compared to 53% across the whole of the UK), this is still 25% higher than the number of people who received alternative therapy online or on the phone. 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<sup>47</sup>, 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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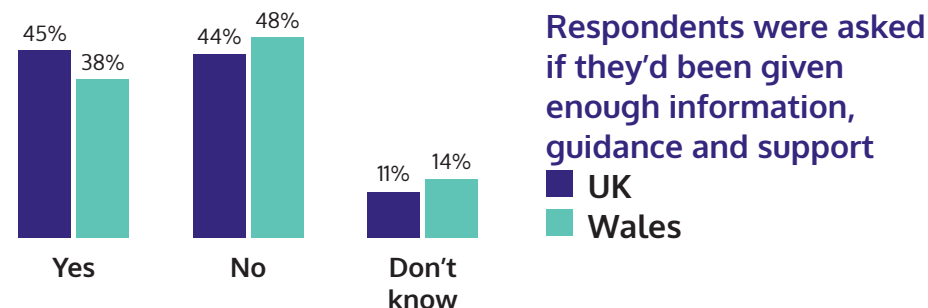
"Increased caring responsibilities whilst maintaining full-time employment. The person I care for has become agitated, stressed and tearful."

**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.

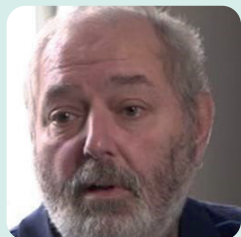


We asked stroke survivors in Wales about **staying safe during lockdown**, and if the government had advised them that they were in the shielding category. Only 14% reported that they believed they were in the shielding category, a far smaller proportion than across the whole of the UK. However, 46% (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 this report, we recommend that:

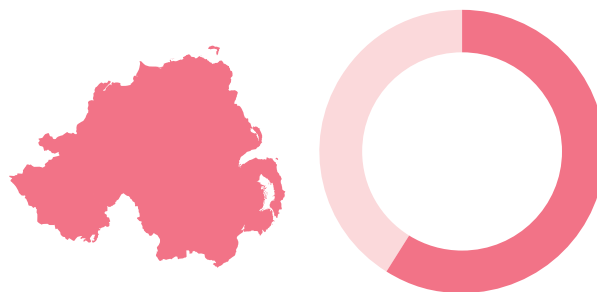
- The pandemic has highlighted the continued need to improve stroke services in Wales. **The Welsh Government should replace the Stroke Delivery Plan when it expires with a new national plan for stroke**, with hyperacute stroke units as its priority, in order to drive improvement across the stroke pathway.
- 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.



# How has Covid-19 affected stroke survivors in Northern Ireland?

104 people affected by stroke (72 stroke survivors and 32 carers and family members) took part in our survey in Northern Ireland. Their comments and responses clearly show that the pandemic has had a profound impact on stroke survivors' lives, wherever they are on their recovery journey, and on the lives of their carers and family members.

Sadly, the issues and challenges experienced by people affected by stroke during the pandemic are not new. Even before this, too many stroke survivors and their carers told us how abandoned they felt when they left hospital and how they struggled to recover. Our 2019 'Struggling to Recover' report found that many stroke survivors in Northern Ireland don't receive enough rehabilitation to help with their recovery, their psychological and emotional needs are often not met, and carers often find it difficult to cope.<sup>48</sup> Rehabilitation services and post-hospital support have long been identified as the 'Cinderella' services of the stroke pathway. The Covid-19 pandemic has simply exacerbated issues that decision makers in Northern Ireland have known about for a long time.



**59% of stroke survivors in Northern Ireland said they have received less support from health and care services than usual**

Stroke survivors have experienced challenges **accessing rehabilitation and support** during the pandemic, which can put recoveries at risk. 59% of stroke survivors in Northern Ireland said they have received less support from health and care services than usual, while half (50%) have had therapy sessions cancelled or postponed, in line with the UK average.

This is especially worrying as there is a wealth of evidence linking the quality, intensity and promptness of rehabilitation with improved outcomes for stroke survivors and reduced long-term costs. A lack of adequate rehabilitation undermines the improvements in acute treatments for stroke, such as life-changing thrombectomy treatment, that have been made over the past decade.



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“My husband was discharged from the community stroke team at the start of the lockdown. There has been very limited contact from any statutory services since then and no indication of how or when he will be able to engage with services in the future”.

**Carer, Northern Ireland**

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Some stroke survivors have been **using virtual rehab and healthcare** during the pandemic, with 38% telling us they have had therapy (such as physiotherapy, occupational therapy and speech and language therapy) online or over the phone. This is higher than the UK average of 28%. However, it is still 13% less than the number of stroke survivors in Northern Ireland who had therapy cancelled or postponed during the pandemic. This suggests that some stroke survivors may have gone without the necessary rehabilitation and support to help their recovery, and who are therefore likely to have additional and more challenging needs in the future.

Positively, satisfaction with virtual or phone appointments was relatively high compared to the UK average (64% said they were satisfied or very satisfied, whilst the UK average was 52%), showing the potential of virtual methods of healthcare to complement face-to-face approaches. However, virtual or tele-rehab is not suitable for everyone, such as those with communication difficulties or who do not have access to the internet or a phone. Access to both face-to-face and virtual support will therefore be required to ensure no stroke survivor is disadvantaged in their recovery.



## **69% of stroke survivors report feeling more anxious or depressed during the pandemic**

The pandemic and lockdown have also caused a **decline in the mental health and wellbeing** of people affected by stroke. 69% of stroke survivors report feeling more anxious or depressed during the pandemic, while 40% have felt abandoned. 62% have worried more about their health, while 65% have worried more about what the future holds.

Before the pandemic, we already knew that 90% of stroke survivors in Northern Ireland felt that their emotional and cognitive needs were not being met.<sup>48</sup> We know that psychology services are under pressure, now more than ever. But it's clear that there must be increased investment in psychological and emotional support services for people affected by stroke to address these unmet needs.

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"I feel like my stroke has heightened my anxiety during the pandemic. I feel like I am reliving my recovery phase, for example being isolated and unable to do basic tasks such as shopping. The unknown aspect of the effects of Covid -19 on stroke patients concerns me"

**Stroke survivor, Belfast**

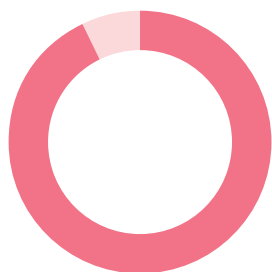
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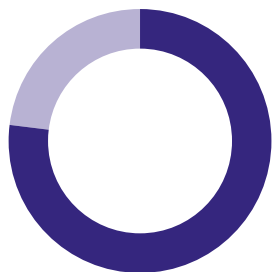
"The Covid-19 virus has made me so terrified to go out. I didn't get a shielding letter but I felt very vulnerable as I also have a heart problem. It has impacted on my confidence in going to the local shop.....it almost seems my recovery has taken a step back"

**Stroke survivor, Northern Ireland**

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Carers in Northern Ireland appear to be particularly impacted with a staggering **93%** saying they are providing more care and support during lockdown, far higher than the UK average of **77%**



Those providing **care during lockdown** have told us they face additional pressures, with 61% of carers saying they feel overwhelmed and unable to cope. Carers in Northern Ireland appear to be particularly impacted with a staggering 93% saying they are providing more care and support during lockdown, far higher than the UK average of 77%. 94% of carers say they are finding it more difficult to carry out practical tasks, such as buying food or picking up prescriptions – this is again higher than the UK average of 80%. Despite this, only half (49%) of the carers who responded to our survey said that they had been given enough information, guidance and support during the pandemic.

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"It has had a big effect on us both. My husband needs professional help from a physiotherapist to improve physically. I am his main carer so life was tough enough before the pandemic. We have both felt quite lonely and trapped."

**Carer, Lisburn**

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"While I was able to cope when my husband had his stroke last year, I have found it gradually becoming more difficult..... My caring 'load' has increased.....It has been stressful not being able to access face to face help for both our needs. This in itself, creates stress and frustration as well as the actual health problems."

**Carer, Belfast**

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## "I just wish all stroke survivors were able to get the appropriate physical and emotional support they need to rebuild their lives"



Willie is 47 and lives in Portadown. Willie was a busy music teacher, performing musician and family man when he had a stroke late one night in October 2017. He spent two months in hospital receiving physiotherapy and occupational therapy and has paid for additional private therapy to help with his recovery. But everything changed for Willie during the pandemic.

"When we went in to Covid-19 lockdown in March, for me, everything just stopped. At that time, I'd been busy swimming and paying for private training sessions with a personal trainer at my local gym. I was receiving physiotherapy and private neuro-physiotherapy and overnight, that all had to stop.

"Since my stroke, physiotherapy and working hard on my fitness has been essential to my recovery and to regaining the use of the left side of my body, particularly my arm and hand. I really struggled at the start of lockdown when I was prevented from doing all these activities that had become a huge part of my life. I kept myself moving at home and doing any floor exercises that I could. But I haven't been going out for walks like I used to. I'm not sure why, as walking was fantastic for me in the beginning, but it might be due to all the talk of social distancing and keeping your distance from others."

Despite the challenges of the past few months, Willie remains positive about his recovery from stroke.

"Since my stroke, I've been determined that I will get better. I just need time and the access to the experts who can work with me to make it happen. I'm very proud of the achievements I've made.

"I just wish all stroke survivors were able to get the appropriate physical and emotional support they need to rebuild their lives no matter where they live or what their circumstances are".

Unfortunately, we received too few responses from those who have had a stroke since March this year to be able to analyse the experiences of **stroke hospital care and discharge** in Northern Ireland during the Covid-19 pandemic. However, we know from extensive engagement with the stroke community over the past few years that acute stroke services in Northern Ireland are currently spread too thin with too many stroke units struggling to maintain quality care and staffing levels.

We were very encouraged that at the beginning of 2020, the Northern Ireland Executive made a commitment to reconfigure hospital provision for stroke and make improvements in stroke care by the end of the year.<sup>50</sup> They emphasised that doing so would deliver better patient outcomes, more stable services and more sustainable staffing in stroke care in Northern Ireland. However, we were very disappointed that the 'Rebuilding Health and Social Care Services Strategic Framework for Northern Ireland', published in June 2020, stated that it was 'unlikely that stroke reforms will progress by end of 2020'.<sup>51</sup>

While we appreciate the challenges posed by the pandemic for the health and social care sector, the Covid-19 crisis should be seen as an opportunity to reform our health system. Change is long overdue and we must do better to improve outcomes for stroke survivors and their families, both now and in the future.

Now is the time to progress with stroke reform in Northern Ireland and to move forward with reshaping stroke services and improving the whole pathway, from prevention to acute care to long-term support, in partnership with the stroke community. Staying as we are is not an option and a lack of progress puts lives and recoveries at risk.





## Our recommendations for Northern Ireland

In addition to the UK-wide recommendations in this report, the Department of Health and Northern Ireland Executive should stand by commitments they made before the pandemic and urgently:

- **Roll-out a new, regional long-term support pathway, which is appropriately funded to meet the needs of people affected by stroke.** In particular, the new pathway should address the following issues which have been exacerbated by the pandemic:
  1. The provision of the right rehabilitation support for people when and where they need it and for as long as they need it.
  2. Increased investment in psychological and emotional support services for people affected by stroke.
  3. Enhanced support for carers to take regular breaks and maintain their wellbeing, as well as a legal recognition of the vital role they play in our health and social care system.
- **Progress with the planned reform of stroke services to create a sustainable and high-quality service for everyone affected by stroke in Northern Ireland.**



# References

1. Sentinel Stroke National Audit Programme (2020). 'An Insight into Stroke Care during Covid-19. Available at: <https://www.strokeaudit.org/SupportFiles/Documents/Webinars/Webinar-slides.aspx>
2. Office for National Statistics (2020). Analysis of death registrations not involving coronavirus (COVID-19), England and Wales: 28 December 2019 to 1 May 2020. Available at: <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/analysisofdeathregistrationsnotinvolvingcoronaviruscovid19englandandwales28december2019to1may2020/technicalannex>
3. British Association of Stroke Physicians (2020). BASP Covid-19 Stroke Services Survey, April 2020. Available at: [https://www.basp.org/wp-content/uploads/2020/05/BASP-Service-Survey\\_April-2020\\_summary-FINAL.pdf](https://www.basp.org/wp-content/uploads/2020/05/BASP-Service-Survey_April-2020_summary-FINAL.pdf)
4. SSNAP (2020). An Insight into Stroke Care during Covid-19.
5. Not all respondents completed every question in the survey, so we've had to base some of the figures given in this report on fewer than 1,949 responses. All of the figures from the individual UK-nations are based on fewer than 1,949 responses.
6. NHS England and Royal College of Physicians (2020). Clinical guide for the management of stroke patients during the coronavirus pandemic. Available at: [https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/04/C0033-\\_Specialty-guide\\_-Stroke-and-coronavirus-V1-update\\_16-April-003.pdf](https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/04/C0033-_Specialty-guide_-Stroke-and-coronavirus-V1-update_16-April-003.pdf)
7. Stroke Association (2016). Strokes and TIAs are medical emergencies. Available at: [https://www.stroke.org.uk/sites/default/files/3.stroke\\_and\\_tia\\_policy\\_final\\_021115.pdf](https://www.stroke.org.uk/sites/default/files/3.stroke_and_tia_policy_final_021115.pdf)
8. Perry, R., Banaras, A., Werring, D.J. et al. What has caused the fall in stroke admissions during the COVID-19 pandemic?. Journal of Neurology (2020). <https://doi.org/10.1007/s00415-020-10030-2>
9. Welsh Government (2020). NHS activity and performance summary: March and April 2020. Available at: <https://gov.wales/nhs-activity-and-performance-summary-march-and-april-2020-html>; NHS England (2020). A&E Attendances and Emergency Admissions April 2020 Statistical Commentary. Available at: <https://www.england.nhs.uk/statistics/wp-content/uploads/sites/2/2020/05/Statistical-commentary-April-2020-jf8hj.pdf>
10. Information Analysis Directorate (2020). Emergency Care Waiting Time Statistics for Northern Ireland (April - June 2020). Available at [https://www.health-ni.gov.uk/sites/default/files/publications/health/hs-niwt-ecwt-q1-20-21\\_0.pdf](https://www.health-ni.gov.uk/sites/default/files/publications/health/hs-niwt-ecwt-q1-20-21_0.pdf)
11. Scottish Government (2020). Urgent Help Still Available. Available at: <https://www.gov.scot/news/urgent-medical-help-still-available/>
12. Eden Stanley, Eden Stanley Health & Disability Tracker. Market research of 1000 people, conducted 1 - 31 May 2020.
13. Eden Stanley Health & Disability Tracker, May 2020.
14. SSNAP. 'An Insight into Stroke Care during Covid-19'.
15. British Association of Stroke Physicians (2020). BASP Covid-19 Stroke Services Survey, April 2020.





16. Office for National Statistics (2020). Analysis of death registrations not involving coronavirus (COVID-19), England and Wales: 28 December 2019 to 1 May 2020.
17. SSNAP (2020). SSNAP Covid-19 Portfolio. Available at: <https://www.strokeaudit.org/results/Clinical-audit/National-Results.aspx>
18. British Association of Stroke Physicians (2020). BASP Covid-19 Stroke Services Survey, April 2020.
19. Stroke Association (2016). A New Era for Stroke. Available at: [https://www.stroke.org.uk/sites/default/files/anefts\\_report\\_web.pdf](https://www.stroke.org.uk/sites/default/files/anefts_report_web.pdf)
20. British Association of Stroke Physicians (2020). BASP Covid-19 Stroke Services Survey, April 2020.
21. Royal College of Physicians (2016). National Clinical Guideline for Stroke. Available at: [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), p18.
22. Adamson J, Beswick A, Ebrahim S (2004). Is stroke the most common cause of disability? *Journal of Stroke and Cerebrovascular Diseases* 13:171-177
23. British Association of Stroke Physicians (2020). BASP Covid-19 Stroke Services Survey, April 2020.
24. Stroke Association (2016). A New Era for Stroke, p.7.
25. British Association of Stroke Physicians (2020). BASP Covid-19 Stroke Services Survey, April 2020
26. Stroke Association (2019). Lived Experience of Stroke – Chapter 1: Hidden Effects of Stroke. Available at: <https://www.stroke.org.uk/lived-experience-of-stroke-report/chapter-1-hidden-effects-of-stroke>
27. Stroke Association (2019). Lived Experience of Stroke – Chapter 1: Hidden Effects of Stroke.
28. Blixen, C. et al. (2014). Stroke recovery and prevention barriers among young African-American men: potential avenues to reduce health disparities. *Topics in Stroke Rehabilitation*, 21(5), pp. 432 – 442.
29. Stroke Association (2019). Lived Experience of Stroke – Chapter 3: Caring for a stroke survivor – what carers need. Available at: [https://www.stroke.org.uk/sites/default/files/lived\\_experience\\_of\\_stroke\\_report\\_-\\_chapter\\_3.pdf](https://www.stroke.org.uk/sites/default/files/lived_experience_of_stroke_report_-_chapter_3.pdf)
30. Stroke Association (2019). Lived Experience of Stroke – Chapter 3: Caring for a stroke survivor – what carers need.
31. Stroke Association (2019). Lived Experience of Stroke – Chapter 2: The Wider Impacts of Stroke. Available at: <https://www.stroke.org.uk/lived-experience-of-stroke-report/chapter-2-wider-impacts-of-stroke>
32. Stroke Association. Information on coronavirus for stroke survivors. Available at; <https://www.stroke.org.uk/finding-support/information-coronavirus-stroke-survivors>
33. Stroke Association (2017). Current, Future and Avoidable Costs of Stroke in the UK Executive summary Part 2: Societal costs of stroke in the next 20 years and potential returns from increased spending on research. Available at: [https://www.stroke.org.uk/sites/default/files/costs\\_of\\_stroke\\_in\\_the\\_uk\\_report\\_-\\_executive\\_summary\\_part\\_2.pdf](https://www.stroke.org.uk/sites/default/files/costs_of_stroke_in_the_uk_report_-_executive_summary_part_2.pdf)
34. Stroke Association (2020). Survey of Stroke Association-funded Researchers, May 2020. Unpublished.

35. British Association of Stroke Physicians (2020). BASP Covid-19 Stroke Services Survey, April 2020
36. Association of Medical Research Charities (2020). Covid-19: The Risk to AMRC Charities. Available at: <https://www.amrc.org.uk/covid-19-the-risk-to-amrc-charities>
37. Zoe Cormier (June 2020). How Covid-19 can damage the brain. Available at: [https://www.bbc.com/future/article/20200622-the-long-term-effects-of-covid-19-infection#:~:text=Now%2C%20more%20than%20300%20studies,speak\)%2C%20strokes%20and%20seizures.](https://www.bbc.com/future/article/20200622-the-long-term-effects-of-covid-19-infection#:~:text=Now%2C%20more%20than%20300%20studies,speak)%2C%20strokes%20and%20seizures.)
38. NHS England (2019). NHS Long Term Plan. Available at: <https://www.longtermplan.nhs.uk/online-version/chapter-3-further-progress-on-care-quality-and-outcomes/better-care-for-major-health-conditions/stroke-care/>
39. SSNAP (2018-2019). The Sixth SSNAP Annual Report Available at: <https://www.strokeaudit.org/results/Clinical-audit/National-Results.aspx>
40. [www.gov.scot/publications/protecting-scotlands-future-governments-programme-scotland-2019-20/](https://www.gov.scot/publications/protecting-scotlands-future-governments-programme-scotland-2019-20/)
41. <https://www.gov.scot/publications/protecting-scotland-renewing-scotland-governments-programme-scotland-2020-2021/>
42. Ganesalingam J, Pizzo E, Morris S, Sunderland T, Ames D, Lobotesis K. Cost-utility analysis of mechanical thrombectomy using stent retrievers in acute ischaemic stroke. *Stroke* 2015; 46(9): 2591-8. [www.stroke.org.uk/sites/default/files/jn\\_1819.144a\\_current\\_future\\_avoidable\\_costs\\_of\\_stroke\\_0.pdf](http://www.stroke.org.uk/sites/default/files/jn_1819.144a_current_future_avoidable_costs_of_stroke_0.pdf)
43. Guijarro P, Veltkamp R, Carpenter I, Claxton LM. Budget implications for the UK NHS of implementing mechanical thrombectomy for the treatment of acute ischaemic stroke patients: calculation with the solitaire<sup>TM</sup> revascularization device. *Journal of Neurology & Neurophysiology* 2017; 8: 2 (Suppl): 79 [www.stroke.org.uk/sites/default/files/jn\\_1819.144a\\_current\\_future\\_avoidable\\_costs\\_of\\_stroke\\_0.pdf](http://www.stroke.org.uk/sites/default/files/jn_1819.144a_current_future_avoidable_costs_of_stroke_0.pdf)
44. Aguiar de Sousa D, von Martial R, Abilleira S, Gattringer T, Kobayashi A, Gallofre M, et al. Access to and delivery of acute ischaemic stroke treatments: A survey of national scientific societies and stroke experts in 44 european countries. *Eur Stroke J.* 2019;4:13-28
45. Scottish Parliamentary records. Question S5W-30611: Alexander Burnett, Aberdeenshire West, Scottish Conservative and Unionist Party, Date Lodged: 09/07/2020
46. <https://www.strokeaudit.scot.nhs.uk/Publications/Main.html>
47. Sentinel Stroke National Audit Programme, SSNAP Annual Portfolio for April 2018-March 2019 admissions and discharges. Available: <https://www.strokeaudit.org/results/Clinical-audit/National-Results.aspx>
48. Stroke Association (2019). Struggling to Recover: Life after stroke in Northern Ireland. Available at: [https://www.stroke.org.uk/sites/default/files/stroke\\_association\\_ni\\_struggling\\_to\\_recover\\_report\\_18.2.2019.pdf](https://www.stroke.org.uk/sites/default/files/stroke_association_ni_struggling_to_recover_report_18.2.2019.pdf)
49. Stroke Association (2019). Struggling to Recover: Life after stroke in Northern Ireland.
50. Northern Ireland Office (2020). New Decade, New Approach. Available at: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/856998/2020-01-08\\_a\\_new\\_decade\\_\\_a\\_new\\_approach.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/856998/2020-01-08_a_new_decade__a_new_approach.pdf)



51. Department of Health (2020). Rebuilding Health and Social Care Services Strategic Framework. Available at: <https://www.health-ni.gov.uk/sites/default/files/publications/health/rebuilding-hsc.pdf>

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Rebuilding lives after stroke

