

To meaningfully support carers, we must rethink their purpose and contribution



What does supporting carers mean in practice, and how can the government fulfil this mandate? Building on recent research commissioned by NHS England, [Melanie Henwood](#), [Mary Larkin](#), and [Alisoun Milne](#) explain that the narrative around carer support needs to be reframed.

Much of the prevailing discourse around 'supporting carers' is presented in terms of enabling people to keep caring and prevent 'additional demands' being placed on health and social care services. But for carers and those they support this may not be the most helpful approach. Indeed, the narrative may need to be reframed to address what people really want from services and what 'support' means to them. [Recent work](#) commissioned by NHS England as part of their 'Commitment to Carers' programme, sheds light on support for older carers, and carers of people with dementia. The findings from this work have implications for carer support more widely, and for challenging the models labelled as such.

Supporting carers – the story so far

A commitment to supporting carers has rightly been part of the care and health policy context for some time. However, this is often addressed at a level of considerable abstraction. Operationalising support to carers and defining how this might translate into strategies or interventions is more complex; it also requires resources. If supporting carers is to be effective, we need to apply some critical scrutiny to the debate.

The importance of supporting carers has been recognised explicitly in policy since the first National Carers Strategy was introduced in 1999 (and in legislation since the Carers Recognition and Services Act of 1995). The 2014 Care Act was intended to create parity of esteem between carers and those they support, strengthening carers' rights to an assessment and introducing a new duty on local authorities to meet carers' eligible needs. The duties of the NHS are less explicit, but both the [NHS Five Year Forward View](#) and the [Next Steps](#) iteration underlined the importance of a new relationship with patients and communities. Thus, the Forward View referred to the need "to find new ways to support carers", particularly the most vulnerable, while the Next Steps document highlighted the need to identify and support carers, particularly to reduce carer breakdown and improve health-related quality of life for carers.

These are objectives that attract broad support, but moving from aspiration to delivery is a different matter. Finding new ways of supporting carers is not just about innovation for its own sake, but rather about looking at the way the caring relationship is understood and developing a model that addresses both carers and those they support.

The evidence base is relatively thin; [two meta-reviews](#) in [recent years](#) have concluded that the best evidence is around interventions that enhance carers' knowledge and skills. Most models of support have not been evaluated, but the findings on 'what makes a difference' to carers points to the value of having contacts with people outside their usual networks. [Others have found](#) that the recurrent feature of a variety of interventions judged to be of value by carers is how they contribute to strengthening carer resilience (including extending social assets; maintaining physical health; quality of life; availability of external resources, and strengthening psychological resources).

What actually matters to carers

When looking at models of support valued by carers we found that what matters most is often not the *nature* of an intervention or support, but the style of that service and the *way* in which it is delivered. In other words the *process* of service delivery. Getting appropriate and timely information were recurrent themes, and for some carers there were easier pathways than for others. When caring develops slowly and over a period of time, the information response is often less developed than for someone who is thrust into caring following a crisis event (such as a stroke, for example). Lack of information can also be due to the response of healthcare professionals following a diagnosis of dementia and an underlying belief that 'nothing can be done'. Supporting people to have a life beyond diagnosis, particularly for those with younger onset who might have many years ahead of them of living with the condition, is critical.

Many older carers are caring for people with dementia, but not all carers of people with dementia are elderly. The NHS England project uncovered the substantial impact on entire families associated with early onset dementia, particularly where there may still be dependent children in the household, or additional caring responsibilities such as for an elderly parent, and where the person diagnosed and their carer are still of working age with all the accompanying financial commitments.

Ensuring that local support services are appropriate requires commissioners to challenge many assumptions about 'carer support'. Establishing carer support groups, for example, may not be what carers actually want if it means they have to make alternative arrangements for the care of a person while they are at the group. The research found enthusiasm for groups that were open to both carers and those they support, but with opportunities for the group to split for some or all of the session, giving people the chance for social contact and peer support.

What constitutes 'respite' is also an area that requires some critical rethinking. If respite is essentially about a break from the usual routine for both carers and those they care for, there is enormous scope for developing imaginative and meaningful activity and engagement, but this is rarely in evidence. Some of the more innovative approaches we identified had developed around age-appropriate models of support for younger people with dementia who would not generally be interested in accessing standard day-care opportunities. The activity and social interaction which participation facilitated would be likely to be valued by many other carers desperate for a change of place and company.

A challenge for all providers, but particularly those in the third sector, concerns the impact that austerity has had on public services and on funding for commissioned services. Many of those we interviewed highlighted the difficulties of not knowing if people would have a contract in the next financial year or if the service would continue. With the NHS typically commissioning services on an annual basis, the lack of security for staff is a recurrent problem. Commissioning over a longer timeframe is required if people are to have some security of funding and the space and scope to expand and develop their model.

Needing to demonstrate outcomes and value is problematic both for commissioners and providers. While it is relatively rare for services to articulate a clear theory of change and to follow this through with demonstrable outcomes, the level of monitoring and reporting required by commissioners is often a hindrance. Counting activity rarely reveals much about the nature of a service or its outcomes, and both commissioners and providers need to develop more sophisticated and relevant measures of evidencing effectiveness in both quantitative and qualitative dimensions.

As we await the green paper on social care, and its promised attention to carers as an integral part of future plans, the messages from this research are highly relevant. The value of supporting carers is *not* just about ensuring the NHS can function properly and avoid delayed discharges because carers are unable to pick up the pieces. A proper strategy for carers needs to address carer resilience for the benefits this will bring to carers' quality of life and wellbeing, and to those they support. It is not just the language of 'carer support' that needs to be reframed, but the understanding of the purpose and contribution of support to dynamic and fragile caring relationships.

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