



RESEARCH

INFORMATION

## HELPING EASE ANXIETY AND DEPRESSION AFTER STROKE (HEADS: UP)



### AIMS

Anxiety and depression are common after stroke, but people do not always have the skills they need to manage their symptoms. Mindfulness Based Stress Reduction (MBSR) is an 8-week, group-based course that teaches people with long-term conditions skills like meditation and mindfulness breathing, that will help them to self-manage their symptoms. Doing the whole course and regularly practicing the skills taught leads to improved 'mindfulness' and better outcomes in terms of managing symptoms. Mindfulness has been described as maintaining a moment-by-moment awareness of thoughts, feelings, bodily sensations, and surrounding environment, in a gentle, nurturing manner. When we practice mindfulness, we tune in to the present moment rather than fretting about the past or worrying about the future.

We know that people often find it difficult to do the whole course and to practice regularly. We aimed to work with stroke survivors, families and other experts to make changes to the standard MBSR course to make it easier for people affected by stroke to follow the whole course, do the personal practice, and get the most out of learning mindfulness skills. We called the adapted course HEADS: UP - Helping Ease Anxiety and Depression after Stroke.

We thought that HEADS: UP would:

- take into account some of the common consequences of stroke e.g. difficulties with communication, fatigue, physical disabilities
- address some of the difficulties associated with attending a weekly class and would include 'hints and tips' to help people to practice regularly
- be designed for stroke survivors and family members working and learning together so that they can support and encourage one another





## KEY FINDINGS

People who had had a stroke and family members thought:

- the HEADS: UP taster sessions were easy to follow
- learning mindfulness could help them self-manage symptoms of anxiety and depression
- practising mindfulness regularly on their own could be difficult
- doing a mindfulness course with partner or buddy might be helpful



## WHAT DID THE STUDY INVOLVE?

This development study was in two phases.

**Phase 1:** We used stroke charities and other community-based organisations to recruit to the research. We recruited people who had had a stroke, and family members, who were interested in learning about how to manage symptoms of anxiety and depression.

Participants attended an MBSR taster session. Each 75-minute taster session included a selection of MBSR 'exercises, e.g. body scan, mindful movement, breathing, seated and walking meditation, and visualisation. After refreshments, participants took part in a focus group.

The focus groups were recorded using a digital recorder and explored participants' thoughts about the MBSR course materials and content, what it was like to do the exercises, and how participants thought we might change things to make it easier for people affected by stroke to follow the course and practice regularly.

The information from the focus groups was coded and analysed using an intervention framework to help us understand how we could adapt the course to make it easier to follow. Then we worked with other researchers and representatives from stroke charities and other community-based organisations to discuss adaptations.

**Phase 2:** We ran the taster sessions again, this time using adapted course material. After the taster sessions, participants took part in a second focus group, this time to discuss what was useful and what was not so useful about the changes to the course.



Development work is  
hungry work!

Working with people  
affected by stroke to  
test adapted course material





## WHAT WERE THE RESULTS AND WHAT DO THEY MEAN?

23 (77%) people who had had a stroke and 7(23%) family members attended taster sessions and focus groups. We held two groups in Glasgow and one in Irvine.

Key areas for adaption that emerged from analysis of the focus group data included:

- Preparation e.g. making the course content 'accessible' and easier to understand
- Approach e.g. delivery should be slow and deliberately repetitive
- Motivation e.g. working in pairs may help improve class attendance and practice

These findings were used to develop a stroke-specific adaptation of the mindfulness course: HEADS: UP (Helping Ease Anxiety and Depression after Stroke).

### HEADS: UP adaptations

- Information about the course, including practicalities of how to get to the venue and where to park or get off the bus, is now in a more accessible format
- Course information will be sent in advance, week by week
- An introductory session has been added to the start of the course to allow people, including the MBSR trainer, to get to know one another and ask questions about the HEADS: UP course
- Course content has been adapted to allow for common consequences of stroke, including fatigue and physical disabilities



## WHAT IMPACT COULD THE FINDINGS HAVE?

### • Patients

- In future research we will test HEADS: UP to see if people affected by stroke find it straightforward to follow the course and to do regular practice
- We will ask people affected by stroke what they think about the research methods we plan to use, and if these need to be changed
- If it is successful, HEADS: UP could be considered as an intervention that could be available as part of routine stroke rehabilitation

### • Practice

- More people may benefit from being able to self-manage symptoms of anxiety and depression if the effectiveness of HEADS: UP is proven in a larger study and implemented in practice
- HEADS: UP is a community-based rehabilitation intervention and may help reduce use of NHS services in this population



## HOW WILL THE OUTCOMES BE DISSEMINATED?

- Poster presentation at the European Stroke Organisation Conference 2018
- Academic paper in an Open Access journal
- A lay summary for stroke charities to use on their websites and in their newsletters
- Social media tweets and posts @StrokePathways



## CONCLUSION

- Anxiety and depression are common after stroke but people do not always have the skills they need to cope with symptoms
- HEADS: UP is a 9-week Mindfulness Base Stress Reduction course, developed in collaboration with stroke survivors and family members
- Based on the findings from this study we have successfully secured funding from the Stroke Association for a feasibility and pilot study of HEADS: UP. We will deliver HEADS: UP to people affected by stroke, to test whether it helps them learn the skills they need to self-manage symptoms of anxiety and depression



## RESEARCH TEAM & CONTACT

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### Additional Information

Funding: We were awarded £85,339

Dates: The project ran from August 2017 - January 2019