

Wellbeing After Stroke (WATERs)

Report on research study findings

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Written with the help of stroke survivors

Study Contact information



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What is this report?

This is a short final report on a research study called 'Wellbeing After Stroke' - or 'WAterS' for short.

It summarises some key points about what we did and what we found.

Why have I received it?

You took part in the study or expressed an interest in it and agreed to receive this report.

The study included stroke survivors who may have had their stroke some time ago. We express our sympathies to anyone since bereaved.

If you have any questions about this report or need support to understand it, please contact us using the details on the front cover.

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Introduction to the WAtErS study

Stroke often affects people's wellbeing. It can bring psychological suffering and difficulties adjusting.

Supporting people to come to terms with life after stroke is a high priority nationally but there has been very little guidance about how best to do this and services are limited. This is because:

- We don't yet know what support might help.
- We don't have the staff to deliver support. Psychological care is often delivered by Clinical Psychologists but there aren't enough of them to reach the large numbers of people affected by stroke.

The WAtErS study was set up in 2019 to try to understand how to improve support in this area.

Who ran the study?

Researchers at the University of Manchester led the study and worked closely with other experts including:

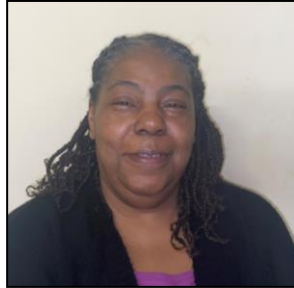
- Healthcare professionals from the NHS.
- Experts by experience; the WAtErS Research User Group (see next page)
- The Stroke Association: a national charity with lots of experience working with people affected by stroke.



You can find out more about the Stroke Association on this website: www.stroke.org.uk.

- **The WAterS Research User Group**

A group of people with first-hand experience of stroke and caring helped with planning, delivering and understanding the study.



The group members and some of them 'in action' during one of our meetings

Study aim

The study aimed to:

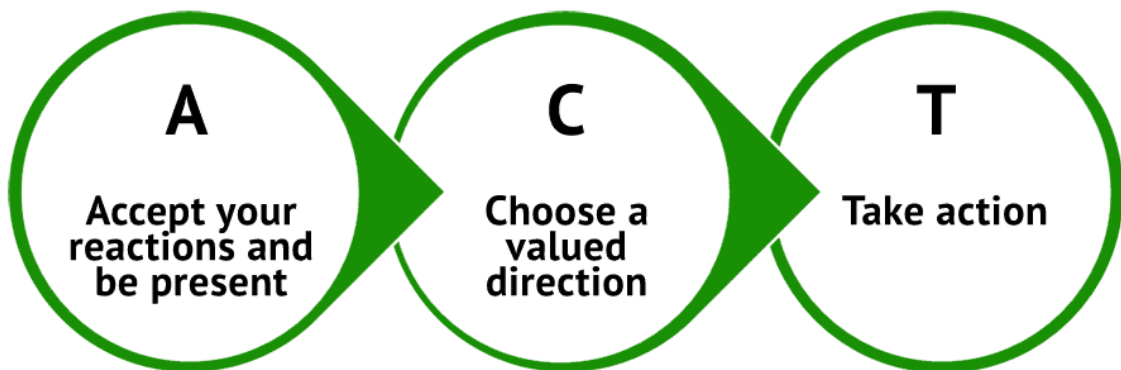
Develop and test an approach to support psychological adjustment after stroke and improve wellbeing (including training staff to deliver it)

- **Pages 3 to 5** describe the approach we developed
- **From page 5**, we describe what we did and what we found when testing the approach in real world settings.

An approach for supporting wellbeing

We started with a psychological therapy called Acceptance and Commitment Therapy or 'ACT' for short.

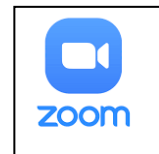
ACT is designed to help us come to terms with difficult situations, including a stroke.



The WAtErS group therapy

We developed the Wellbeing After Stroke Group (**WAtErS Group** for short)

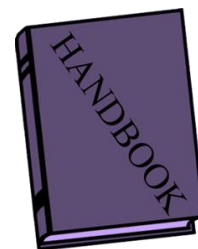
- It is delivered over **9-weekly sessions** to **small groups of stroke survivors** using **Zoom** (*Zoom meant we could continue even during the COVID-19 pandemic*)



- It includes extra resources to make it more accessible such as:



Learning resources



a user handbook for sessions

The WAtErS group therapy (continued)

- Each session is **2 hours long** with **comfort breaks**.
- Stroke survivors do '**home practice**' to give **added benefits**.
- Some **tools** and **strategies** used in sessions are:



Tips to work around common issues after stroke: forgetting, word-finding problems, and tiredness.



Work with **core values**.

These are the things that **matters to us**.



Practices to help people '**drop anchor**' in the moment; called **mindful noticing** and **mindful breathing**.



Introducing **helpful ways to think** about our feelings.

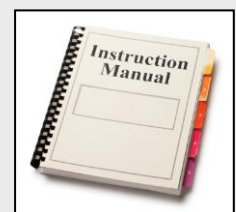
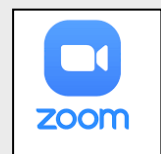


Planning for the future

Staff training package

Stroke Association staff with no experience of ACT were trained to deliver the WAtErS group:

- 4 half-day training sessions delivered using Zoom
- Weekly guidance from a Clinical Psychologist
- Including specially prepared resources, such as an instruction manual with 'scripts'



Testing the WAtErS group in a research study

We wanted to **explore** the WAtErS group in **early testing**, to see how it worked in practice.

This kind of study is **not big enough to know for sure if the support ‘works’**. That is, it won’t tell us whether the WAtErS group will *definitely* improve wellbeing. But it will help us understand if it should be tested more and *how* future studies should be designed. This is a way of making sure we invest time and money wisely.

We wanted to answer some **study questions**:



1. Will enough stroke survivors sign up?
2. Can we collect information to understand if it has been helpful?
3. Can we deliver group sessions as planned and are they safe?
4. What are stroke survivors’ experiences of the WAtErS group?
5. What are Stroke Association staff experiences of training and delivering the WAtErS group to stroke survivors?

We collected **different types of information** in this study including:



People completed **online surveys** about their experiences, mood and wellbeing.

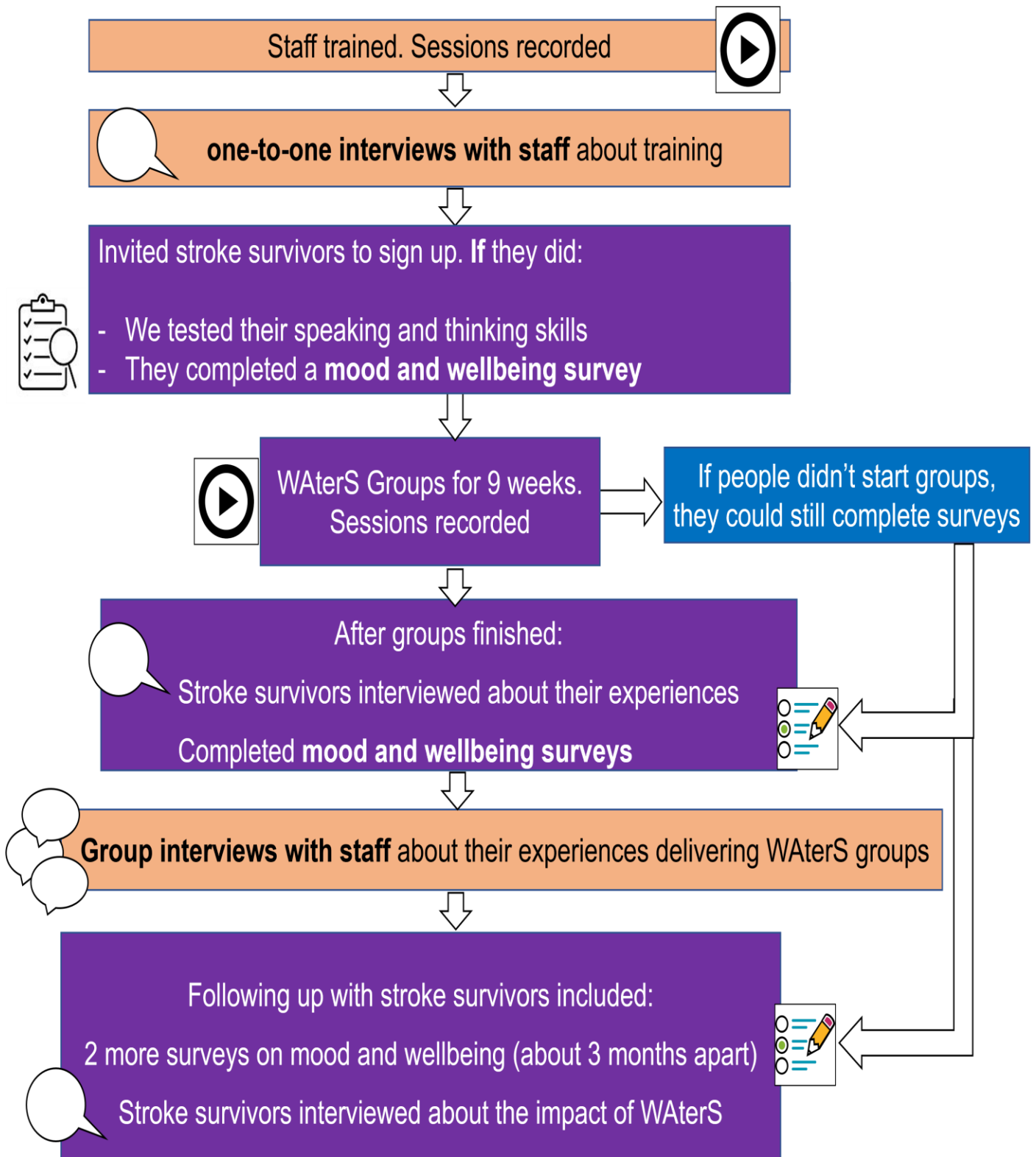


We **spoke to people** in one-to-one and group interviews. This helps us understand people’s experiences in their own words.



We took **video-recordings** of staff training sessions and WAtErS group support sessions with stroke survivors. This meant we could check if sessions had gone as planned.

A diagram of the study process



Who took part?

Stroke survivors

17 signed up for the study:

- 12 joined WAtErS groups.

We ran 3 groups between August 2021 and December 2021.

Each group included 4 stroke survivors and 2 trained staff.

- 5 only agreed to complete surveys. They felt that they didn't need support after all or were too busy to join.

Of the 12 stroke survivors who joined groups and received support:



5 were female and 7 were male.

10 were White British.



The average age was 54 years old.

The youngest was 34 and the oldest was 76 years old.

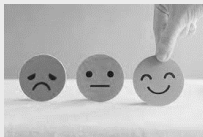


On average, stroke survivors joined 2 years after stroke.

But this ranged from 2 months to 7.5 years after stroke overall.



People had mild to moderate difficulties speaking and thinking



People had mild to severe mood difficulties

Stroke Association staff

We trained 8 staff and 7 of them helped deliver group support sessions.

All were female with at least 1 years' experience.

Each group had 1 'lead' (a counsellor) and 1 'support' (non-counsellor).

What we found

1. Will enough stroke survivors sign up?

The short answer is “**Yes, but not always**”.

17 stroke survivors agreed to take part but 5 of them did not agree to join group support. Those 5 still help us understand whether we could collect helpful information (*see question 2 below*).

There was excellent attendance from the 12 stroke survivors who joined groups. People even continued group sessions when they went on holiday!

For future research, we probably need to:

- Give specific information about group timings so people can ‘save time’ in their diaries.
- Keep waiting times as short as possible.

2. Can we collect information to understand if it has been helpful?

The short answer is “**Yes**”.

We had excellent response rates to surveys. People completed all questions in 20-30 minutes on average.



Some needed telephone support with a researcher but most could complete surveys independently.

For future research:

- We think online surveys are a good way to collect information on mood and wellbeing.
- We should offer support to complete, as needed.

What we found (continued)

3. Can we deliver the group sessions as planned and are they safe?

The short answer is “**Probably Yes**”.



We rated recordings of sessions:

- Planned group content was delivered.
- Sessions sometimes took longer than expected.
- Different Staff were not always consistent in *how* they worked.
- People could get upset in groups, but our staff were mostly able to support them to feel better. Nothing ‘unsafe’ happened.

For future research:

- We may need to look at the length of sessions.
- There may be ways to improve the staff training and guidance to make sure that the therapy is consistent across different staff.
- We think the groups are safe to run online but would need more testing with different kinds of staff.

What we found (continued)

4. What are stroke survivors' experiences of the WAtErS group?

Some **“direct quotes”** from interviews are included below.

Most people's experiences of the group were positive. They got upset at times, but were glad they took part and felt they had learned some valuable tools to help with **“the daily struggle”**:

“There were about four or five different strategies given to us... some hit, some miss, but that's the nature, when you try things”.

“If it wasn't for the WAtErS study, like I say, I don't know where I would be ... in my mental issues, mentally or physically”.

Whilst some would prefer face to face sessions, most had used to Zoom during the COVID-19 pandemic and found it acceptable.

Most people felt the sessions were **“a nice steady pace”** but at times there might be **“too much being fed in”**.

Everyone felt the staff running the groups were **“really caring”** and **“supportive”**.

The course felt like a **“journey”** and it sometimes felt like a **“loss”** to end.

For future research:

- We think the groups work well but there are ways we could improve the content and the pacing to make it more accessible.
- We could consider whether the group size and mix might help people feel even more comfortable.
- We could consider ways to help with endings.

What we found (final)

5. What are Stroke Association staff experiences of training and delivering the WAtErS group to stroke survivors?

Some “**direct quotes**” from interviews are included below.

Overall, staff experiences were very positive. They were glad to be trained in Acceptance and Commitment Therapy as a new way to support stroke survivors’ wellbeing. They felt stroke survivors gained a lot from sessions.

Staff were “**quite daunted**” at the beginning but grew in confidence “**once we got into it**”.

It took more time than expected to prepare for sessions, and to support to stroke survivors if they became upset.

Staff suggested ways to make the sessions “**more inclusive**” in future for people with more difficulties thinking and speaking.

Two members of staff per session was essential and helped them “**relax**” and work with Zoom effectively. Support staff felt confident to lead sessions after a few weeks.

For future research:

- Staff training and guidance works but we may need to protect more time for staff to support stroke survivors and prepare for groups.
- We have some suggestions for ways to improve sessions.
- In the long-term, support staff could lead groups after having some experience. But there should always be two staff running sessions. We may even explore whether stroke survivors themselves could support delivering sessions.

What does this mean?

The WAtErS study has been successful. We developed:

- A group therapy that may help people in future;

and

- Training that prepares staff to deliver it.

We know we can get stroke survivors to sign up. When they join groups, they tend to enjoy it, find it valuable, and attend almost all sessions.

We also know we can collect information that would help us measure whether the groups improve wellbeing over time.

What happens now?

We are committed to learn from the research and share learning widely.

The people who receive this report helped to make the study possible and you are amongst the first to hear about the WAtErS study findings. We still have a lot more work to do so we are:

- Working on ways to improve WAtErS groups;
- Working with the Stroke Association to develop staff training;
- Working with other researchers and have applied for funding to develop and test the WAtErS group for different populations and in different settings;
- Preparing scientific reports so that others can find out about our work;
- Sharing the work with researchers and healthcare professionals.

How can I find out more?

If you have any questions about the study or about getting involved in research, you can contact us



(0161) 275 3401



WAterS@manchester.ac.uk

There will be detailed scientific reports available soon and we would be happy to send you a copy, on request.

If you would like a printed copy of this report, please let us know.

If you would like to hear the contents of this booklet read out loud, please visit: <https://www.youtube.com/@watersstudy>



... to everyone who played a part in this study.

Special thanks to the **WaterS Research User Group**, who helped to make this book easier to read. The group consists of: Stephen Taylor, Lorretta Hanley, Ann Bamford and Nigel Bamford.

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