



# Stroke Group Network Conference

Monday 25 - Tuesday 26 September 2023

Rebuilding lives after stroke

**Stroke**  
Association

# Housekeeping



How support groups can help members  
to recognise and live well with the  
hidden effects of stroke

**Josh Murphy** - Stroke Knowledge Development Lead

**Lori Rowsell** – Group Leader, Nailsea Stroke Survivors Club

**Louise McCann** - Group volunteer, Scotland Online Café

**Amanda Bennett** – Head of Diversity, Equity & Inclusion  
at Guide Dogs for the Blind Association

**Stroke**  
Association

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

# Introductions



**Josh Murphy**

Stroke Knowledge  
Development Lead

**Lorraine Rowsell**

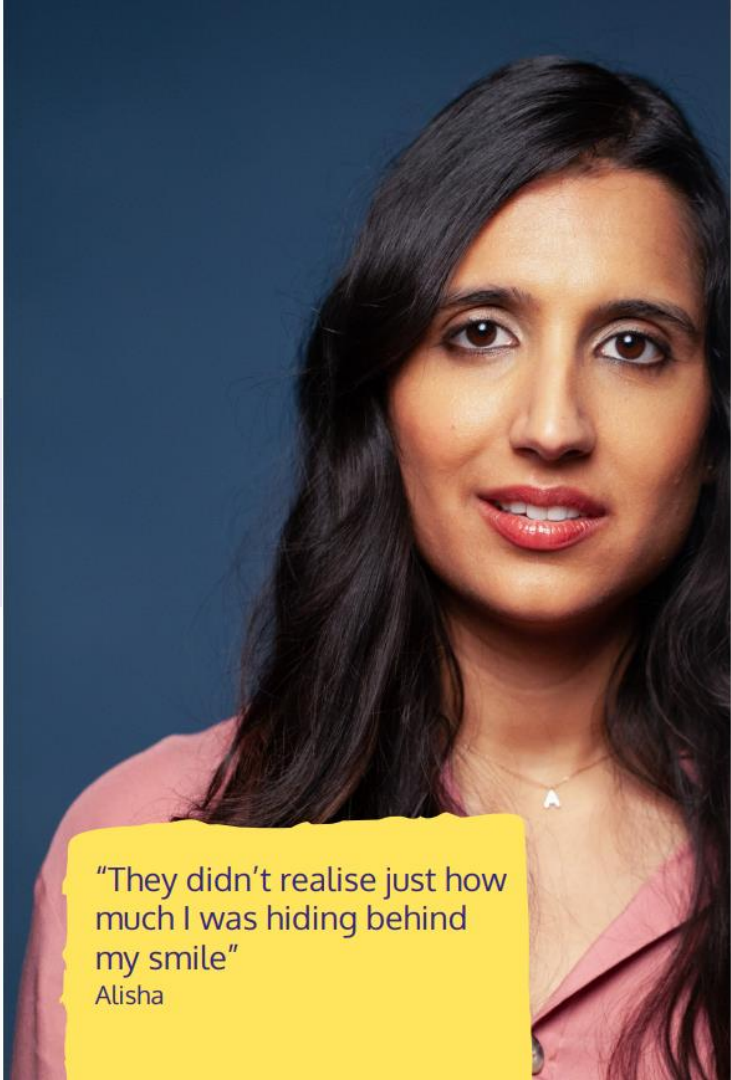
Nailsea Stroke Survivors Club





# Hidden effects of stroke

While some effects of a stroke are obvious to see, many are hidden.

A portrait of a woman with long, dark, wavy hair, wearing a pink top and a necklace with a small white pendant. She is looking slightly to the right of the camera with a subtle smile. The background is a dark blue-grey color.

"They didn't realise just how much I was hiding behind my smile"

Alisha

# Hidden effects of stroke

## Fatigue

Feeling of weariness, unrelated to exertion, which is not improved by rest.

## Emotional effects

Low mood, depression, anxiety, or emotional lability.

## Memory and thinking

Problems with attention, memory, perception and problem solving.

## Vision problems

Visual field loss, double vision, processing problems, or over-sensitivity to light.

## Pain

Long term pain, such as muscle and joint pain, or neuropathic pain.

# Get to know your members

## Step 1

Identify their needs



## Step 2

Understand their needs



## Step 3

Meet their needs







# Step 1

## Identify their needs

- Speak to individuals and their family members/carers.
- Observe.
- Membership forms
- **Remember** – the needs of longstanding members may change.

## Step 2

# Understand their needs

- Information on our website and in our factsheets.
- Draw on your personal experience.
- Consider what has previously worked well or not so well when running your group.





## Step 3 – Meet their needs

- Seek regular feedback on what's helpful and what's not.
- Include members in planning activities.
- Follow up with members who seem quiet, distracted or not themselves
- Co-create a set of group values or principles.
- Signpost appropriate information and support if needed.

# Fatigue

- Consider the time, duration, location and accessibility of the group.
- Look out for signs of fatigue e.g. red eyes, drowsiness, irritability, worsening communication.
- Empower members to say “no” if they feel too tired.
- Incorporate regular breaks before and after any activities.
- Allow extra time.



“It’s hard to describe the fatigue I experienced after my stroke – it’s not like normal tiredness. I was completely wiped out.”

Nicola

# Emotional effects - Louise video

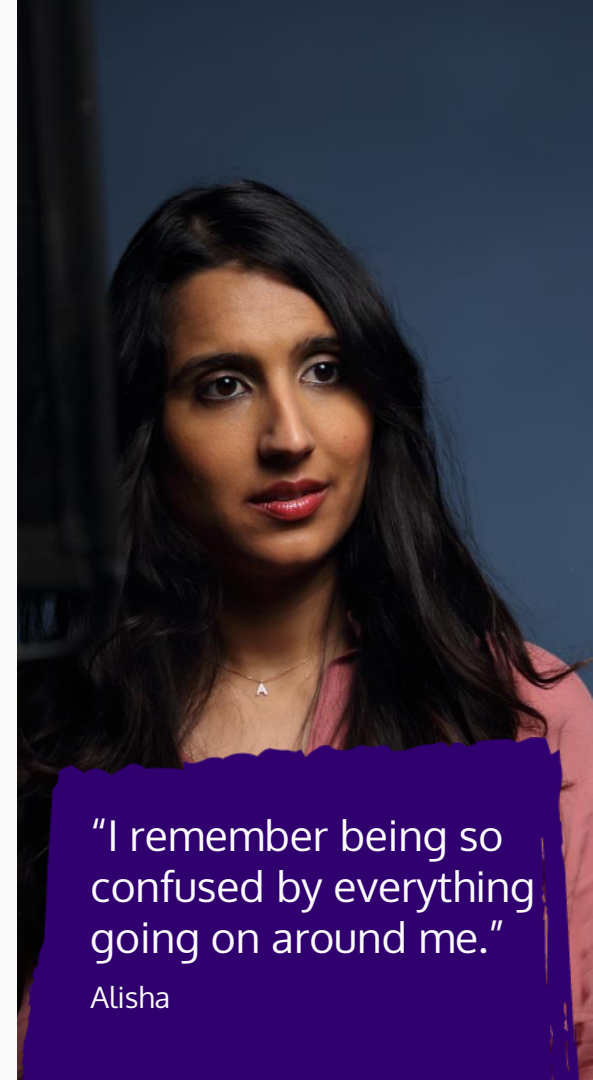


# Emotional effects

- Promote your group as a safe space where members can feel comfortable sharing how they feel, without fear of being judged.
- Follow up with members who seem quiet, distracted or not themselves.
- Don't judge and listen first before suggesting solutions.
- Don't forget to look after yourself too.

# Memory and thinking problems

- Try to minimise background noise and distractions.
- Encourage members to be patient and give each other time to respond.
- Discourage members from interrupting or talking over each other.
- Splitting into smaller groups may be helpful for some people.



"I remember being so confused by everything going on around me."

Alisha



# Pain

- Ask what they find helpful.
- Respect what they can and can't do.
- Remember that pain can fluctuate considerably.
- Regular breaks may be helpful.
- Ensure members feel comfortable to manage their pain without fear of judgement.

# Visual problems

- Don't assume. Ask members in advance what they need.
- Ensure that the space, if in a physical room, is free of clutter, coats, handbags, trailing wires.
- Ask everyone to introduce themselves at the beginning and then to say who is speaking as it changes.
- Remember, not everyone who has a vision impairment has no useful vision in fact most people have some vision.

# Resources

- Website
- My Stroke Guide
- **Guides:**
  - On each of the hidden effects
  - The hidden effects of stroke – A guide for group volunteers
  - Emotional changes after stroke – A guide for supporting your group members and volunteers



Thank you

Questions

**Stroke**  
Association



Rebuilding lives  
after stroke