Carers highlight notice

Background
For this funding highlight notice, our definition of a carer is ‘anyone, including children and adults who looks after a family member, partner or friend who needs help because of their illness, frailty, disability, a mental health problem or an addiction and cannot cope without their support. The care they give is unpaid’¹. More than 6 in 10 stroke survivors rely on the help and support of a carer, with the numbers of people providing informal care and the associated costs expected to increase dramatically – the number of stroke survivors in the UK is expected to more than double in the next 20 years, with informal care costs rising by 171% over this period²,³.

Carers play a vital role in the rehabilitation and long-term support of stroke survivors. Carers deal with a range of day-to-day care needs including mobility, self-care, and communication difficulties as well as learning to cope with the mood and personality changes that can occur in their loved one post stroke. They can also provide the connection to service provision: monitoring stroke symptoms and general health; managing medications; organising and co-ordinating care with providers⁴.

Being a carer can be very demanding, which can have a negative effect on the caregiver’s psychological well-being and physical health. In a recent Stroke Association survey 87% of carers felt at least one negative emotion, such as stress or exhaustion³. The negative emotions that carers experience increase over time, with carers who have been caring for longer than three years more likely to feel exhausted or anxious than those who have been caring for less than three years²,³.

The Care Act 2014 placed an obligation on local authorities to carry out carers’ assessments and needs assessments. It also set out how local authorities should determine who is eligible for support and how local authorities should charge for care⁵. In August 2019 NICE published new draft guidance which aims to improve the wellbeing of adults who provide unpaid care. The recommendations emphasise how local authorities and health and social care practitioners can support carers⁶.

Current intervention evidence
One systematic review of non-pharmacological interventions for caregivers of stroke survivors has been conducted, which found there was a lack of robust evidence for any intervention. There were several limitations to the studies, including, a lack of a precise definition of an informal caregiver, lack of appropriately defined control group, the design, conduct and size of the studies⁴. ‘Information and support’ and
'psycho-educational' interventions, had insufficient data to support or refute their use, whilst 'Teaching procedural knowledge' type interventions appeared to the most promising. However, the evidence for this was from a single-centre randomised trial.

Since the Cochrane review the TRACS trial, a large study investigating a training programme for caregivers, found no significant benefit from the intervention\(^7\). This may be because the intervention should be integrated into community care, rather than the immediate post-stroke period, that was tested in this study. Task shifting, whereby family members are trained in hospital to deliver rehabilitation at home, with the aim of improving recovery, was tested in a large RCT based in India. However, this approach did not improve outcomes, which may have been due to insufficient training, effectiveness of training and family dynamics\(^8\).

A 2017 updated meta-review of evidence on support for carers, which looked across diseases found there was not a 'one size fits all' model for carers\(^9\). Overall, the best evidence for interventions was in the carers of people with dementia and cancer. For example, the STrAtegies for RelaTives (START) programme reduced depression and anxiety for family carers of people with dementia, with the effect lasting long term\(^10,11\). Psychosocial interventions on family functioning of carers for people with stroke showed promise, and were highlighted as needing more research\(^7\).

The ongoing Biopsychosocial Intervention for Stroke Carers (BISC) study is testing whether a biopsychosocial intervention can be delivered in a group setting in a randomised controlled trial\(^12\). The recent Organising Support for Carers of Stroke Survivors (OSCARSS) study aimed to investigate the clinical and cost-effectiveness of a carer-led approach to individualised assessment and support that had been adapted for stroke\(^13\). This study has completed and reported results at the European Stroke Organisation Conference in May 2019, with further analysis to be presented at UK Stroke Forum in December 2019. One of the challenges highlighted by this study was that most people do not recognise themselves as ‘carers’; therefore, we need to be careful about the recruitment strategies and language used to bring ‘carers’ into this type of research.

**Research topics**

The areas below highlight some of the topics that are important to carers. These are not exhaustive, but indicate some of the areas, where health and social care challenges remain for stroke caregivers. You are not required to address one or more of these topics in this call, they are suggested research areas.
Identifying as a carer, recognition of role and navigating information

Family members and those in close relationships with someone who has recently had a stroke, are focusing their thoughts on the stroke survivor. They often do not identify themselves as a carer, and are sometimes resistant to this term. This can be a barrier in people recognising their needs, which means they don’t access the support that might help them. It can also cause a barrier for clinical studies, as eligible people might not seem themselves as carers, having an effect on recruitment. Researchers should to carefully consider their language and recruitment strategies for this type of research.

The healthcare system is a complex and foreign environment that caregivers find hard to navigate and do not know what is available to them. The Stroke Association’s report on the lived experience of carers found that 85% of carers don’t get the support and information they need to help them in their caring role\(^3\). Carers want to be kept informed and can feel disempowered through lack of information\(^14\). When and how people receive information will vary, and people need a range of information along their journey\(^15\). Carers need clear information, signposting and engagement from the health and social care system that is tailored to their needs.

Help for carers in their caregiving role

Carers say that they need support in the transition home from hospital, particularly as they play a pivotal role at this time. Carers say they are unprepared for discharge, and want more control and information relating to the process following discharge. Not all needs are anticipated prior to discharge, so carers need to know the appropriate resources to initiate services\(^14,15\).

There is a lack of training to prepare caregivers, which is appropriate for the home environment and they often require more practise and training\(^14\). Healthcare professionals focus on the stroke survivor during rehabilitation, while carers are not routinely involved. It is important to carers that they are a stakeholder in the recovery of the stroke survivor, and they’re often frustrated when not involved in therapy\(^12\). Carers want to understand the likely trajectories for recovery and the rationale for the therapy, and would like to have feedback on progress of the rehabilitation\(^14\).

Support for carers to look after themselves

Becoming a carer is a life-changing event which can affect them in many ways, including their autonomy, mental and physical health and wellbeing. Carers dedicate a large proportion of their time to caring, so they have little free time. It can be difficult for carers in separating and managing their own needs from their role as a
A carer, which can result in poor management of their own health. The transition home for carers includes an adjustment to their perception of the future, possible changes in their relationship with the stroke survivor and the new responsibilities associated with being a carer.

Emotional distress is common for carers, who are adjusting to their new life, coping with uncertainty, feeling shocked and experiencing grief and loss. People who have been caring for stroke survivors over longer periods of time are more likely to feel stressed or anxious\(^2\),\(^14\),\(^15\). There is a need to have effective emotional, psychosocial and practical interventions to support carers\(^2\),\(^14\),\(^15\).

When someone becomes a carer for another who has had a stroke, this can impact on their relationships. This is particularly felt by spouses, and can also lead to feelings of abandonment. It is important for carers to connect with other carers for emotional and practical support. However, there can be barriers to peer support for carers, such as limited time, uncertainty around care for the stroke survivor and age-appropriate support. Carers need to be enabled to take time out to address their own needs. More research is needed into peer support delivery of respite care for carers\(^9\).

**Scope**

With the lack of evidence for stroke carer interventions, we would particularly welcome research focused on intervention development or testing. New intervention development should be underpinned by theoretical models and follow appropriate frameworks, such as those that have been developed for complex interventions or implementation research. We would expect researchers to learn from limitations identified in previous studies\(^9\). All outcome measures proposed should have a clear rationale and be evidence based. Any interventions, and how they are delivered should be clearly defined, as well as any control groups proposed. These aspects have been lacking from previous carers research studies\(^8\). We expect all research teams to involve carers in developing their application and continue to do so should the application receive funding.

There is some evidence of benefit of interventions for carers of other conditions, such as dementia and cancer. Therefore, there may be potential to learn from or adapt existing evidence. There may also be potential to learn from carer journeys from other conditions and the similarities or differences from stroke. We welcome research that builds on existing research from other conditions, however there must be a clear focus on the carers of people living with stroke for this call.

Carers often have different needs at different points in their caring journey so it is unlikely that there will be a ‘one size fits all’. Therefore, there is a need to develop
more personalised approaches, whereby various support options are on offer. We would encourage research that includes carers from hardly reached groups, such as ethnic minority communities and young carers under the age of 25. These are groups that lack research, and for which interventions may need be different compared to general populations that are involved in most studies. We recognise that obtaining statistically viable numbers for these groups will be a challenge, but stress that scientific rigour should not be undermined. We want to highlight their importance, and will commend any successful efforts to do this without affecting study rigour.

1 https://www.england.nhs.uk/commissioning/comm-carers/carers/ [last accessed 28 October 2019]
3 https://www.stroke.org.uk/sites/default/files/jn_1819.144b_current_future_avoidable_costs_of_stroke_0.pdf [last accessed 28 October 2019]
9 Thomas, S et.al. (2017) Updated meta-review of evidence on support for carers. Health Services and Delivery Research. ISSN 2050-4357
10 Livingston G et al. (2014) START (STrAtegies for RelaTives) study: a pragmatic randomised controlled trial to determine the clinical effectiveness and cost-effectiveness of a manual-based coping strategy programme in promoting the mental health of carers of people with dementia. Health Technol Assess;18(61)
13 Patchwood, E. et al. (2019) Organising Support for Carers of Stroke Survivors (OSCARSS): study protocol for a cluster randomised controlled trial, including health economic analysis. Trials 20, 19
15 Denham AM) et al. (2019) ”This is our life now. Our new normal”: A qualitative study of the unmet needs of carers of stroke survivors. PLoS ONE. 14(5): e0216682