

# Peer Support after stroke

Katherine Staley – Associate Director – Services

11<sup>th</sup> March 2024

**Stroke**  
Association

[stroke.org.uk](https://stroke.org.uk)

## Disclosure statement

There are no conflicts of interest to declare.

# Overview

The case for peer support

Our network of peer support

- Online peer support
- Telephone peer support
- Community peer support

Our learning and impact

# The case for peer support

# UK Context



**100,000**

There are more than 100,000 strokes in the UK each year.



**1.3 million**

There are over 1.3 million stroke survivors in the UK.



**£26 billion**

The cost of stroke to society is around £26 billion a year.



**4th**

biggest killer in the UK, England and Wales, and 3rd biggest killer in Scotland and NI. 38k deaths.



**Two thirds**

Almost two thirds of stroke survivors leave hospital with a disability.

# The case for peer support

- Of the **1.3 million** stroke survivors living in the UK, we know that:
  - **75%** report at least one **mental health problem**<sup>1</sup>.
  - **44%** experience **depression**.
  - **64%** told us their **hobbies** had been impacted by their stroke.
  - One third feel **abandoned when they leave hospital** because they aren't getting the help and support they need.

# The case for peer support

We know that stroke survivors and those at higher risk of stroke are more prone to **isolation and loneliness**:

- Characteristics of people who are more likely to experience isolation and loneliness include those with **poorer health** and those with **long-term illness** or **disability**<sup>3</sup>.
- The number of **over-50s** experiencing loneliness is set to reach 2 million by 2025/6. This compares to around 1.4m in 2016/7 – a 49% increase in 10 years<sup>4</sup>.

<sup>3</sup>Courtin, E., & Knapp, M. (2017). Social isolation, loneliness and health in old age: a scoping review. *Health & social care in the community*, 25(3), 799-812

<sup>4</sup>Age UK 2018, All The Lonely People

# The case for peer support



“Everyone thought I’d had a miracle recovery because I could walk and ‘looked fine’. But **every day is a struggle**. My speech is still badly affected and I feel trapped and lonely.”

Lindiwe, stroke survivor

## The far-reaching impacts of stroke

The impact of stroke reaches way beyond the UK’s **1.3 million** stroke survivors. It affects entire families, carers and friends. It is estimated that in the UK **over 1.06 million people help care for a stroke survivor**<sup>5</sup>

<sup>5</sup>[Eden Stanley’s Health & Disability Tracker](#). Total sample n=16,610 people whose loved one has had a stroke (Aug 2016-Feb 2022).





Our network of peer  
support

# Online peer support

Accessed through our website 24/7.

Over 28,000 registered.

Connects thousands of stroke survivors, carers and professionals, offering a 'safe space' to ask questions, make friends and discuss topics of interest.

The screenshot shows the Stroke Association website's forum interface. At the top, there is a navigation bar with the Stroke Association logo and a 'Sign Up' button. Below the navigation bar, there is a sidebar menu on the left with categories like 'Topics', 'News', 'Blog', 'Stroke information', 'Videos', 'Help with this site', 'Forum rules', 'Categories', 'Tags', and 'All tags'. The main content area is divided into sections: 'About the forum' (122 posts), 'General' (3 / week), and 'About stroke' (4 / week). Each section has a brief description and a list of sub-topics. On the right side, there is a 'Latest' section with a list of recent posts, including 'Having a Stroke ... put your brain on ice', 'Introduction Topic', 'Anyone get dental implants after stroke?', 'Initial Research Findings - Benefit Finding Amongst Young Stroke Survivors', 'Fatigue - does everyone get it', 'Fatigue years on', 'Asphasia and other speech issues', and 'Stroke and PFO'.

"It's great to 'chat' with other who are going through a similar situation and to bounce ideas off them. Listening, sharing experiences and most importantly having the support and encouragement from other stroke survivors. **People who haven't been touched by stroke don't always understand the daily struggle.**"

Online Community user

# Online peer support

Wide programme of online activities facilitated live by staff or volunteers.

332 active users.

Safe and supportive environment.

Carers and families welcome too.

Some bookable and some drop in.



- Welcome session
- Me and my Stroke
- Stroke specific exercise
- Genealogy
- Young People Connect
- Social activities

"The exercise class **helps with my motivation**, it pushes me to exercise because we're in a group, I wouldn't do it on my own."

# Telephone peer support

Weekly calls with trained volunteers  
8 weeks.

Two types of calls available:

- Lived experience volunteers – sharing experiences to understand stroke and learn new ways to cope. (75%)
- Connect and chat – social chat about things that are important to you, like hobbies or interests. (25%)

“I referred a patient to your Here For You service in January of this year. His allocated volunteer, A, has been a godsend, and has made a real difference to my patient’s mental health. Having peer support from A has been central to my patient’s recovery, and I wanted to pass on my thanks to your organisation, and to A, for their support.”  
**Referrer into the Here For You service**



# Telephone peer support

Aims to build confidence and social connection.

Matches based on impact of stroke, availability and interests.

Available in 21 different languages.

Over 350 active volunteers.

4,000 people have been referred.

"Fantastic service, it has helped me enormously. The only regular contact I've had since having a stroke with people who know about stroke. I can't thank you enough."

Stroke survivor

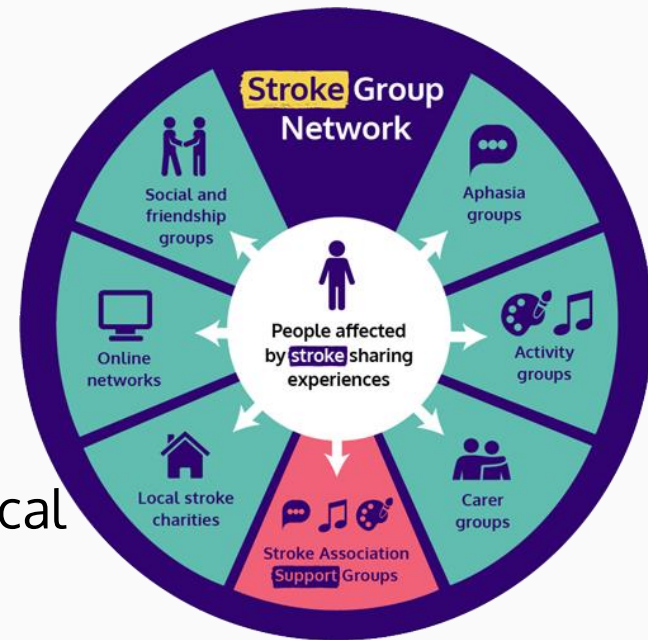
# Community peer support

**Network** of over 390 community stroke support **groups** across the UK.

Helps volunteer **group leaders** to share experiences, learnings and ideas & offers practical tools, resources and information.

**Stroke Association groups** are part of our charity – operating under our legal and charitable status

**Independent groups** are able to access resources, insurance packages and access to email support



# Community peer support

- **Social:** being with and talking to people who experience stroke.
- **Activity-based:** could be a range of activities or a specific activity, e.g. exercise, art, singing.
- **Virtual:** delivered online, such as via Zoom.

Provides vital support, reassurance and motivation to people in their local area.

## Stroke Group Network



- **Aphasia specific:** provides help and support with communication.
- **Identity specific:** a Welsh language group or working age group.

# Our impact and learning



# Online peer support


"Being able to message those who understand what it is to live with the after-effects of a stroke is invaluable. I don't know anyone like me and feel disassociated with the world outside, but the Forum has eased that loneliness."


Regular surveys to users of our online community tell us that being part of the Online Community helps people feel more **supported**, **confident** and **positive** about the future.

## We've learnt...

- ✓ The Forum requires clear rules and moderation to maintain a safe space for everyone.

Forum rules  
[About the forum](#)

ForumAdmin  13 Sep '21



Please read these along with our website terms and conditions and our forum terms and conditions.

**What is the forum for?**  
Our forum is a place where people affected by stroke can share experiences, exchange views and support one another.

# Online peer support

Users of our **online activities hub** tell us they:

- **know and understand more** about stroke.
- feel more **confident** and **positive**: "It's helped my **mental health**. I was really down before."
- Some reported making **positive lifestyle changes**: "I'm taking steps to **avoid it happening again**, for example adjusting my salt intake, and doing what I can with exercise."

## We've learnt...

- ✓ Good facilitation is key.
- ✓ Keep the sessions short to support with fatigue.
- ✓ Important to have a balanced programme including larger "drop-ins" and more intimate small-group discussions.
- ✓ Social side of the group feels more important than activities offered.
- ✓ Make sure people know what to expect.

# Telephone peer support

- 86% report that they can **cope better** with life after stroke: "It helped with finding out more about how people cope after a stroke and different symptoms we all get."
- 89% report that they feel **more confident**: "It made me more confident and secure with my own faults."

## We've learnt...

- ✓ To continually iterate the structure of support based on user feedback.
- ✓ Shorter 'blocks' work better (reduced from 12 to 8 weeks) – less drop off.

# Community peer support

"It's my sanctuary. I don't feel like I'm different and it's wonderful to be able to bounce ideas off people who are in a similar situation to you. I feel alive there and have made some terrific friends."

Sharon, stroke survivor and support group member

## We've learnt...

- ✓ Involving groups in how we run and develop the network is critical.
- ✓ Finding ways to connect groups across the network is really important for sharing and learning.

### Feelings about stroke groups



**97%** of both stroke survivors and carers said they were **satisfied** with the group



**98%** would recommend to stroke survivors

### Difference made by attending the group



**81%** said they were more active



**80%** said they do more things outside the home



**96%** said they made more friends

"The fact we do activities that encourage us to speak. Helps me not be embarrassed at group."

### Wellbeing



**86%** felt less alone



**80%** felt more positive about their life

"I was all alone watching tv now I have friends playing golf and playing table bowls, we even meet up without the stroke association."

"I find that coming to the group is a very positive move as it helps to see that I'm not alone! But one of many"

"Good to talk with the other stroke survivors and how they cope with life. Their experiences are similar"

# The power of sharing...

“During my time recovering one important thing has stood out to me: the **power of sharing** with other stroke survivors.

Once I returned home from my first stroke I felt completely lost.

From the first contact phone calls and then attending a group, I have found the **genuine warmth, support and understanding** from all involved to be incredible and uplifting.” Stroke survivor



Rebuilding lives  
after stroke