

Issues Paper: Stroke survivors' experiences of using health and social care services in North Tyneside

Summary

We spoke to 19 people who had experienced stroke or supported someone who had. People told us about their experiences of using health and social care services during and following stroke.

People shared positive experiences of the equipment service and some good examples of care received by hospital staff, their GP and social care staff. People highlighted areas for improvement in relation to the follow-up support post hospital discharge, the consideration of mental wellbeing as well as physical and the use of accessible communication by healthcare staff. People also noted the importance of support groups and social activities but noted several barriers to accessing such support.

We have also highlighted gaps between what people told us about their experience and the National Institute for Health and Care Excellence (NICE) guidelines.

1. Background

Healthwatch North Tyneside is the independent champion for local people using health and social care services. We gather feedback about services from the general public and through targeted engagement with specific groups of people.

We understand that people who experience long-term health conditions will have unique experiences of using health and social care services. We are talking to groups of people who have different long-term conditions and common experiences to understand the issues they face.

There are more than 1.2 million stroke survivors in the UK and stroke is one of the leading causes for disability for those leaving hospital (Stroke Association, 2017). As part of the NHS Long Term Plan stroke has been identified as a key clinical priority. In North Tyneside, we have higher prevalence of stroke on average in comparison to the national average.

2. What we did

In August 2019, we spoke to 14 people who had experienced stroke and 5 carers or family members. 11 of the people we spoke to were male and 8 were female. Of those we spoke to some people had experienced stroke within the last year and for some it was several years prior.

3. Key issues

People talked to us about a range of good experiences of using services and several areas where their experiences could be improved. The key issues we heard about are outlined below.

What worked well?

- a. The timeliness of **aids and adaptions** being put in their home to support them to live independently following their stroke. A number of people told us that the appropriate equipment, such as stair banisters and bath seats, were arranged quickly and put in place before they came home from hospital which they found very useful.
- b. Care given when they were first in **hospital**. They were often initially treated at Northumbria Specialist Emergency Care Hospital (NSECH) before being transferred to North Tyneside General Hospital (NTGH). People felt they were happy with the care received at NTGH commenting positively about staff and the food.
- c. Quality of care received from **care staff** once they had left hospital. A person described having had 3 visits a day for 10 weeks after their first stroke, another said they were given a care worker for 6 weeks and they were “brilliant”. One person described their GP organising Care Plus who they found “pretty good”. Generally they described the care support being gradually reduced over a period of time which helped to ease the process of discharge from services.
- d. Positive experience of some of the services they had encountered for their **other health needs**. One person told us about having easy access to GP appointments and that their GP would often come to do house visits which was very useful. Another noted an experience whereby their GP referred them to NTGH and on arrival were seen straight away – “didn’t have time to sit down” – they felt the treatment and staff approach was very good. However, people’s experiences were varied, and people felt that some services were challenging to access because of poor information and transport issues.
- e. Overall, the people we spoke to who had more recent experiences of stroke tended to have more positive experiences of using health and social care services, which highlights improvements in the way services support people who experience stroke.

What could be improved?

Stroke services:

- a. **Follow up care** - A key issue people discussed was the inconsistency and limited nature of follow-up support provided when they left hospital. People felt suddenly on their own with no contact from different services such as their physio and their district nurse team. One person discussed only having two visits by their speech therapist. Another person said that their contact was infrequent and unpredictable and has now ended. Of those we spoke to, no one mentioned being offered or receiving either a mental wellbeing or carer's assessment following discharge. Experiences post-discharge were often variable, and many people felt isolated and abandoned - "It was like falling off the edge of a cliff".

People who had experience of other long term conditions, including diabetes and heart conditions, described the follow up support for these conditions as much better than what they had received following their stroke. The lack of follow-up support was particularly notable in relation to the support offered through their GPs. The majority of people we spoke to reported limited experiences of support from their GP practice (even annually) unless they had another health condition.

- b. **Psychological and emotional support** - When considering the support offered for people's recovery, most people discussed receiving some level of support for their physical recovery such as their speech and mobility, however no support was offered for their mental wellbeing following stroke. One person discussed experiencing poor mental health when coming to terms with the impact on their mobility: they were given the number for talking therapies to ring but no further information.
- c. **Access to social activities** and sessions to support both people's physical and emotional wellbeing was deemed as important, but often challenging. This was due to both limited information being given about what activities are available and issues relating to transport to activities. Transport difficulties meant that sometimes activities and support was missed out on. For example, one person told us that they were offered access to a hydro-pool for a year but were unable to find a way that they could get transport there. Another person relied on their family to transport them to exercise classes or experienced long waits to get transport to supported activities.
- d. **Communication** - The majority of those we spoke to had communication difficulties following stroke. One carer told us about having to repeatedly advocate on their family member's behalf in order to ensure they were showered and cared for when they went into hospital following a fall.

Another person described being verbally asked what they wanted for lunch when they were an in-patient at hospital. The staff then complained that they couldn't understand what the person had requested. To ensure people can meaningfully engage in decisions about their care and preferences other communication methods need to be available. In this case, a visual menu would have enabled the person to independently communicate their preference.

- e. **Need for support when accessing services** - A key concern for a family member we spoke to was the lack of basic care received in hospital and the constant struggle to advocate for their family member's care to be addressed, often due to a person not being able to express or communicate their needs. A support worker echoed these concerns when stating that they felt the people they supported were treated better when the support worker was present. Family members felt that due to their family member's communication difficulties, their needs were not adequately addressed without the input of the family member.

Other services

When people were engaged with their **GP**, they discussed experiencing long waiting times, such as waiting a month for an appointment.

Podiatry services were highlighted as an area for improvement. One person had a District Nurse visit to cut toenails, which was later discontinued. Another person experienced delays due to it being really busy and this meant that toenails had been catching on bed sheets.

People's experiences of using **dentists** were mixed. One person who had recently been to dentist said they were "in and out" quickly. Although they also noted that the practice had removed the magazines and TV screen which was not helpful as they got anxious whilst awaiting an appointment.

Although people told us about some positive experiences of treatment at hospital, there were also concerns raised about the care they received when going to **hospital for other health issues**.

4. Suggestions for providers and commissioners

This issues paper presented an overview of experiences from 19 stroke survivors and carers. Although the number of people we spoke to was limited there were a number of common issues that service providers and commissioners should consider to best support people recovering from stroke.

NICE Stroke rehabilitation in adults guidelines have been included to reflect how such suggestions relate to national good practice.

A. Communication

NICE Guideline 1.8.12 states “Help and enable people with communication difficulties after stroke to communicate their everyday needs and wishes, and support them to understand and participate in both everyday and major life decisions”.

Suggested action 1: All health and social care services should work to ensure all staff are trained in accessible methods of communicating for those who need to communicate non-verbally. Particularly in emergency settings or services which people don't have regular contact with. Staff should also be aware that they need to be more proactive in establishing communication as often the person may be unable request support when they need it.

B. Follow-up support

NICE Guideline 1.11.5 states “Review the health and social care needs of people after stroke and the needs of their carers at 6 months and annually thereafter. These reviews should cover participation and community roles to ensure that people's goals are addressed”.

Suggested action 2: Follow-up support for people experiencing stroke is a key issue as often people experience it as limited and inconsistent. Providers and commissioners should look at ways to holistically improve follow up support across the system. GPs play a key role in this and should ensure that NICE guidelines are followed as a minimum.

Suggested action 3: Patients and carers should be offered both a mental health assessment and a carer's assessment prior to leaving hospital, as part of their discharge plan.

C. Mental and emotional support

NICE Guidelines 1.5.2 and 1.5.3 state “Support and educate people after stroke and their families and carers, in relation to emotional adjustment to stroke, recognising that psychological needs may change over time and in different settings.

When new or persisting emotional difficulties are identified at the person's 6-month or annual stroke reviews, refer them to appropriate services for detailed assessment and treatment”.

Suggested action 4: Follow-up support often only focuses on a person's physical recovery; however people's mental health and wellbeing can also be significantly impacted. Services and pathways should be reviewed to ensure psychological support needs are identified and met.

D. Access to social activities

NICE Guideline 1.11.3 states “Encourage people to focus on life after stroke and help them to achieve their goals. This may include:

- facilitating their participation in community activities, such as shopping, civic engagement, sports and leisure pursuits, visiting their place of worship and stroke support groups
- supporting their social roles, for example, work, education, volunteering, leisure, family and sexual relationships
- providing information about transport and driving”

Suggested action 5: Work with local support groups and the statutory services to identify what support services and activities are available and improve how people are informed about the support that is available. People told us that access to both information about what activities are available and access to such activities was very important in supporting their wellbeing.

Suggested action 6: Ensure travel and access issues are discussed when a referral to a support service is made. Support individuals to understand what transport support there is to access other services and action is taken so that users can access the services they need.