

# Adapting group support

Beth Scrimshaw

1 July 2021



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

## Stroke Association vision

Our vision is for there to be fewer strokes, and for people affected by stroke to get the help they need to live the best life they can.



# Our Goals

Make stroke the  
priority it needs  
to be

Ensure that  
everyone affected  
by stroke has  
access to the  
rehabilitation and  
lifelong support  
they need

Partner with  
people and  
communities to  
help them take  
action on stroke

# How do we make a difference?

Service Delivery

Research

Influencing

Community  
Engagement

## Peer support groups

We deliver 216 peer support groups across the UK

- Led by 1,120 Stroke Association volunteers
- Supporting 3,682 members

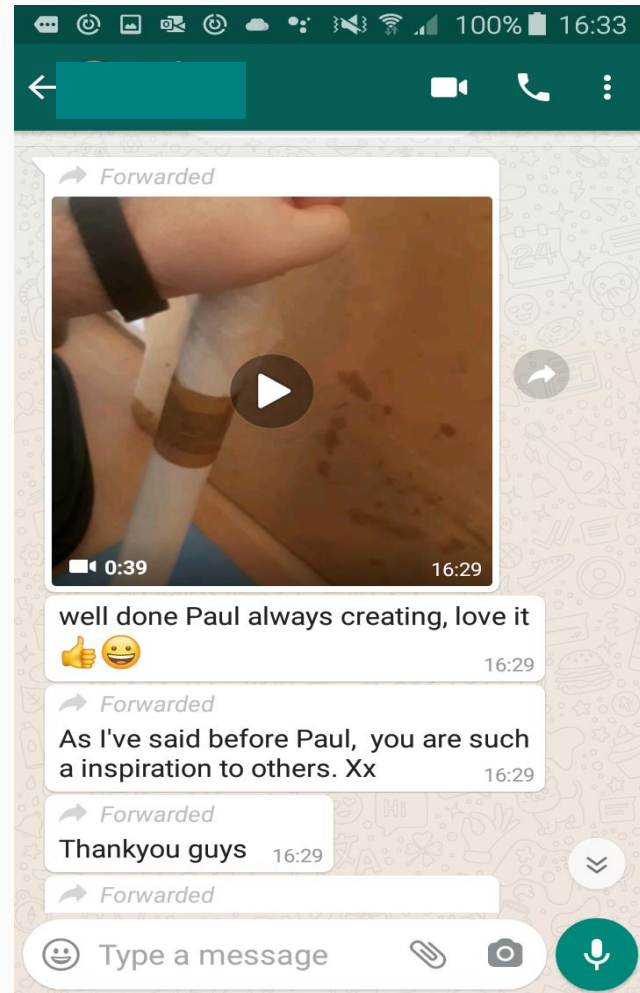
We also work with 238 independently run stroke support groups

## COVID-19 and peer support

- Role of peer support in enabling people to cope became even more apparent
- Translating core values of mutuality, choice, control, equity and safety into remote environments
- Best response models co-produced, and not always online, with change happening at pace of people's growing confidence with remote tools

# Phone trees, WhatsApp Groups

The members really appreciate and look forward to the calls. They feel fed up with everything going on and the calls really lift their mood and they like to chat!



# Newsletters



Hello Everyone,

Once again, thank you to everyone who is contributing to the News Bulletins. It is lovely to hear from you and about what you are doing. If you

Success After Stroke  
News Bulletin No. 14  
Friday 29th June 2020

  
**Success  
AfterStroke**  
Registered Charity No. 1115016

started to look around for a new challenge. Having spent much of my life engaged in sports activities I decided to take up the increasingly popular sport of cycling. Following two long-distance challenges, Lowestoft to St David's Head and London to

## June 2020 Newsletter Singing and Sound

Well here we are into June time is going fast .Hope to find you and your families are well.

Second Chance Stroke Club

## Newsletter

July 2020  
Issue 3

### Penny's Ponderings

On behalf of Penny

Another month has gone by, and we are still not clear when we can all get out and about and meet again. I am sure that this is frustrating for all, and lonely for some.

  
**Second Chance  
Stroke  
Group**

#### *Do you enjoy Singing?*

We have had contact from [Arts La'Olam](#), who are an Ipswich based arts organisation, about the Telephone Singalong they



# Regional and national online meetings

- Communities of identity (BAME and younger stroke survivor groups)
- Communities of interest (singing)

I appreciate the fact that it concentrates on the BAME groups. Being from a minority myself, it's good to know what others are experiencing and to share knowledge.






Being of a working age group meant that we were all better able to understand each other's struggles and share what works for us.



# Supporting volunteers

# 1. Understanding

## Who responded to the survey?

<b>260</b> Stroke group members and volunteers	<b>118</b> Stroke groups across England, Scotland, Wales and N Ireland
 People <b>aged 31 to 92</b> years old, averaging 67 years old	 A similar number of <b>men and women</b> took part
 23% live alone and <b>65% with family</b>	 43% said they had poor health and <b>53% reported good health</b>
 <b>14%</b> had received a ' <b>shielding</b> ' letter	



## RESEARCH HIGHLIGHTS

Dear stroke group members and volunteers,

Many of you have helped with the 'Community Groups for Post-Stroke Support' research.

Between November 2019 and March 2020, many of you completed a **paper survey in your groups**.

We wanted to repeat this survey again a year later, but this plan changed when COVID-19 arrived.

We decided to do a second **online survey in June/July 2020** to find out how you were coping while groups were not meeting face-to-face. We call this our 'lockdown survey'.

Ruth has also enjoyed talking to a number of you **over the phone**.

**Thank you** to everybody who took part.

In this update, we share with you some **highlights from the 'lockdown survey'**.

This is just some of the **helpful information you have provided** by supporting this research.

All the best from the research team at the University of Exeter.



## Wellbeing during lockdown



Members **reported high well-being**.



Average scores for well-being were **just a fraction below the norm** for adults.








Those with **poor health** were much **more likely to be lonely**.



Those **living alone** were much **more likely to be lonely**.

## How stroke groups kept in contact

During the lockdown, stroke survivors stayed in contact with their groups in the following ways:

	62% had telephone contact		60% used email		52% used text messages
	47% used video calls		25% used social media		13% reported no/minimal contact

## The importance of group volunteers

- **Most contact was with the group leader or a volunteer.**
- The group leader or volunteer often made contact first.

## A range of support

- Groups were good at '**keeping in touch**' and '**checking-up**'.
- They also provided some **emotional and practical support, and information**.
- This was often through volunteers.

## Not without its problems

- Staying in touch was often difficult.
- **Difficulties with technology** often got in the way.
- Stroke-related **disability** stopped some people from making contact.
- Others did **not feel close enough to the group** to keep in touch.

“ I have received 1 call from [redacted] who co-ordinates the stroke meeting I attend. She was just checking I was keeping ok and she had been calling other group members. Very appreciated. ”

“ I get a call from the leader once a fortnight and they called me when I went into hospital. I call one of the ladies every other week who I know better as she can get down sometimes. ”

“ If I am able to get people on the phone we usually have a good natter, but it is limited by their disability which often means it is short and sweet! ”

## Improving support for stroke group members

### Member-to-member contact

- **Contact between group members was not as common** as with volunteers.
- Some people suggested sharing members' numbers with permission and **buddying systems**.



For those wanting to **connect group members**, here is some **guidance**

[CLICK HERE](#)

The guidance includes how to safely share details and ideas for ways to facilitate member-to-member contact

### Technology-based solutions

- Some people need **help to get access to the internet, smart phones and computers**.
- Some people need **help to learn how to use the technology**.



If you want help for members to get online, here are some free resources:

- Free IT support from: [abilitynet.org.uk](http://abilitynet.org.uk)
- A guide for people with aphasia: [CLICK HERE](#) (free to download/print or order from [online](#))
- **Call/email the Stroke Helpline** for information on grants to buy **technology for members**:  
Call: 0303 3033 100 or email: [helpline@stroke.org.uk](mailto:helpline@stroke.org.uk)

# Understanding

- Online support not a panacea
- Facilitating online peer support requires training and support
- Prioritise resuming face to face
- Address the digital divide, improve inclusivity and focus on co-production

# 2. Guides



## Phone conversation guide for volunteers

### Before the call

- Find a **quiet place**.
- Think about **what you want to say**.
- **Hide caller ID** ([this guidance](#) can help you find out how)

### Beginning of the call

- How are you **feeling** today?
- What have you been **doing** since we last spoke?

### Check they are doing OK

- Do you have the **practical help** you need?
- Have you been **worried** about anything?

## Using Facebook Groups

This information is for volunteers to help you use Facebook groups to stay connected with other volunteers and your group members.

Some of you may already be familiar with Facebook groups but others may not be. This information will help with the basics but there is much more than can be done through Facebook. If you are less familiar with Facebook, speak to those you work and volunteer with so you can help each other. In the coming weeks we will be looking to develop further resources to make the most of connecting digitally.

### Contents

What is Facebook?.....	3
What is a Facebook Profile? .....	3
What's the difference between a Facebook group and Facebook page? .....	3
Who should set up a group? .....	4



## Connecting Members within Voluntary Groups

With groups not meeting face to face, members may want to [be put](#) in touch with each other. [Or](#) volunteers might want to offer this option to give members more opportunities to socialise remotely. To facilitate this, members contact details must be shared which means we must do this in accordance with data protection laws.

Stroke Association Voluntary Groups must follow the process below when putting group members in touch with each other - by phone or email. Independent stroke clubs may use this to inform on their own approach.

# Clubs and groups resources

This page is here to support our clubs and groups leaders during the coronavirus outbreak.

Always follow the latest advice from the government, the NHS and any organisational decisions that we've communicated.

## Communications guidance and templates —

Use these guides to learn how to use different platforms:

- [Using Facebook groups](#)
- [Using WhatsApp](#)
- [Keeping data safe on WhatsApp](#)
- [Using WhatsApp on your computer](#)
- [Making video calls](#)
- [Installing zoom](#)
- [Joining a zoom meeting on a laptop](#)
- [Keeping zoom meetings secure](#)
- [Zoom video tutorials](#)
- [Joining zoom by telephone](#)
- [Tips for having online discussions](#)

## Latest information and advice

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Where local and national restrictions allow, Stroke Association Voluntary Groups volunteers can meet with members outside in groups of up to 30 to offer social and peer support. Volunteers must follow our [Outdoor Chats Guidance](#) (PDF) guidance. Volunteers do not need to complete a risk assessment for this as we have an organisational risk assessment which you can view [here](#).

From the 5 July, Stroke Association Voluntary Groups can resume indoor meetings, subject to local restrictions. You can use our [Requirements for Resuming Groups Indoors](#) (PDF), [risk assessment template](#) (word document) and [template letter to members](#) (word document) to help you prepare.

For more information, see our [Coronavirus Recovery FAQs for voluntary groups](#) (PDF) or go to the main [coronavirus page](#) for links to the latest government advice.



# Getting online for people with aphasia

Rebuilding lives after stroke


**Stroke**  
Association



- Can be downloaded in full or by chapter
- Free printed copies available


# Videos to support each chapter on YouTube

1




**Section 1 - Aphasia and technology**  
My Stroke Guide

2



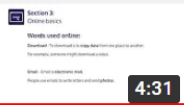
**Section 2 - Why get online**  
My Stroke Guide

3




**Section 3 - Online basics (part 1)**  
My Stroke Guide

4



**Section 3 - Online basic terms (part 2)**  
My Stroke Guide

5



**Section 4 - Online safety**  
My Stroke Guide

# Additional video calling resources

## Video calling for people with aphasia



Video calling is a popular way to connect with family and friends.

You can use a computer, tablet or smart phone to make a call.

When you video call you are able to see the person you are talking to.

People with aphasia often find video calling better than a phone call.

There are many different video call platforms.

This guide will give you information about 3 popular options:



Skype



Zoom



WhatsApp

- How to download on different devices
- How to use the video call platform

## Feedback so far

At last a guide that Stroke Survivors of all ages can use without feeling patronised

It's like the idiots guide, it just works for me!

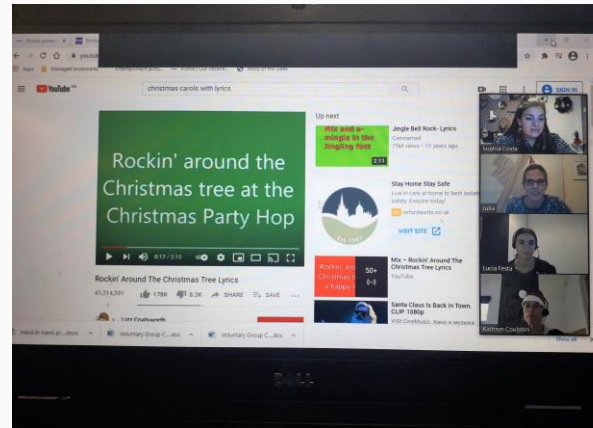
This is the perfect level for my dad who has never used a computer before

### 3. Opportunities to build confidence & skills

- 1-1 support to build confidence and learn about tech
- Update on changes to tech
- Building partnerships



## 4. Connecting leaders together



## 5. Evaluate

### What happened?

Give information on the activity, and the reasons why it happened this way. Consider what resources or help you needed to make it happen, such as working with another group or members making donations.

### What feedback did participants give?

Any comments, ideas or suggestions given by who benefited from the activity. Use quotes when possible.

### Long for: What do you want to see in the future?

- Zoom activity
- Sent out Zoom instructions and guidelines
- Had 1-1 with the Chair via to practice
- Prepared art assignment
- They voted to upgrade the Zoom account with group funds allowing more time and more features, like having more than one host

"It has **given me motivation** to do something because we can now share with others and have some support"

"I was **surprised** that group members were **able to log on** and participate"

They suggested all members be allowed to share screen that way those with aphasia could present, one member did this and showed photographs of work he used to do |



### Lacked: What could we have done better?

Share what hindered you and why this was. Try to give specific examples.



# Key learnings and opportunities

- Online has potential to widen access to peer support
- Face to face group support is important
- Exploring hybrid approach going forward
- Understanding where online has a unique value

Although I enjoy my regular chats with Christine and other members of the group, it isn't the same as being together and I really look forward to the day that we can all reunite.

Sheila, Stroke Group Member





Rebuilding lives  
after stroke