

# **Organising Support for Carers of Stroke Survivors (OSCARSS)**

Report on research study findings

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Written with the help of carers and stroke survivors

## Study Contact information



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## **What is this report?**

This is a short final report on a 3 year research study called 'Organising Support for Carers of Stroke Survivors' - or 'OSCARSS' for short.

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

## **Why have I received it?**

You, or your family, kindly took part or expressed an interest in the OSCARSS study and agreed to receive this report.

The study included people caring for 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. We can make it available in different versions – please ask.

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*Throughout this report, we use the term “carer” to describe anybody who supports a loved one in any way after a stroke, even though they might not describe themselves as a carer.*

## Introduction to the OSCARSS study

Stroke can affect a person's ability to look after themselves or take part in daily life. Partners, family members and friends often provide support to their loved one after a stroke, which can come in many forms:



*Image used with permission of Carers UK / Carers Week*

Providing support to a stroke survivor can be rewarding but can also affect a carers' health, well-being and finances.

Supporting carers is a high priority nationally but there has been very little guidance about how best to look after carers.

The OSCARSS study was set up in 2015 to understand how to improve carer support.

## Who was involved?

Researchers at the University of Manchester and Salford Royal NHS Foundation Trust ran the study and worked closely with:

- **The OSCARSS Carer Research User Group**

A group of people with first-hand experience of stroke and caring helped with every aspect of planning, delivering and understanding the study. You can find out more about the group on this website: <https://www.clahrc-gm.nihr.ac.uk/projects/oscarss>.



We also worked closely with the Stroke Association. They are a national charity with lots of experience working with people affected by stroke. They also have a wide variety of approaches for supporting carers.



You can find out more about the Stroke Association on this website: [www.stroke.org.uk](http://www.stroke.org.uk).

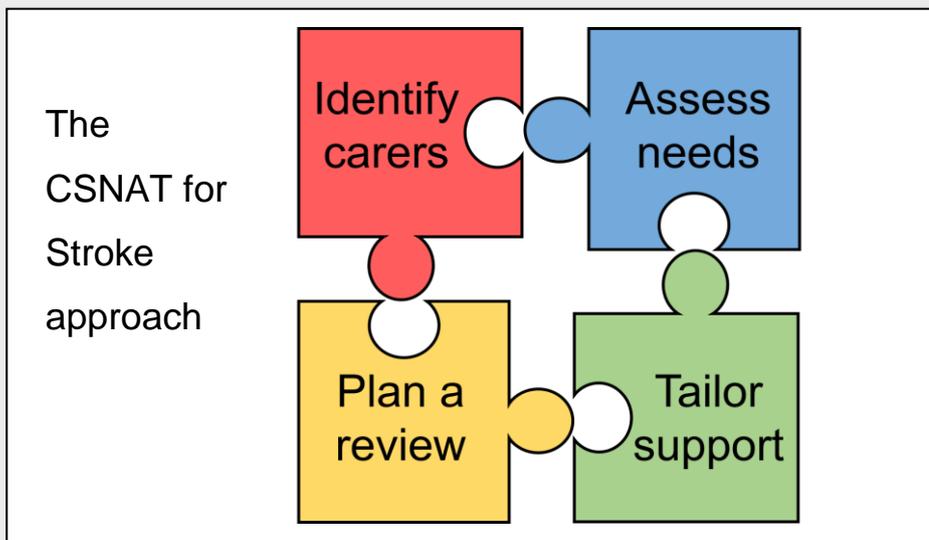
## Study aim

The study aimed to understand how to improve support for carers.

## An approach to supporting carers

We started with an approach called the 'Carer Support Needs Assessment Tool' or 'CSNAT'. You can find out more on this website: <http://csnat.org/>.

The Carer Research User Group helped adapt this to make it work better for people who are caring for stroke survivors.



The CSNAT for Stroke was used when Stroke Association staff visited carers. It encouraged carers to 'take the lead' thinking about what is most important for themselves and how they might want to be supported.

## Study questions

We compared the CSNAT for Stroke approach to usual ways that staff supported carers to ask:

1. Does the CSNAT for Stroke approach reduce strain on carers and improve their well-being?
2. Which approach to supporting carers is better value for money?
3. What are carers' experiences of receiving support?
4. What are Stroke Association staff experiences of providing support?

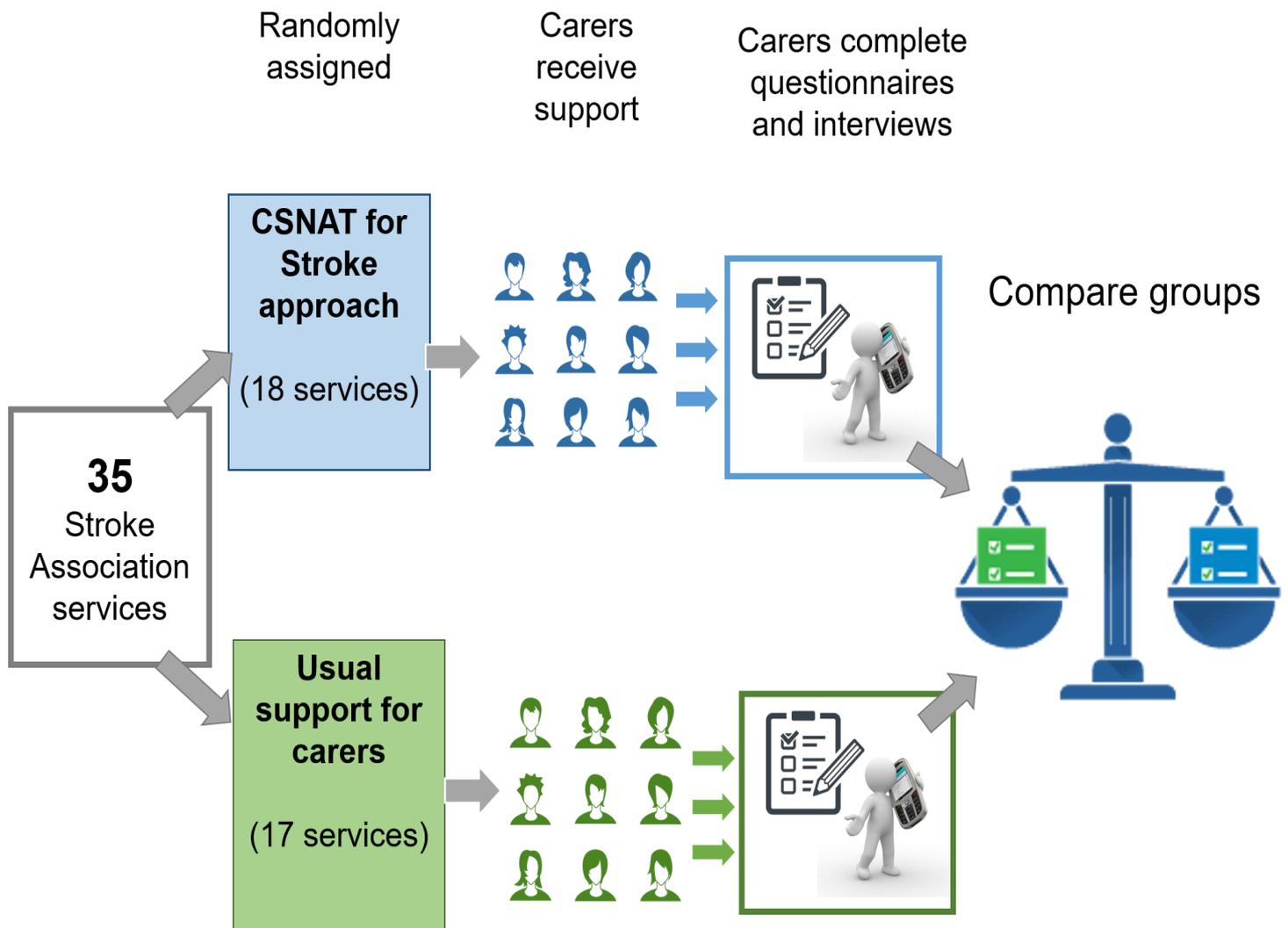
## How we evaluated carer support

We carried out what is called a '**cluster randomised controlled trial**'.

We took 35 Stroke Association services across England and Northern Ireland and **randomly** assigned:

- 18 services to have all staff trained in the **CSNAT for Stroke** approach;
- 17 services with staff to continue supporting carers in their usual way.

## A diagram showing the OSCARSS study process



## Who took part?

### Carers

414 carers who were seen by Stroke Association staff agreed to take part:

- 208 from services trained in the CSNAT for Stroke approach.
- 206 from usual support services.



77% of carers who joined the OSCARSS study were female and were partners / spouses of the stroke survivor.



The average age of carers was 62 years old, although the study included carers from 21 to 88 years old.



On average, carers were seen by Stroke Association staff 2 months after the stroke. Although the study included carers who were seen by staff immediately and up to 12 years after the stroke.

### Stroke Association staff

Over 100 staff were involved in the OSCARSS study. They completed questionnaires and interviews about the service they provided to carers.

We also interviewed 11 managers and senior staff in the Stroke Association to understand their views on carer support.

## What we found

### **1. Does the CSNAT for Stroke approach reduce strain on carers and improve well-being, compared to usual ways of working?**

The short answer to this question is “No”. Carers receiving either the CSNAT for Stroke approach *or* usual support within the Stroke Association reported similar levels of strain and well-being.

### **2. Which approach to supporting carers is better value for money?**

To answer this question we compared costs and benefits. Benefits are similar but the CSNAT for Stroke approach costs slightly more.

Because of this, it is unlikely that the CSNAT for stroke approach is better value for money than usual support. However, costs are quite low overall and understanding costs can be tricky. For example, something might cost more in the short-term but save money in the long-term in ways that we haven't measured.

### **3. What are carers' experiences of receiving support?**

Carers sometimes found it hard to think about receiving support for themselves. They tended to focus more on support for the stroke survivor and didn't often think of themselves as "carers".

However, all carers in the OSCARSS study did receive *some* support from the Stroke Association and they were generally happy with that support, whether it was the CSNAT for Stroke approach *or* usual ways of working. Carers tended not to get much support from other organisations.

### **4. What are staff experiences of providing support?**

The Stroke Association believe that it is important to support carers and that an approach like the CSNAT for Stroke could be useful.

However, some important parts of the CSNAT for Stroke approach were not provided as planned.

Stroke Association staff often worked alone and felt that they would like more opportunity to learn from each other.

## What does this mean?

The OSCARSS study was successful: we collected high quality research evidence from a large number of carers and staff across Stroke Association services nationwide.

In research, it is easier to spot differences if we compare ‘something’ to ‘nothing’, but all carers received *some* support from the Stroke Association, which carers appreciated.

However, when we compared the two approaches to carer support, we found no differences. Why might that be?

**Most carers found it hard to think about themselves as “carers”, or think about their support needs shortly after the stroke.**

- We need to help people think of themselves as “carers” when they are supporting a loved one. This could encourage carers to consider their own needs and the types of support that might benefit them.

**Despite our best efforts, the CSNAT for Stroke approach was not carried out exactly as planned. This means that:**

- We don’t know whether the CSNAT for Stroke approach *could* be better than usual support.
- We have learnt how we could improve training and support for staff to deliver an approach like this in the future.

## What happens now?

The research has finished but we are committed to learn from the findings and share this learning widely. The people who receive this report helped to make the study possible and you are amongst the first to hear about the OSCARSS study findings. We still have a lot more work to do and we are:

- Working with the Stroke Association to help develop staff training and practical ways of supporting carers in the future;
- Collaborating with other researchers to explore ways to fund more research and support services for carers;
- 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



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You can find out more about the study and watch a short video about it by visiting this web page: <https://www.clahrc-gm.nihr.ac.uk/projects/oscarss>

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



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

Special thanks to the **Carer Research User Group**, who helped to make this book easier to read. The group consists of: Kelly Burke, Christine Halford, Natalie Halford, Geoff Heathcotte, Kath Purcell, and Ben Wright.

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The views expressed are those of the author(s) and not necessarily those of the NIHR, the Department of Health and Social Care, or the Stroke Association.