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# Older Carers and Carers of People with Dementia: Improving and Developing Effective Support

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*The policy drive to support carers is a longstanding national and international priority. Research about the design and delivery of support for carers is critical to the underpinning evidence base. Through a timely exploration of a third sector perspective, the UK-based study discussed in this article provides insights into approaches to, and the commissioning of, support for older carers and carers of people with dementia. The study highlights the importance of: embedding carers' perspectives in service developments; the provision of both generic and targeted support which adopts a nuanced and tailored approach; titrating the delivery of information and advice at a pace to match carers' needs; capturing quantitative and qualitative dimensions in service evaluation; and increased quantity and longevity of funding. Such insights not only complement existing research but are also generalisable to other countries at a similar stage in the development of carer support.*

**Keywords:** Carer support, older carers, carers of people with dementia, third sector, commissioning.

## Introduction

Understanding the needs of carers and providing appropriate support have been long standing policy goals locally, nationally and internationally (Larkin and Milne, 2014; Pickard *et al.*, 2015; Galiatsatos *et al.*, 2017). This article presents the findings of a study the Open University was commissioned to undertake in 2017-8 by the National Health Service England's *Commitment to Carers* programme. Its aim was to capture third sector (namely non-governmental and non-profit organisations) perspectives about exemplar models of support for two intersecting groups of carers – older carers and carers of people with dementia – and how such models can be developed and sustained by commissioning agencies. The study was informed by a recent comprehensive scoping review of carer-related research and knowledge (Henwood *et al.*, 2017; Larkin *et al.*, 2018).

The article begins with a profile of older carers and carers of people with dementia before turning to policy background, the design of the study itself and the key findings. The ensuing discussions contribute to the generation of new knowledge by offering a unique distillation of the views of leading UK third sector organisations on both approaches to,

and dimensions of, support for older carers and carers of people with dementia that ‘work,’ 39  
and what would render them deliverable and scalable. 40

### **Older carers and carers of people with dementia** 41

Older carers merit attention for a number of reasons. At present over two million of the 42  
UK’s seven million carers are aged sixty-five-plus and of these, more than 400,000 are 43  
aged over eighty. Whilst the overall number of older carers is rising, the greatest increase is 44  
in those aged eighty-five years and over (Health and Social Care Information Centre, 45  
2015; Age UK, 2018; Carers Trust, 2019). Caring in later life typically takes place in the 46  
context of a long-term dyadic relationship, such as with a spouse or partner. As a 47  
consequence of the embedded nature of their caring role, and their co-residency, older 48  
carers tend not to self-identify as a carer (Corden and Hirst, 2011). Older carers often 49  
undertake intensive caring which includes personal care, quasi-medical care (e.g. 50  
administering medication), and help with mobility issues (Rinaldi *et al.*, 2005). Reciprocity 51  
and mutuality are common dimensions of older care dyads, especially in respect of 52  
spousal care (Pickard *et al.*, 2000; Perkins and Haley, 2013; Hydén and Nilsson, 2015). 53  
The fact that older carers are often managing their own health and disability issues 54  
alongside caring is also relevant (McGarry and Arthur, 2001; Carers Trust, 2016). 55

Not all older carers are caring for a spouse or partner. Approximately a quarter have 56  
been caring for a disabled adult son or daughter for most of their adult lives; most of the 57  
cared for population are adults with learning disabilities (Carers Trust, 2015). In addition to 58  
the strain of caring for so long they have concerns about the future if they pre-decease their 59  
adult child or when they are no longer able to care (Bowey and McLaughlin, 2007; Perkins 60  
and Haley, 2013). Another group of older carers that is increasing in size comprises 61  
people in their sixties supporting a very elderly parent. This group of mainly women carers 62  
is often referred to as the ‘sandwich generation’ balancing caring alongside paid 63  
employment and providing support for adult children and sometimes grandchildren too 64  
(Grundy and Henretta, 2006; Do *et al.*, 2014; Carers UK, 2015). 65

Although dementia is a common feature of later life caring, this is not always the case; 66  
it is estimated that more than five per cent of those with dementia are aged below sixty-five 67  
years and experience what is referred to as ‘young-onset dementia’. As might be expected, 68  
carers of those with ‘young-onset dementia’ tend to be younger. Many of them are 69  
spousal/partner carers, but they can also include parents, young adults, siblings or friends 70  
(Richardson *et al.*, 2016; Alzheimer’s Society, 2019). 71

There are positive aspects to being a dementia carer, such as feeling useful or 72  
experiencing pride in one’s own abilities to cope. However, whatever their age, carers 73  
of people with dementia have to cope with specific physical and emotional demands e.g. 74  
dementia-related behavioural and personality changes (Bremer *et al.*, 2015). Given that 75  
residential and nursing home care is increasingly reserved for those with very high levels of 76  
needs, there are growing numbers of carers providing intensive support to a relative with 77  
moderate to severe dementia (Newbrunner *et al.*, 2013; Jones *et al.*, 2019). Other 78  
challenges faced by carers of people with dementia include isolation caused primarily 79  
by friends withdrawing and reduced opportunities to socialise (Charlesworth *et al.*, 2008). 80  
The widely noted negative role played by stigma is implicated in these losses (Milne, 2010). 81

Whilst the challenges for those caring for someone with ‘young-onset dementia’ are 82  
similar to those faced by older dementia carers, there are important differences. This is 83

mainly because younger people with dementia are likely to be in paid employment, have dependent children, have older parents who may need support and have ongoing financial commitments (Rosness *et al.*, 2011; Alzheimer’s Society, 2019). There is evidence that carers of people with young onset dementia experience increased emotional distress and stress because of concerns about loss of employment, income and future relationships, and worries about the lives and wellbeing of younger and older family members (Rosness *et al.*, 2011; Lockeridge and Simpson, 2013; Richardson *et al.*, 2016).

**Policy background**

In the UK the policy goal to support family carers was first made explicit in the 1999 National Carers Strategy and has remained a foundation stone of subsequent carer-related policy (Larkin *et al.*, 2018). A landmark piece of legislation was the 2014 Care Act (HM Government, 2014) which, for the first time, entitled all carers to an assessment of need and, where carers meet eligibility criteria, to have those needs met by their local authority. It also introduced the principle of ‘parity of esteem’ between carers and service users. In 2018 the cross-government Carers Action Plan 2018-2020 was published. This reinforced the policy commitment to supporting carers and included ‘effective identification’ of older carers and carers of people with dementia as specific aims (Department of Health and Social Care, 2018).

Two key strategies addressing the interface between the NHS and carers were the NHS Five Year Forward View (NHS England, 2014a), and the subsequent Next Steps Refresh (NHS England, 2017). The Five-Year Forward View placed particular emphasis on finding new ways to identify and support carers, especially the ‘most vulnerable groups’ such as carers aged over eighty-five years. Specific reference was made to helping health and social care organisations signpost carers to advice and support to improve their health-related quality of life and reduce the risk of ill health and/or carer breakdown.

The Department of Health and Social Care’s annual mandates for NHS England set out the Government’s objectives for the NHS. The 2014 mandate stated that the NHS must ‘become dramatically better at involving patients and their carers and empowering them to manage and make decisions about their own care and treatment’ (Department of Health, 2014: 11). In responding to the 2014 mandate, NHS England developed a dedicated *Commitment to Carers* programme (NHS England, 2014b). The study discussed in this article was commissioned as a part of this programme of work.

**Design and Methods**

Taking account of knowledge gaps identified in the aforementioned scoping review, the study aimed to capture perspectives of the third sector in relationship to the range types and effectiveness of support for older carers and carers of people with dementia. The focus was not on carers per se but on frontline carer support services. It is noteworthy that many of the staff in carers services are current or former carers. The study was carried out in three iterative stages between May 2017 and March 2018. Ethical principles were adhered to throughout.

The first stage of the study comprised an invitation to national offices of nineteen leading third sector organisations to undertake an on-line survey. The nine organisations

that completed the survey (47 per cent of those invited) represented a mix of agencies with a specific focus on carers and carers of people with dementia, and those that provide support to people with a particular health condition and their families: Age UK, Carers Federation, Carers First, Carers Trust, Carers UK, Dementia UK, Parkinson’s UK, Royal Mencap Society and The Stroke Association. Two of the organisations invited to complete the survey responded to say that, although they found it of interest, they did not think it was directly relevant to them. The potential total of responding organisations was therefore seventeen, and the response rate of 53 per cent is considerably higher than is often achieved by similar surveys.

Six of the organisations also took part in a follow-up semi-structured interview. This enabled in-depth exploration of emergent issues captured by the survey, particularly around support and innovation. In order to enhance the breadth and depth of the data, stakeholders from additional third sector agencies were interviewed; these were identified from the research team’s networks and by snowballing information from survey participants. Interviewees included people closely involved with local initiatives, as well as carers using those services. A total of thirteen interviews were undertaken (mainly) via telephone to ensure the fieldwork was completed in a timely and cost-effective way. All interviews were digitally recorded (with the consent of participants), transcribed and thematically analysed using QSR-NVivo 11 software.

In February 2018, the research team held a consultative workshop<sup>1</sup> to explore the emerging findings, preliminary conclusions and recommendations for commissioners and service providers with NHS England and other key stakeholders. There were fifteen participants, including: two carers (both existing members of other panels such as Research Advisory Panels); two Local Authority Carers Leads; four Local Authority and NHS Commissioners; two members (including the lead) of the NHS England ‘Experience of Care’ team; five representatives from carers organisations, and condition-specific (e.g. dementia) organisations. Following the workshop the report and its recommendations were revised before submission to NHS England (Henwood *et al.*, 2018).

### **Supporting older carers and carers of people with dementia: third sector perspectives**

The analysis integrated the survey and interview findings. Topics were coded through content and frequency analysis (Lavrakas, 2008; Bowling, 2014; Bengston, 2016). The multiple themes and issues emerged were combined into three overarching themes: the needs of older carers and carers of people with dementia; models of support; and the development and commissioning of carers support. Findings relating to these three themes are discussed below. Verbatim comments from the range of those surveyed and interviewed are used for illustrative purposes. Findings relating to the third theme also include reflections and discussion from the consultation workshop. The nature of ‘exemplar’ models of support and the implications of developing, commissioning and providing these are explored in the discussion.

#### *The needs of older carers and carers of people with dementia*

A number of key issues emerged of key relevance to older carers. The need to reduce their isolation and loneliness was widely recognised, as was the fact that this was made

more difficult by older carers often failing to self-identify and/or resist having contact with services:	170 171
we kind of need to change the word, a bit more about 'do you look after somebody?' or 'do you help somebody?', you know, because the word 'carer'- people say 'I'm not their carer, I'm their wife!' it's what I do, I do it; they're my family.	172 173 174
<i>and</i>	175
you don't come across them until . . . . .somebody's been admitted to hospital or there's been a complete breakdown of the situation . . . . And so they're very vulnerable, very isolated.	176 177
Older carers' isolation can be amplified by a range of factors, such as no longer being able to drive. This was identified not only as a practical problem e.g. getting to hospital appointments or to the shops, but also because of its impact on their ability to take trips out or visit friends and family that improved both their own, and their relative's quality of life. For instance, one respondent recalled a carer telling him that being able to use his car meant that he could 'drive my wife [down to the coast] where we can just sit and look out at the sea . . . at least we feel we're out.'	178 179 180 181 182 183 184
In addition to the hidden nature of many older carers' lives, they are often simultaneously caring and managing their own deteriorating health. As one interviewee remarked 'it's two people limping along'. A change in health status for one partner can disrupt the care balance whereby 'mutual support becomes active caring'.	185 186 187 188
Participants highlighted the shared <i>and</i> different needs of older carers and carers of people with dementia. Both groups can face challenges when the underlying relationship is not strong:	189 190 191
Some people may be in a very difficult situation where they might not have had a positive relationship, then they find themselves caring (. . .) twenty-four hours a day, seven days a week.	192 193
In terms of differences, carers of people with dementia were widely seen to have 'unique needs . . . . because it's a very different caring experience than with an older person whose cognition is intact.' Caring for someone with a changed personality is especially stressful:	194 195 196 197
They say 'I know what to do when I have to give them their dinner, or put a bandage on, or take them to the toilet. That's practical – it's hard and it's tiring but you can just get on with it. But I don't know how to manage the personality, the changing behaviours, the repeated information, the repetitive questions.'	198 199 200 201
Long term dementia carers face the additional strain of living with the knowledge that the needs of the person for whom they care will increase over time:	202 203
when you've got somebody who's caring for somebody with a degree of dementia, they . . . know that that level of dementia is likely to progress, and I think that is very scary (for them).'	204 205

There was concern about the challenges specific to carers of people with young-onset dementia. These were mainly a consequence of the fact that those affected by this condition are:	206 207 208
... still in work; they've got a mortgage; they've got youngish children or children at university. They had a future ahead of them, a retirement future, that will never be realised ... and I think that loss and that grief reaction from not only the person with dementia but their carer, can be huge.	209 210 211 212
In addition, the rarity of younger onset dementia often results in delays in diagnosis or misdiagnoses:	213 214
Very often when a person goes to the GP, or a family goes to the GP about somebody they are worried about, they will choose a different diagnosis – they will give the <u>wrong</u> diagnosis. They'll say its depression, relationship problems, it's stress at work – so they'll give lots of other labels for what is presenting.	215 216 217 218
<i>Models of support</i>	219
Generic and inclusive models of support predominated, as opposed to services specifically for older carers and/or carers of people with dementia:	220 221
... all of our services and support are open to everyone ... including older carers and carers of people with dementia.	222 223
<i>and</i>	224
... all our support is open to all.	225
Amongst the more targeted services were those aimed at groups of carers with shared needs. As carers of people who develop vascular dementia following a stroke are likely to have similar needs to other carers of people with dementia, some of the organisations had developed joint initiatives particularly around information sharing and signposting.	226 227 228 229
Some of the condition-specific organisations were extending their services to incorporate carers <i>and</i> the person with the condition. This reframing was evident in a change to the language used in agency literature or on websites; for example, support is offered to 'people affected by' the condition rather than 'with' the condition. One such organisation had appointed a Strategic Carers Lead to take forward its work on supporting families and carers ensuring that they were integral to its 'expanded' service offer.	230 231 232 233 234 235
Common dimensions of models of 'support' were: the provision of information; peer support services; respite care; and wellbeing support. In terms of the provision of information, organisations recognised the importance of this being both 'appropriate and timely'. Participants acknowledged the challenges of getting relevant information to carers early enough and in a manner that facilitated good decision making and of 'matching information' to the changing needs of both the cared for person and the carer. In situations where the cared-for person's condition deteriorates and the caring role intensifies over time – as is the case for dementia – it was pointed out that information needs to be titrated and appropriately nuanced. For example, ensuring that the symptoms associated with	236 237 238 239 240 241 242 243 244

later stage dementia are communicated in a sensitive way to carers supporting a relative in the early stages of the condition. This needs profile is very different from that of a carer facing a sudden onset of caring responsibilities, such as following a stroke. Associated with this role is signposting carers to other services and/or sources of help and advice. As one participant said this requires:	245 246 247 248 249
understanding and developing our knowledge of what other organisations do and where we can make use of their resources and signpost people to them, rather than trying to recreate everything.	250 251 252
Locally based community services built around peer support and social opportunities were rated highly, particularly in the dementia field:	253 254
What I would say works effectively are your social situations . . . for instance, we have a group where it's people that are living with young onset dementia, but their families as well – usually a spouse or partner – will come along and once a month we'll go out for a meal (. . .) go to different venues; we have a meal, we have a chat and we have a laugh.	255 256 257 258
This interviewee went on to comment on the importance of not 'labelling' groups:	259
. . . like not calling something a 'dementia group' or whatever; that's unfortunately what tends to happen, or 'dementia café'. People don't want to live by labels; I wouldn't want to live by a label.	260 261 262
Volunteers often play a key role in providing peer support. Many are current or former carers. In addition to being a service in its own right, peer support was sometimes embedded into other services such as telephone befriending. This service matches a caller with a volunteer befriender who shares a similar experience of caring. The befriender then builds up a supportive relationship with the carer over time.	263 264 265 266 267
Respite care is a common, and popular, type of support. It can take a number of forms, including day care or a regular break in a care home. Although support for carers of younger people living with dementia is an underdeveloped area, this study identified an innovative model offering day respite for both younger people living with dementia and their carers (e.g. see <a href="http://www.ypwd.info">www.ypwd.info</a> ). In this service a range of activities are available including running, cycling, rock climbing and canoeing; people with dementia and their carers could either take part in these together or separately. The drive to develop this model was a recognition that:	268 269 270 271 272 273 274 275
Most fifty-year-olds really would not access 'day care' where the average age of people was over eighty. Nor would their carers – their spouses, partners, would say well no, that's not appropriate.	276 277 278
Similarly, focusing on what people <i>can</i> do, rather than what they <i>cannot do</i> and engaging people in what interests them was seen as a pivotal dimension of developing services that challenge existing models. A number of interviewees described 'traditional day care' as (often) little more than a 'holding centre . . . for the people living with dementia'.	279 280 281 282



A home-based respite model for people living with dementia was also highlighted. This model involved recruiting volunteers to open up their home to three or four people with dementia twice a month for three hours to offer their carers a break. With the support of a care worker, activities and lunch would be provided with a view to encouraging those attending to ‘mix with each other and make new friends and connections within their community.’	283 284 285 286 287 288
Many services focused on protecting carers’ wellbeing and resilience: some offered them training and education, others gave them the opportunity to have some ‘me time’ such as being able to engage in social contact, maintain existing interests or establish new ones (e.g. online forums and choirs). Supporting the care relationship was also widely considered to be vital to protecting the carer’s wellbeing and resilience. This was mainly facilitated by the provision of services which focus on bringing carers and those for whom they care together. As one interviewee said, ‘we’ve found that . . . , when the carer and cared for come together, their relationship kind of rekindles or improves’. These services provide structured opportunities for carers and those they care for to engage in discussions and express their views, whilst simultaneously helping carers to relax and participate in group activities as people rather than as ‘carers’ or ‘cared for.’:	289 290 291 292 293 294 295 296 297 298 299
When they’re in the group, you can see some of that at the beginning and then they kind of relax because they know that there is no judgement. . . . . in the memory project we don’t distinguish at all between who’s who. Everybody does the same thing.	300 301 302
Carers were sometimes involved directly in decisions about the (re)design and (re) development of services. Responsiveness to carers’ views is perhaps best evidenced by a move away from standalone ‘carers groups’ to:	303 304 305
support that enables carers to go along with the person they care for, because . . . separate carers groups . . . create a barrier in terms of accessing support because there might be (shared) issues around the cost of care, around transport.	306 307 308
Several distinctive elements of support for dementia carers also emerged from the findings. Helping carers to understand the nature of dementia as a condition both in the present and the future, including (probable) behavioural and psychological changes, was very important. Carers of those with young onset dementia were used in illustration; many people with young onset dementia ‘get the diagnosis and that’s the end’. Support for carers in this situation needs to focus on advice at an early stage around managing the condition over the short and longer term, maintaining a ‘life beyond diagnosis’ and accessing specialist dementia services in a timely manner.	309 310 311 312 313 314 315 316
There were some messages about support more generally too; its role in building carers’ confidence and reducing isolation and the importance of early intervention and prevention. This helps carers to plan for the future in terms of support needs and avoid crises:	317 318 319
. . . trying to find ways that we can avoid the crisis really and make it a more planned approach that people feel more in control of . . . and more informed about the decisions and choices.	320 321
Another such message was that it is not always the specific ‘intervention’ that makes a difference to carers, but the style of the service and/or the combination of ‘types of support’	322 323

that are most effective in bolstering resilience. It is not simply the ‘what’ of a service that is important but also ‘how’ it is offered and delivered that is valued by carers.

*Carers services – development and commissioning*

Many of the findings within this theme related to *barriers* to the development and effective commissioning of carer services. The impact of austerity on public services was widely cited as a barrier, as was the limited – and often time limited – funding for third sector initiatives, and the considerable transactional costs involved in short-term commissioning by the NHS and local authorities. Respondents described how the absence of reliable longer-term funding led to a sense of operating ‘hand to mouth’ and having to perpetually deal with problems of uncertainty, particularly in relation to staffing:

There’s a lot of uncertainty – we train and we develop staff, and we have such brilliant passionate staff and then they have to move on because we don’t know from one year to the next what’s happening.

*and*

This is a problem for lots of organisations – the NHS commissions on a yearly basis. So, it is very hard if you’re a small organisation. You want staff to be on permanent contracts, but it isn’t safe that you’ll get the funding next year.

The way that services are typically audited and monitored by commissioners was seen as another barrier to sustainable service development. Such processes tend to focus on short-term quantitative metrics and key performance indicators which typically involve reporting on costs and ‘activity counting’. For example, participants discussed how they were asked to provide figures relating to the number of people using a service and/or the number of residential and hospital admissions that had been ‘avoided’ over the last six months. Not only might such ‘activity counting’ fail to reflect the wider value of a service but adopting a short-term focus overlooks benefits that may accrue over the longer term. The linked prioritisation of costs-savings similarly fails to take account of ‘softer’ qualitative or longer-term outcomes, such as the value of the service to the carer, improvements to the relationship with the cared for person, better health and wellbeing, and/or a return to paid work. As these outcomes would generally *not* result in cost savings to commissioners, they are often overlooked or discounted. The following two quotes illustrate these points well:

‘we ... want to measure quality. So we will work with the families, we’ll get feedback from the families (...) but the majority of commissioners will only ask how much does it save?’

*and*

‘we’re kind of measuring the wrong things a lot of the time!’

Monitoring outcomes becomes even more complex when an NHS commissioned service ‘saves’ the local authority resources by reducing demands on social care rather than relieving the NHS budget.

All of these concerns led participants to question what ‘counts’ as evidence of effectiveness for commissioners, and how this drives models that threaten the sustainability of services and undermine the viability of support for older carers and carers of people living with dementia. Too often, there is a ‘lack of fit’ between what is important to carers and what is important to commissioning agencies.

A related issue is that carers services are often under pressure from commissioners to disseminate information about ‘successes’. There was a consensus among participants that the process of dissemination is neither straightforward nor cost free. Organisations report being ‘unconfident about how to share’ information effectively. As one interviewee explained, ‘we don’t necessarily know which doors to knock on’ to ‘spread the word’.

## Discussion

Whilst the findings from this study mirror and reinforce themes in existing research about the support needs of older carers and carers of people living with dementia, a number of new insights have also emerged. Most significant is the centrality of ensuring there is congruence between what carers say they need and value and the development, delivery and commissioning of carers’ services. Another is the importance of the approach and manner of service provision i.e. the process of support appears to be *at least* as important as the service itself.

Although there are common experiences shared by all carers, this study also highlights the distinctive needs of carers of older people and of people living with dementia (Bremer *et al.*, 2015; Carers Trust, 2015). The findings suggest that a more nuanced and tailored approach to support may be required for both groups if it is to be effective. Support for dementia carers, for example, needs to include face-to-face help with understanding the nature of dementia and the implications of its trajectory for the future health and wellbeing of the cared for person and the carer. Support for those caring for a younger person with dementia needs to incorporate information about: the progressive nature of the condition, planning ahead including financial issues, and being offered opportunities to maintain a ‘normal’ quality of life including remaining in paid employment over the longer term. Crucial to this group of carers – and the younger person with dementia – is prompt diagnosis and propitious post diagnostic support. This issue has particular implications for GPs and other primary health care staff involved in NHS specialist referral processes.

It was clear that the way for information is delivered is critical; its delivery should be at a speed and in a medium and quantity that the carer and cared-for person are able to make use of to aid decision-making and plan care. Some people prefer information that is in the written form, others like to discuss it; opportunities to ask questions and engage in discussion is highly valued by carers. The value of well-timed and crafted information to help carers cope with the changed and changing nature of their relative’s condition, support being provided by peer carers and/or volunteer befrienders and social opportunities that reduce the risk of isolation were repeatedly highlighted in the study. The evidence showed that this is particularly relevant for dementia carers of all ages.

The development of support for *both* the carer and the cared for person together was also viewed as positive and as demonstrating agencies’ responsiveness to carers’ wishes. Examples include ‘Carers Hubs’ and the innovative forms of respite care noted above. These models emphasise meaningful activity and engagement with both carers and their

relatives (Carers UK, 2019; Rokstad *et al.*, 2019). Increasingly services are recognising the importance of supporting the care relationship, for example, dyadic psychological interventions such as Cognitive Stimulation Therapy (Clare *et al.*, 2003, 2014; Moniz-Cook *et al.*, 2011).

In relation to future commissioning, the findings highlight the paramountcy of embedding carers' views and experiences in service developments. If future forms of support are to be meaningful, acceptable and to 'fit with' carers' lives and needs, commissioning models and practices must capture and take account of what matters to carers and what improves their quality of life. The development of joint support for the care dyad is one such example; supporting the care relationship is another. These kinds of developments also require 'reimagining' traditional models of support, such as the home-based respite service (noted above) and offering these alongside the established and trusted types of support such as befriending and carers support groups.

Short term contracts and/or annual tenders were identified as undermining the sustainable development of innovative services and threatening staff recruitment and retention. This was especially the case for smaller organisations that do not have the capacity to fund new developments or offer secure longer-term contracts for staff without a reliable source of funding. Furthermore, the uncertainty created by short-term contracts is very difficult for carers to deal with as they often come to depend on particular service(s) and particular members of staff with whom they have developed a relationship. The closure of carers services, especially at short notice, is damaging to carers' capacity to continue to provide care, feel supported and protect their own wellbeing (Lewis and West, 2014; Pickard *et al.*, 2018; Carers UK, 2019). Lack of long-term funding threatens the sustainability of a responsive, reliable carers support system.

Commissioning models not only need to move beyond evaluating 'effectiveness' of support based on enumerating short-term activity but also need to adopt a more sophisticated approach to evidence. Both quantitative and qualitative evidence – and outcomes that are over the longer term – are needed if the depth, breadth and capacity of third sector support is to be effectively captured. In the UK policy context these messages are particularly relevant as developing outcomes-based commissioning is a key current priority for the NHS and local authorities (NHS England, 2019). In order to ensure that the funding and commissioning of services reflects what matters to carers there is a linked need for commissioners and local authority partners to have a better understanding of what carers want from a service, what they think 'effectiveness' means, how third sector agencies can – and do – meet carers' needs and how these can be translated into outcomes and outcome measures such as carers' improved well-being (Milne and Larkin, 2015).

Revisiting the mechanisms and measures that are currently used to capture outcomes could help address these issues. Greater use could be made of reliable and validated tools such as the Adult Social Care Outcomes Toolkit (ASCOT) <https://www.pssru.ac.uk/ascot/>. ASCOT aims to measure users' – and/or carers' – care-related quality of life. It is already used to assess the effectiveness of social care interventions and inform agencies about the specific elements of their service that are more, or less, effective (Rand *et al.*, 2015; Callaghan *et al.*, 2017). There is also scope for greater involvement of carers in commissioning decisions, particularly around what they find valuable and how a service impacts on their life and wellbeing, beyond whether it prevents or delays hospital admission or use of long-term care.

Whilst national policy aims to ‘support carers’ to live full lives, and duties are placed on statutory agencies to ensure that ‘carers’ wellbeing is protected’, services are commissioned in a local context by agencies preoccupied by financial concerns. It is clear that commissioning decisions are primarily driven by NHS and local authority funding; as this has been under enormous pressure over the last decade, it is not surprising that it has had a corrosive effect on the quantity, range and sustainability of carers services (Brimblecombe *et al.*, 2018; Pickard *et al.*, 2018). Whilst this study has highlighted some of the key ingredients of effective support for older carers and carers of people living with dementia, for this to be consistently translated into practice, national funding challenges and their negative impact on models of commissioning and support for carers need to be acknowledged and addressed. If policy commitments to carers are to be made meaningful, much greater attention needs to be given to the connectivity between these different elements of the carers support ‘equation’ and to what matters to carers and what is valued by them. Imaginative creative services for carers exist – as has been evidenced in this study – but for these to be facilitated across England, and sustained, the building blocks of effective support need to be in place.

### Concluding comments

This study contributes new knowledge about supporting older carers and carers of people with dementia and ways in which services, and the associated commissioning processes, can be improved. The distinctive third sector perspective it brings to bear on these critical twin issues complements existing research. In addition to identifying the ‘key ingredients’ of models of support that are valued by both groups of carers, it has identified the pivotal role played by the ‘process of support’ alongside the delivery of the support itself, and the importance of consistency of provision and of relationships between carers and care workers. It is clear that a much greater ‘fit’ between carers’ needs and meeting those needs is likely to be achieved if carers’ perspectives are taken account of in service development, models of commissioning and evaluation of effectiveness.

A primary barrier to the development of sustainable and effective support services for older carers and carers of people with dementia is limited access to funding that extends beyond a year. Not only would extending the duration of funding protect existing services, including the workforce, but it would also help facilitate innovative developments and contribute to achieving improved outcomes for carers – and their relatives – in the short and longer term.

Although this study was focused on England, its findings have relevance beyond the UK context, particularly where there are comparable policy challenges regarding the funding, development and commissioning of effective carer support. Given the growth in the number of carers expected over the next twenty years it is critical that these issues are explored and addressed and the third sector is enriched and promoted to maximise its potential to provide effective and valued support for older carers and carers of people with dementia.

### Note

- 1 Ethical approval not required

<b>References</b>	<b>497</b>
Age UK (2018) <i>Why Call it Care When Nobody Cares?</i> , London: Age UK.	498
Alzheimer's Society (2019) <i>Younger People with Dementia</i> , <a href="https://www.alzheimers.org.uk/about-dementia/types-dementia/younger-people-with-dementia">https://www.alzheimers.org.uk/about-dementia/types-dementia/younger-people-with-dementia</a> [accessed 05.11.2019].	499 500
Bengston, M. (2016) 'How to plan and perform a qualitative study using content analysis', <i>Nursing Plus Open</i> , 2, 8-14.	501 502
Bowey, L. and McLaughlin, A. (2007) 'Older carers of adults with a learning disability confront the future: issues and preferences in planning', <i>British Journal of Social Work</i> , 37, 1, 39-54.	503 504
Bowling, A. (2014) <i>Research Methods in Health</i> , Maidenhead: OUP.	505
Bremer, P., Cabrera, E. and Leio-Kilpi, H. (2015) 'Informal dementia care: consequences for caregivers' health and health care use in 8 European countries', <i>Health Policy</i> , 119, 11, 1459-71.	506 507
Brimblecombe, N., Pickard, L., King, D. and Knapp, M. (2018) 'Barriers to receipt of social care services for working carers and the people they care in times of austerity', <i>Journal of Social Policy</i> , 47, 2, 215-33.	508 509 510
Callaghan, L., Brookes, N. and Palmer, S. (2017) 'Older People receiving family-based support in the community: a survey of quality of life among users of 'Shared Lives' in England', <i>Health and Social Care in the Community</i> , 25, 5, 1655-66.	511 512 513
Carers Trust (2015) <i>Caring About Older Carers Providing Support for People Caring Later in Life</i> , London: Carers Trust.	514 515
Carers Trust (2016) <i>Retirement on Hold</i> , London: Carers Trust.	516
Carers Trust (2019) <i>Key Facts about Carers and the People They Care For</i> , London: Carers Trust.	517
Carers UK (2015) <i>Caring into Later Life: The Growing Pressure on Older Carers</i> , London: Carers UK.	518
Carers UK (2016) <i>Half a Million Voices: Improving Support for BAME Carers</i> , London: Carers UK.	519 520
Carers UK (2019) <i>Carers at Breaking Point Making the Case for Carers' Breaks in England</i> , London: Carers UK.	521 522
Charlesworth, G., Shepstone, L., Wilson, E., Reynolds, S., Mugford, M., Price, D., Harvey, I. and Poland, F. (2008) 'Befriending carers of people with dementia: randomised controlled trial', <i>British Medical Journal</i> , 336, 7656, 1295-7.	523 524 525
Clare, L., Woods, R. T., Moniz Cook, E. D., Orrell, M. and Spector, A. (2003) <i>Cognitive Rehabilitation and Cognitive Training for Early-Stage Alzheimer's Disease and Vascular Dementia</i> . The Cochrane Collaboration, Hoboken, NJ: John Wiley and Sons.	526 527 528
Clare, L., Woods, R. T., Nelis, S. M., Martyr, A., Markova, I. S., Roth, I., Whitaker, C. J. and Morris, R. G. (2014) 'Trajectories of quality of life in early-stage dementia: individual variations and predictors of change', <i>International Journal of Geriatric Psychiatry</i> , 29, 616-23.	529 530 531
Corden, A. and Hirst, M. (2011) 'Partner care at the end-of-life: identity, language and characteristics', <i>Ageing and Society</i> , 31, 2, 217-42.	532 533
Department of Health (2014) <i>The Mandate. A Mandate from the Government to NHS England: April 2014 to March 2015</i> , London: Department of Health.	534 535
Department of Health and Social Care (2018) <i>Carers Action Plan 2018-2020. Supporting Carers Today</i> , London: Department of Health and Social Care.	536 537
Do, E. K., Cohen, S. A. and Brown, M. J. (2014) 'Socioeconomic and demographic factors modify the association between informal caregiving and health in the sandwich generation', <i>BMC Public Health</i> , 14, 1, 1-14.	538 539 540
Galiatsatos, P., Gurley, A. and Hale, W. D. (2017) 'Policy and advocacy for informal caregivers: how state policy influenced a community initiative', <i>Journal of Public Health Policy</i> , 38, 4, 503-8.	541 542
Grundy, E. and Henretta, J. C. (2006) 'Between elderly parents and adult children : a new look at the intergenerational care provided by the 'sandwich generation'', <i>Ageing and Society</i> , 26, 5, 705-22.	543 544
Health and Social Care Information Centre (2015) <i>Personal Social Services Survey of Adult Carers in England, 2014-15</i> , Health and Social Care Information Centre.	545 546

Henwood, M., Larkin, M. and Milne, A. (2017) <i>Seeing the Wood for the Trees. Carer Related Research and Knowledge: A Scoping Review</i> , <a href="https://www.scie-socialcareonline.org.uk/seeing-the-wood-for-the-trees-carer-related-research-and-knowledge-a-scoping-review/r/a110f00000RCtCnAAL">https://www.scie-socialcareonline.org.uk/seeing-the-wood-for-the-trees-carer-related-research-and-knowledge-a-scoping-review/r/a110f00000RCtCnAAL</a> [accessed 05.11.2019].	547 548 549 550
Henwood, M., Larkin, M. and Milne, A. (2018) <i>Exemplar Models and Support for Older Carers and Carers of People with Dementia: Informing Commissioning</i> , NHS England.	551 552
HM Government (2014) <i>Care Act 2014 Chapter 23</i> , <a href="http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted">http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted</a> [accessed 05.11.2019].	553 554
Hydén, L-C. and Nilsson, E. (2015) 'Couples with dementia: positioning the 'we' ', <i>Dementia</i> , 1, 6, 716–733.	555
Jones, S. M., Mioshi, E. and Killett, A. (2019) 'Coping but not allowing the coping to be everything: resilience in informal dementia care', <i>Health and Social Care in the Community</i> , 27, 4, 289-97.	556 557
Larkin, M. and Milne, A. (2014) 'Carer empowerment in the 21st century – a critical reflection', <i>Social Policy and Society</i> , 13, 1, 25-38.	558 559
Larkin, M., Henwood, M. and Milne, A. (2018) 'Carer related research and knowledge: findings from a scoping review', <i>Health and Social Care in the Community</i> , 27, 1, 55-67.	560 561
Lavrakas, P. J. (2008) <i>Encyclopedia of Survey Research Methods</i> , Thousand Oaks, CA: Sage Publications.	562
Lewis, J. and West, A. (2014) 'Re-shaping social care services for older people in England', <i>Journal of Social Policy</i> , 43, 1, 1–18.	563 564
Lockeridge, S. and Simpson, J. (2013) 'The experience of caring for a partner with young onset dementia: how younger carers cope', <i>Dementia: the International Journal of Social Research and Practice</i> , 12, 5, 635-51.	565 566 567
McGarry, J. and Arthur, A. (2001) 'Informal caring in later life: a qualitative study of the experiences of older carers', <i>Journal of Advanced Nursing</i> , 33, 2, 182-9.	568 569
Milne, A. (2010) 'The D word: reflections on the relationship between stigma and dementia', <i>Journal of Mental Health</i> , 19, 227-33.	570 571
Milne, A. and Larkin, M. (2015) 'Knowledge generation about care-giving in the UK: a critical review of research paradigms', <i>Health and Social Care in the Community</i> , 23, 1, 4–13.	572 573
Moniz-Cook, E., Vermooij-Dassen, M., Woods, B., Orrell, M. and Network, I. (2011) 'Psychosocial interventions in dementia care research: the INTERDEM manifesto', <i>Aging and Mental Health</i> , 15, 3, 283–90.	574 575 576
NHS England (2014a) <i>Five Year Forward View</i> , London: NHS England.	577
NHS England (2014b) <i>NHS England's Commitment to Carers</i> , London: NHS England.	578
NHS England (2017) <i>Next Steps on the NHS Five Year Forward View</i> , London: NHS England.	579
NHS England (2019) <i>The NHS Long Term Plan</i> , London, NHS England.	580
Newbronner, L., Chamberlain, R., Borthwick, R., Baxter, M. and Glendinning, C. (2013) <i>A Road Less Rocky – Supporting Carers of People with Dementia</i> , London: Carers Trust.	581 582
Perkins, E. A. and Haley, W. E. (2013) 'Emotional and tangible reciprocity in middle- and older-aged carers of adults with intellectual disabilities', <i>Journal of Policy and Practice in Intellectual Disabilities</i> , 10, 4, 334-44.	583 584 585
Pickard, L., Brimblecombe, N., King, D. and Knapp, M. (2018) 'Replacement care for working carers? A longitudinal study in England, 2013–15', <i>Social Policy and Administration</i> , 52, 3, 690-709.	586 587
Pickard, L., King, D. and Knapp, M. (2015) 'The 'visibility' of unpaid care in England', <i>Journal of Social Work</i> , 16, 3, 1-20.	588 589
Pickard, S., Shaw, S. and Glendinning, C. (2000) 'Health care professionals' support for older carers', <i>Ageing and Society</i> , 20, 6, 725-44.	590 591
Rand, S. E., Malley, J. N., Netten, A. P. and Forder, J. E. (2015) 'Factor structure and construct validity of the Adult Social Care Outcomes Toolkit for Carers (ASCOT-Carer)', <i>Quality of Life Research</i> , 24, 11, 2601–14.	592 593 594
Richardson, A., Pedley, G., Pelone, F., Akhtar, F., Chang, J., Muleya, W. and Greenwood, N. (2016) 'Psychosocial interventions for people with young onset dementia and their carers: a systematic review', <i>International Psychogeriatrics</i> , 28, 9, 1441–54.	595 596 597

Rinaldi, P., Spazzafumo, L., Mastroforti, R., Mattioli, P., Marvardi, M., Polidori, M. C., Cherubini, A., Abate, G., Bartorelli, L., Bonaiuto, S., Capurso, A., Cucinotta, D., Gallucci, M., Giordano, M., Martorelli, M., Masaraki, G., Nieddu, A., Pettenati, C., Putzu, P., Tammaro, V. A., Tomassini, P. F., Vergani, C., Senin, U. and Mecocci, P. (2005) 'Predictors of high level of burden and distress in caregivers of demented patients: results of an Italian multicenter study,' <i>International Journal of Geriatric Psychiatry</i> , 20, 2, 168-74.	598 599 600 601 602 603
Rokstad, A-M., McCabe, L., Robertson, J., Strandenæs, M., Tretteteig, S. and Vatne, S. (2019) 'Day care for people with dementia: a qualitative study comparing experiences from Norway and Scotland', <i>Dementia</i> , 18, 4, 1393-409.	604 605 606
Rosness, T. A., Mjorud, M. and Engedal, K. (2011) 'Quality of life and depression in carers of patients with early onset dementia', <i>Aging and Mental Health</i> , 15, 3, 299-306.	607 608