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Stroke  
association

# Caring and you

An evaluation of the 'Caring and You' pilot programme

Executive summary



## Introduction

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This is an executive summary of the report produced to evaluate the success of the 'Caring and You' pilot programme. It describes the background, aims and the way the education and support programme was delivered, together with its value and impact for carers of stroke survivors.

### Caring and You

'Caring and You' is designed for carers of stroke survivors. Delivered face-to-face, carers can access the expertise of the Stroke Association, gain new skills, confidence and a support network.

The sessions within the programme cover topics including:

- What is a stroke and how does stroke affect people?
- What support is available for carers and stroke survivors?
- Caring for a stroke survivor who has complex care needs
- Dealing with emergencies
- Carer health and wellbeing

### Why did we develop Caring and You?

#### The demand for informal carers has grown significantly

4 out of 10 stroke survivors require help with tasks such as washing, dressing and eating.<sup>1</sup> Nearly a fifth of these stroke survivors are cared for by informal carers such as a partner, relative or friend.<sup>2</sup>

#### We wanted to give carers the support and education they require

Carers often have no time to prepare and adjust to the role and receive little support and education. This can have a considerable impact, causing them to feel stressed, anxious, depressed and isolated. Often, these problems are made worse by the financial impact of stroke.

#### We wanted to invest in carer support

Carers provide indisputable value to the health system, their communities and loved ones. Without carers, it is widely recognised that our health and social care services would be overwhelmed and thrown into crisis.<sup>3</sup> Yet, there has been little investment in carer support.

#### What were the aims of the Caring and You programme?

- Increase carers' knowledge of and its effects
- Increase carers' knowledge of services and entitlement
- Improve communication with healthcare professionals
- Help carers to feel more prepared and confident in the caring role
- Reduce levels of care-related stress or anxiety
- Improve carers' self-care
- Create a safe space to share and learn
- Help carers to feel less isolated.

#### Piloting Caring and You

The pilot programme was delivered between September and November 2016 in Pembrokeshire, Manchester and Kent and involved twenty-one carers. All carers were involved in sharing feedback.

The aim of running the pilots was to find out:

- How helpful carers found the programme
- Which parts of the course worked well and which were less successful
- Whether or not the programme made a difference in the lives of carers.

# What did carers say about Caring and You?

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Our 'top 10' key findings and learning points are outlined here.

## Programme relevance and quality – addressing carer needs

- 1 The carers taking part were often looking after stroke survivors with complex disabilities and support needs. Most were not used to addressing their own needs and did not always find this easy. Despite this, **attendance and engagement levels were very high**. Participants enjoyed the pilot and had a clear interest in the programme.
- 2 Carer feedback on the programme was really positive, rating it as useful, well-delivered and enjoyable. We achieved an important aim in creating a safe space where people could share and learn and feel comfortable even when topics were emotional or difficult

## Programme outcomes – supporting change and improvement for carers

- 3 Carers reported **increased knowledge of stroke and understanding about the support they can access** for themselves and their loved one, and an **increased confidence about getting the support they need** - feeling more able to ask for help and express their needs assertively.
- 4 Carers reported improved understanding of stroke, and of the hidden effects of stroke on their loved one. They felt empowered, more confident and better equipped to care whether they were new to caring or had been a carer for some time. For some, greater empathy led to an improved relationship.
- 5 Carers reported feeling **more positive** about caring, in part as a result of what they had learnt but also as a result of **feeling supported, reassured and encouraged** by the, the facilitators and their peers.
- 6 By the end of the programme the majority of carers had made a new commitment **to making time for and looking after themselves better**.
- 7 An important positive benefit of the programme is its potential to reduce isolation and loneliness in carers – which in itself can be a contributor to emotional ill health. At the end of the pilot a majority of the participants reported feeling less isolated and all bar one said they had made friendships they believed would be a lasting source of mutual support beyond the programme.

## Programme impact – making long-term changes

- 8 We followed up with 15 carers after the pilots ended. They told us they were **feeling more confident, and more open to and assertive about asking for help** as a result of the programme. They were using some of what they had learnt as needed to help them in their caring role.
- 9 Caring and You has the potential to improve social and emotional wellbeing in the longer-term as carers go on to maintain friendships and join support groups. It can help improve the relationship between carer and cared-for over time. Signs are promising and need to be measured over time.

## 3 key factors that enabled us to meet the aims of the programme

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  1. The relevance and engaging nature of the content.
  2. The delivery of the course by knowledgeable and empathetic coordinators.
  3. The safe space enabled for peer discussion and sharing.

## Conclusion: What next for Caring and You?

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The evidence collected and feedback from participating carers shows that we **have met the aims of the pilot and the programme is making the kinds of differences to carers that we hoped it would**. Although the sample size was small, the signs are already promising that some of the positive changes seen during and at the end of the programme may be significant and sustained longer-term.

The strongest theme to emerge from the feedback was the carers' concern around not wanting others to go through what they had. They wanted to see all carers' lives made easier through having access to the programme and the lived experience of their peers.

Several carers who had originally felt they did not need the programme were amongst the strongest advocates that the programme had value for all and that the Stroke Association should make this programme available nationwide.



*"I want things to be better for others not just for us (...) it shouldn't be a battle like this (to be a carer), to get the things you need."*

*"I didn't think I needed this ... I thought why should I go and pour out my heart. But, you need to tell people that they do need it and it makes you feel tonnes better. It really was a good thing."*

*"I understand it has been a trial, but I really hope the (Stroke) Association will run it throughout the country almost as an automatic thing for us."*

Quotes from programme attendees

1 Royal College of Physicians Sentinel Stroke National Audit Programme (SSNAP), "National clinical audit annual results portfolio March 2015-April 2016" [Online]. Available: <http://bit.ly/1M5R3Op> [2016, October].

2 SSNAP, "National clinical audit annual results portfolio March 2015-April 2016"

3 Carers UK (2015). 'Facts about carers, Policy Briefing October 2015' [Online]. Available at: [https://www.carersuk.org/images/Facts\\_about\\_Carers\\_2015.pdf](https://www.carersuk.org/images/Facts_about_Carers_2015.pdf) [Accessed 5 Dec. 2016].

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**Want to know more?**

Email: [services@stroke.org.uk](mailto:services@stroke.org.uk)

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# Together we can conquer stroke

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