

# Reshaping Stroke Care

## Consultation response

### Carers NI

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Without carers, the UK's health and social care system would completely fall apart. As our population ages and people live longer with illness and disability, carers are becoming more and more important. Far too many carers are stretched to the limit looking after loved ones, while also having to worry about making ends meet. We want a world where carers are supported not only to cope with the challenges of looking after someone, but to build a life of our own too. A life which includes caring but is not overwhelmed by it. This matters to all of us. At some point, we will all care for family or friends who are older, ill or disabled, or we will need that care ourselves. At that point, we will realise how important it is to make a better world for carers. For there is nothing more human than looking after loved ones, and no more pressing social issue than making that care possible.

Carers NI are here to make life better for carers. Working as part of Carers UK, we give expert advice, information and support to carers across NI. We connect carers so no-one has to care alone, we campaign together for lasting change and we innovate to find new ways to reach and support carers. Our key strategic priorities are to battle for greater understanding of carers and support for carers in our society, be there for carers with information and advice from the start and build a network of carer positive employers.

There are around 220,000<sup>1</sup> carers in Northern Ireland with recent polling suggesting it could be as many as 272,460<sup>2</sup> (that's 1 in 5 of us here) plus many more who, despite carrying out regular caring responsibilities, do not see themselves as carers.

### Summary

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We welcome the Department's 7 commitments as part of this consultation including to:

- establish a network of Hyperacute Stroke Units (HASU's) and Acute Stroke Units (ASU's)
- increase the hours of operation of thrombectomy service

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<sup>1</sup> Valuing Carers, Carers UK, 2015

<sup>2</sup> Carers Week report 2019, Carers UK

- build on the Stroke Association's recent report *Struggling to Recover* and implement the recommendations particularly in relation to carer support, access to information and increasing investment in statutory services and commissioning of voluntary sector to meet unmet need.
- a workforce review within stroke services

Overall, we are supportive of the need to change and reconfigure existing services and believe this is a great opportunity to create a world class stroke service in Northern Ireland that saves lives and reduces disability.

We understand that the more HASUs across NI delivering stroke support the better the access to those who need it but that under the Transformation programme we need to consider the option that fewer sites would equal patients receiving more specialist care and would ultimately be more sustainable going forward. Whilst our current model of 11 stroke units performs well in terms of accessibility, it doesn't achieve as well in terms of outcomes for patients. There is also significant variation in the standards of care provided across these 11 units. However, if we create fewer, larger, 24/7 specialist centres or hyperacute stroke units, we can save more lives and reduce disabilities from stroke as patients will consistently receive high quality care. These centres would also be more sustainable in the long run. That said, Carers NI do not have a preferred model of locations of hospital-based stroke care in NI but would echo the research from the University of Exeter which suggest that any of the options presented by the Department offer significantly better outcomes for patients than our current configuration of stroke services.

However, we are concerned that increased demand for HASU beds could mean that patients will be pushed out of hospital before they are ready. It's therefore absolutely vital that community supports are put in place before they reconfigure acute care.

In the current model, 5 non-acute hospitals provide ongoing rehabilitation and care to approximately 13% of stroke survivors who require a longer stay in hospital to support their recovery. We are also concerned that in a new model, where all inpatient rehab will be provided on an acute stroke unit, that there won't be the capacity to keep these patients for longer and again they will be discharged from hospital too quickly. Obviously, this will have a significant effect on carers if the appropriate supports are not in place and resourced accordingly.

## **Main points**

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There are around 37,000 people living with the effects of stroke in Northern Ireland<sup>3</sup>. Almost 2/3 of stroke survivors leave hospital with a disability and rely on the support of loved ones and carers for daily tasks<sup>4</sup>. This can put enormous physical and emotional strain on carers.

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<sup>3</sup> *Struggling to Recover*, Stroke Association NI 2019

<sup>4</sup> *Struggling to Recover*, Stroke Association NI 2019

Unlike some other conditions, stroke tends to strike unexpectedly and therefore families have little or no time to prepare. Carers regularly tell us of their difficulties surrounding a lack of consultation and information at the point of hospital discharge. The Stroke Association's recent carers survey which informed their "Struggling to Recover" report<sup>5</sup> showed that 85% of carers did not feel prepared for their loved one to come home from hospital following a stroke. Similarly, our State of Caring survey (2017)<sup>6</sup> showed that 58% of carers here with experience of hospital discharge in the past year, were not consulted about the discharge or were only consulted at the last minute. In 7% of those cases, patients were discharged too early and as a result were re-admitted to hospital in the following months.

Around ¼ of stroke survivors are of working age (under 65) and may have to give up work or change roles as a result<sup>7</sup>. This obviously has a huge personal and financial impact for the individuals and carers. According to our most recent State of Caring survey<sup>8</sup>, 37% of carers of stroke survivors are struggling to make ends meet with 32% of them using their savings to get by. Similarly, 27% of carers looking after someone with a stroke said they had to cut back on essentials (like food and heating) in order to make ends meet. Not only does the person who has taken the stroke often have to give up work as a result of their condition but their loved one providing care for them often has to too which is a double-blow to the family income. In fact, 26% of stroke carers here have had to give up work in order to care. When considering community-based support it is important to ensure that stroke survivors and their families are not put into a position where they have to pay for basic services further impacting on their already tightly squeezed budgets. There are also financial implications on family members/carers of having to drive further to HASU/ASUs, get buses/trains and pay for parking at hospitals to visit patients which should be considered as part of this process.

Around 1/3 of stroke survivors will have a communication disability<sup>9</sup>. This can be isolating for the individual and also for the carer who faces a huge barrier when communicating with their loved one. 78% of stroke carers responding to our State of Caring survey 2019<sup>10</sup> said they often/always or sometimes felt lonely. We would like to see a commitment from the Department and other relevant organisations to ensure they provide emotional as well as practical support to carers of stroke survivors and that local community and voluntary organisations are well resourced to provide avenues for combatting/preventing loneliness where possible.

Many carers of stroke survivors tell us they feel "abandoned at the hospital gate" and don't receive adequate support when the person they are caring for is discharged to the community to continue their recoveries. In fact, the Stroke Association's carers survey<sup>11</sup> showed that only 20% of carers felt they had enough care and support at home and only 28% said they

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<sup>5</sup> Struggling to Recover, Stroke Association NI, 2019

<sup>6</sup> State of Caring NI report, Carers NI, 2017

<sup>7</sup> Struggling to Recover, Stroke Association NI 2019

<sup>8</sup> Data from State of Caring NI 2019, Carers NI, unpublished

<sup>9</sup> Struggling to recover, Stroke Association NI, 2019

<sup>10</sup> Data from State of Caring NI 2019, Carers NI, unpublished

<sup>11</sup> Struggling to Recover, Stroke Association NI, 2019

would know who to contact if they needed more help. This highlights the need for more information on the condition, services and supports available are needed, including carer support in the community. Often, stroke survivors have a range of other medical conditions which require lots of co-ordination with health professionals. Carers can often struggle to navigate the system and don't know where to turn for help or to access key services like Speech and Language Therapy (SLT), physio etc. Carers tell us they spend hours/days trying to get the help they need and this wears them out. A lot of carers of stroke survivors express frustrations that the current pathway/transition from statutory to voluntary sector is not seamless and takes too long. There can be delays in signposting people to services and this can lead to unnecessary delays in accessing services and support such as SLT services and Life After Stroke grants. We would therefore call on the Department of Health to ensure that as part of reshaping stroke care in Northern Ireland, a clearer pathway for stroke patients and survivors, and better communication among health professionals and between health professionals and patients/carers is implemented.

Many carers do not know about or how to avail of Carers Assessments, in fact 66% of stroke carers had not had a Carers Assessment or re-assessment in the last 12 months<sup>12</sup>. Where some have had a Carers Assessment (or re-assessment) carried out, 42% of carers of stroke survivors who responded to our recent State of Caring survey felt that the support they needed to look after their own mental and physical health alongside caring was not properly considered in the assessment process or in the support they receive. Only 12% of stroke carers felt their quality of life would improve within the next year whilst 46% expected it to get worse. 98% of respondents to the Stroke Association survey<sup>13</sup> said they sometimes found it difficult to cope as a carer. All of this means that carers are often close to breaking point and suffering mental and physical ill-health which can often result in them needing care and support themselves.

With this in mind, we are concerned that the efforts being made to return stroke patients to the community as soon as possible will only work if the community-based infrastructure, resources and supports are improved from what currently exists. This will include an element of the review of the community-based stroke care workforce in line with existing work being undertaken under the Review of Adult Social Care and Support<sup>14</sup>, but it will also include things like streamlining the process for support for stroke survivors, clearer pathways, better communication with family members/carers around hospital discharge and clearer signposting of information for further supports within the community and voluntary sector. This consultation process must be about improving and investing in the whole stroke pathway in order to achieve the best outcomes for people affected by stroke. Poor long-term community-based support undermines any advances made in hospital stroke care. Adequate, well-resourced and well-funded support is needed to help stroke survivors continue with their recovery and for family carers to continue to provide care at home.

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<sup>12</sup> Data from State of Caring NI 2019, Carers NI, unpublished

<sup>13</sup> Struggling to Recover, Stroke Association, NI 2019

<sup>14</sup> Power to People: Proposals to reboot adult care and support in NI, Kelly and Kennedy, 2017

## Conclusion

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Overall, we are supportive of the need to change and reconfigure existing services and we believe this is a great opportunity to create a world class stroke service in Northern Ireland that saves lives and reduces disability. However, reform will only be successful if the Department can address public concerns about ambulance response times and travel, look at how they intend to address the workforce challenges in stroke care across the region, urgently address gaps in rehabilitation and community-based support and invest in better long-term support for people rebuilding their lives after stroke (including supporting family carers).

We would also encourage greater improvements and investments in community-based support for stroke survivors and carers to take into account their emotional and practical needs. It is vital that this process is about reshaping the whole pathway and that adequate investment in and consideration of post-hospital, long-term care in the community is urgently required to help people make the best possible recovery from stroke.

Reshaping stroke care in Northern Ireland is more than just a Department of Health issue. We would like to see cross departmental collaboration in relation to this consultation to include discussions around transport/roads/infrastructure as well as the financial impact stroke can have on families (including having to leave work as a result of stroke and the double whammy of perhaps the second earner in the home having to leave work to provide care). As part of reshaping stroke care in Northern Ireland, we would like the relevant Departments to:

- Address concerns around travel times to stroke units, in particular for those in rural areas, but also to include the financial impacts on families of travelling to hospitals some distance away to visit loved ones.
- Consider the financial impact on families of stroke and providing care (both short and long-term)
- Address the gaps in long-term practical support for carers including appropriate short breaks/respite, domiciliary care, training for carers and access to carers support groups
- Ensure more Carers Assessments and re-assessments are carried out with stroke carers and relevant supports are offered from the Health and Social Care Trusts
- Improve communication between and from Health professionals particularly at point of hospital discharge. Family members/carers need to be consulted prior to hospital discharge in a meaningful way which addresses their concerns and sets out a clear pathway for support.
- Ensure more clarity around information and support on the condition is available and to ensure simpler transitions back into the community with relevant signposting for carers

We would also like to see more information/awareness raising on stroke and caring, for example the Stroke Association's 'My Stroke Guide' which is a free digital resource that provides access to information about stroke and its' risk factors and effects. Similarly, Carers NI's Adviceline and

website offer a range of information and support around rights and entitlements for carers including our Looking After Someone Guide and our factsheet on Carers Assessments (<https://www.carersuk.org/northernireland/policy/factsheets>)

Based on feedback from carers and others we would also recommend a public awareness campaign of the hidden effects of stroke and how it can be quite isolating not just for the stroke survivor but also for the carer if the public (and sometimes health professionals) don't recognise the issues and challenges they face

We have focused on the impact of stroke on families in this response as Carers NI do not have a particular preference for any of the options outlined in relation to the location of HASUs. However, we would be of the opinion that any of the options outlined offer significantly better outcomes for stroke patients than what currently exists and we would encourage the Department to act as quickly as possible to implement the decision on the location of the units on the back of this consultation as soon as possible.

Please note, Carers NI State of Caring 2019 data was taken from as yet unpublished survey findings of 60 respondents from Northern Ireland who were looking after a stroke survivor. It cannot therefore claim to be representative of all carers of stroke survivors in Northern Ireland. The Stroke Association data taken from their 2018 survey findings were from the experiences of 75 local carers of stroke survivors.

## Contact us

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