

Carers' breaks and respite services

Rapid Review Summary for DHSC 28 February 2019

Introduction

Drawing on a focused literature review of recently published research combined with selected Carers UK Breaks Survey data, this summary report outlines key themes and issues relating to the provision of carers breaks and respite in England since the introduction of the Care Act 2014. Findings are informing the development of guidance for commissioners and providers and the dissemination of advice and information tool for carers being produced by SCIE and Carers UK respectively.

A presentation based on an earlier version of this paper was presented at the Reference Group for discussion on 12 February. The guidance will include examples of good practice and current services collated from a SCIE Call for Practice.

Key themes and messages from research

- The evidence base on the effectiveness and cost effectiveness of specific interventions for carers is weak despite extensive literature on *potentially* effective interventions. There is a tension between cost-effectiveness and what is valued by carers.
- The meaning and value of carer breaks and the way in which the dynamics of the caring relationship impact on whether, and how, carers access services needs to be better understood by commissioners and providers.
- There is “no one size fits all” - the diversity of carers and carer needs require more personalised, tailored support in relation to breaks
- There is a need for appropriate, timely information and advice about respite
- Carers cite a lack of flexibility, choice and accessibility as key concerns along with issues of cost and concerns around quality of current provision
- There is an acknowledged need to rethink and reimagine respite approaches and develop more creative forms of breaks support and models of delivery which have carers at their centre.

Definitions and language

The language and terminology around respite provision needs revision. The term “respite” is contested as implying a burden and a negative representation of the relationship in which care takes place. Services need to meet both the needs of the carer and the person receiving care and for this reason the term “short breaks” is preferred as more reflective of the mutual benefit of the support provided. The term “carer breaks” may also encourage a more innovative approach by commissioners and a wider range of potential providers.

In the research literature the terms are used interchangeably and the following definitions from the **Think Local Act Personal “Jargon Buster”** have been included as useful in this context.

Respite *A service giving carers a break, by providing short-term care for the person with care needs in their own home or in a residential setting. It can mean a few hours during the day or evening, 'night sitting', or a longer-term break. It can also benefit the person with care needs by giving them the chance to try new activities and meet new people.*

Short breaks *When a person with care and support needs spends regular short periods of time away from their main carer, in order to give the carer a break and to give the person with needs a chance to do something different. These breaks may take place in the person's own home, in the home of an approved carer or in a place such as a hospice.*

In the context of this review “replacement care” in the sense of emergency cover at a time of carer crisis, or to allow carers to access their own medical appointments is not deemed to constitute a carer break but should be part of core service provision.

Rapid evidence literature review

Searches with a date limit of 2014-2019 were undertaken using Social Care Online, Google and Google Scholar together with the websites of relevant organisations.

The review aimed:

- to identify the main barriers and enablers in developing and delivering accessible, appropriate quality break services for adult carers of other adults and young carers (16-25 years) in transition to adult services
- provide examples of good and emerging practice which have been shown to meet identified carer needs and improve carer outcomes

Areas explored in relation to the above included:

- the meaning and value of breaks
- commissioning and market shaping
- funding arrangements
- specific needs of different carer groups

- respite models and approaches to provision
- the use of assistive technologies.

Carer research on breaks - the evidence base

Breaks services for carers are one element of a spectrum of measures designed to support carers to have a life alongside their caring role and contribute to carer resilience. Others include information and advocacy, home adaptations, equipment hire, befriending, therapeutic and peer support, supported employment, education and leisure opportunities which are beyond the scope of this review. The specific role of breaks needs to be considered alongside other support measures when looking at carer outcomes and benefits.

There has been significant carer research over the past 20 years mostly focusing on carer characteristics, the impact of caring and the lived experience of carers. Whilst research shows the importance of breaks from the viewpoint of carers, the evidence around respite and the particular types of interventions which are most effective remains inconclusive (Henwood,2017)

- There is extensive literature on a wide range of potentially effective interventions to support unpaid carers - both indirect support (i.e. for the cared for person) and direct which is focused on support for the carer. However, there are significant gaps in the evidence base with regard to interventions, outcomes and types of caring situation studied, and a dearth of evidence on cost-effectiveness with few evaluations of recent policy initiatives (Brimblecombe,2018).
- Reliance on cross-sectional studies using standardised measures is a major weakness of existing research and fails to capture the multidimensionality of the carer role and the lived experience of the carer (Henwood,2018)
- The effectiveness of respite care remains a paradox given the apparent conflict between the empirical evidence and the views of carers (Thomas,2017)
- There is a tension between cost-effectiveness and what is valued by carers with a need to develop more robust evaluative models (Larkin,2019)

The key variables of respite/breaks are

- the setting and location (at home/in a residential or institutional setting/community-based)
- the duration and timing of the break (hours/days/weeks)
- the activities engaged in and/or type of care involved
- how the service is funded and delivered and who is involved

The meaning and value of breaks for carers

Breaks are regarded by carers, providers and care staff as essential in helping carers to continue a caring role and maintain their own health and wellbeing. Being able to take time away from the pressures of a caring role is one of the most frequently-voiced carer demands.

(Data from Carers UK State of Caring Report and Carers' Breaks survey 2018)

- 25% of carers said they hadn't had a day off from caring for more than five years
- 40% of carers said they hadn't had a day off for more than a year.
- Carers who reported not having had a break from caring within the last year, were also more likely to report having suffered mental ill health as a result of caring or that their physical health has worsened as a result of caring, with 73% and 64% stating this respectively, compared to 70% and 61% for all groups
- For those struggling to get a break from caring, the most common reasons that people gave were the costs of paying for or contributing to the cost of a break, or that the person they care for isn't willing to accept care and support from others, which 3 out of 10 people reported for each (31%).
- 33% of carers who had a carers assessment in the last year stated that their need to have regular breaks from caring was not considered in their assessment.
- Only 8% of respondents stated that they were able to take sufficient breaks in the past five years – these carers were more likely to be caring for fewer hours per week, less likely to be caring for a spouse/partner and less likely to be living with the person they care for (distance carer).

It is clear from the responses that carers value breaks for a wide range of different reasons, practical, emotional, social and psychological – and all of these are important factors when planning and evaluating services. If the aim of a break is to improve carer wellbeing, breaks must be perceived as acceptable and beneficial to both the carer and cared for person.

- Three steps have been identified in carer research regarding the acceptance of respite for carers – recognising the need to get out; giving themselves permission temporarily to leave the carer world; having availability of social support to facilitate getting out (Neville,2015)
- The “default” understanding of breaks by carers and care staff is they equate to a period of residential care in a setting other than the carer/ cared-for person's own home (Macdonald,2016)
- There is indicative evidence that respite services can reduce carer-related stress and reduce the likelihood of a carer breaking down (Babudu,2016)
- For some a break has value beyond the allotted time it affords **“to look forward to a break has the same effect as the break itself”** (Carers UK Breaks survey)
- For some carers there may be negative connotations and even stigma associated with pursuing respite care or breaks (Neville,2015)
- Some survey respondents reported no impact or a negative impact from taking breaks due to concerns around the poor quality of care, constant worry about

leaving the cared for person, or additional stress caused by having a break in established routine for the cared for person (Carers UK Breaks Survey 2018)

Personalisation and quality of support

The type, amount and quality of carer support available generally (publicly funded or otherwise) varies widely across the UK, and in relation specifically to respite and breaks provision is also inconsistent.

Carers want more choice and control, a range of breaks, short and longer term in a mix of settings and breaks which reflect diverse needs and preferences. It is important to work with carers to develop activities and goals most likely to improve their wellbeing as the amount of time provided by respite may not be as important to carers as what they do with it.

- “Traditional respite” is not achieving its full potential, greater personalisation is needed (Shared Lives,2017)
- The concept of respite/breaks needs to be “reimagined” to reflect the needs of carers and the move towards more integrated, personalised, home-based care (Older People’s Commissioner Wales,2018)
- There are particular issues around availability of respite care for carers looking after someone with complex needs
- Multiple reviews looking at family/unpaid carer outcomes for respite have reported that the potential of respite in delivering outcomes will only be effective when respite is provided in a more individualised manner, and is designed to meet the needs of the carer (Neville, 2015)
- Services should be flexible, high quality and appropriate, and part of an integrated offer from joined-up services which talk to each other and have the carer’s needs at the centre.

Diversity of carers and the carer journey

“Account for all the different caring roles – and recognise multiple caring roles, co-caring and long-distance caring” (Carers UK Breaks Survey 2018)

Although carers share some common concerns there is immense carer diversity and particular groups have distinctive needs which may be overlooked when developing universal services.

It is challenging to predict which carers will benefit from respite given the enormous diversity of people involved, the nature of services offered and the type of research carried out into their effectiveness (Henwood,2018)

Respite care is a vital part of the home management of people with **dementia** allowing carers to maintain the caring relationship and potentially delaying the admission to long-term residential care but uptake of respite services by carers of people with dementia is relatively low. (Neville,2015)

Around 5% of people with dementia have the **young onset type** (people under 65) and the impact of this diagnosis for their carers and wider family is likely to be significant

with the needs of carers in this situation having had relatively little research focus (Henwood 2018).

Most barriers identified were potentially relevant to all carers irrelevant of ethnic group. However, **BME carers** are more likely not to access support services (Greenwood, 2015). Possible reasons for this include concerns from carers around language and cultural appropriateness but also may relate to assumptions made about BME carers and cultural aspects of caring from those commissioning and providing services (Mohammed,2017).

The 2016 DHSC call for evidence showed that more needs to be done to support **young carers** - 67% of young carers had not received any support for their caring role. Less than 1% of respondents to the Carers' Breaks Survey were aged 18-24. Evidence on barriers to respite access for young adult carers and the types of interventions and care models acceptable to younger carers is difficult to find but age appropriateness of what is offered is a key factor as is a whole family approach to support.

Working carers need information and support that is specifically tailored to their circumstances – which may for example be support during evenings, nights and weekends not during the day. There are issues in relation to the inflexibility of respite services when trying to plan and make advance booking for breaks which align with annual leave.

My largest issue is I take a lot of my paid holidays and use them for my mother's appointments and hospital visits so trying to get extra time off is almost impossible

"I am having to work even when my son is away in respite care."

- The availability and quality of respite services and the attitude of carers and the cared for to receipt of services have been identified as potential barriers for working carers and implications for carers ability to reconcile care and employment (Brimblecombe & Pickard,2018)
- New research by Carers UK reveals that 2.6 million have quit their job to care for a loved one who is older, disabled or seriously ill, with nearly half a million (468,000) leaving their job in the last two years alone - more than 600 people a day. (Carers UK press release,2019)
- Use of short term breaks are associated with carers employment *when combined* with other services. (Pickard,2015)

There may be specific needs in relation to short breaks and respite for carers supporting people with **mental ill health** where there is the potential for greater stigma and lack of acknowledgement of needs, and often more caring at a distance. The Carers Trust identified that there is ongoing confusion about what constitutes respite care and carers breaks in mental health (Carers Trust, 2015)

For Carers of **people with learning disabilities and autism** residential respite care appears the default conceptualisation for carers, service users and stakeholders. The familiarity and safety of residential care can be hard to give up in favour of non-residential alternatives (Southby,2017)

In the Carers UK survey on breaks 80% of respondents identified as female (Carers UK, 2019). **Male carers** are acknowledged in the research literature as often harder to reach and in comparison with female carers, research with male carers is underdeveloped. The evidence suggests male and female carers share many common experiences, but that male carers are less likely to access services and are more ambivalent about seeking help. (Greenwood,2015)

Finding out about and accessing support and services are described as particularly challenging for **older carers**. Remaining independent, a strong sense of duty to provide care without help and not expecting support were also all raised as reasons for not accessing services. Many also did not want to bother their friends or families who they perceive as having their own busy lives. (Greenwood, Identifying research priorities about older carers, 2018)

Being **lesbian, gay, bisexual or transgender** and a carer can bring additional challenges around concerns about whether the services available are LGBT friendly and fears of discrimination particularly when the cared for person is a spouse/partner.

A recently published exploratory study of **distance carers** in UK found a range of challenges for those caring from a distance but a general lack of awareness of their experiences. Living in a different location to the person they care made it harder to access services and support when the assumption made by local providers is that people live together or in the same locality. (White,2018)

Sandwich carers describes a variety of multiple caring responsibilities for people in different generations. In the Carers UK Breaks Survey 19% of respondents say they also have childcare responsibilities for a non-disabled child under 18 whilst 10% say they care for multiple people and am unable to take a break from all their caring roles.

Information and advice

The research literature cites insufficient information and low awareness of services and service availability as key reasons why carers do not access respite care. The challenge of accessing the appropriate information at the right time is a recurrent theme. There are particular challenges in ensuring certain groups for example, older people and carers of people with dementia have access to the information they need.

- 27% of Carers UK survey respondents said they had not been able to take break was because “***I did not know how to find information about taking a break***”. 35% said they had no information at all on how they can take a break. Information about funding, costs and what is available locally is most popular.
- Research on carers information needs reveals frustration with what can be a complicated process. Negative experiences of information seeking can create additional stress for carers and contribute to delays in take-up, or not using services at all (Phillipson,2019)
- 51% of survey respondents say they use the Internet (Carers UK Breaks Survey,2018) Information and communication about breaks needs to encompass traditional and online forms in order to be fully accessible.

Assessment, arranging breaks and costs

“Have a carers assessment every year and be honest...if you don’t recognise yourself in that assessment. ..do it again”

The importance of getting the basics right in regard to carers’ assessment is vital in understanding the type of breaks and respite services needed and the matching of services to the needs of individual carers at local level. This includes understanding why carers may find it difficult to ask for breaks or to make complaints about the frequency or quality of any services they do receive.

The survey data shows that some carers want support in explaining their need for a break to the person they care for or wider family. There may be tensions in the ideas about respite held by carers and the cared for which can impact on whether services are accessed or continued with. Nearly 30% of survey respondents who stated they did not want to take break said their reason was because the person they cared for was unwilling to accept replacement care (Carers UK Breaks Survey,2018)

The time-consuming nature of arranging breaks and the bureaucracy involved can be very off-putting for carers who already have multiple demands on their time. Breaks should be easy to arrange in terms of advance planning and booking, clearly indicate the type of setting and support, the duration and cost and be matched to what is available in the local community.

- Many carers do not self-identify as carers and do not access assessments and services. Strategies which address the attitudinal and resource barriers that influence some groups in the carer population who may be more vulnerable to service non-use are essential (Phillipson,2014)
- The State of Caring 2018 report notes that although 67% of carers in England confirm they had a carers assessment in the previous 12 months the need to have regular breaks from caring was reported to be the most likely issue *not* to have been properly considered in that assessment by 33% of those assessed.
- Carers are also entitled to their own personal budget but little is known about how local authorities assess and allocate resources to carers. Carer eligibility criteria are used but thresholds vary and are often unclear. A wide variation in how social workers assess calculate and distribute resources to carers has been identified as an issue (Mitchell & Glendinning,2017)
- Key recommendations from the 2018 State of Caring report emphasise the need to put sufficient ringfenced funding in place to provide affordable breaks for carers (Carers UK,2018)
- Survey data indicates 67% of carers organised replacement care themselves and only 11% did so with support of their local authority.
- 29% of respondents said that family and friends provided the replacement care they needed so there were no costs.
- Only 13% said that the local authority covered all the replacement care cost and another 13% said the council contributed to the overall cost.
- 10% of carers paid for the care themselves and 15% said that the person they care for did so (unclear if paid from a personal budget or direct payment)

- 38% said the reasons why they had not been *able* to take a break was that they were unable to afford replacement care.
- Affordability was also cited by a number of carers (22%) who had stated that they did not *want* to pursue replacement care. Over 20% said that they could not afford to do any activities during the free time the replacement care might offer them. 87% said that they did not receive any financial support to help with the costs of a holiday or activity during a break period.
- Research on the use of personal budgets and older people has found that their needs may not be best served by taking personal budgets as direct payments and that take-up can be limited (Woolham,2015). The study found that the administrative burden of arranging care was off-putting and stressful. Carers of people with direct payments reported higher stress levels relating to the additional responsibilities of arranging, managing and accounting for care.

Use of technology

Carers UK have published a guide for carers outlining how digital technologies can help support someone to live more independently, contribute to the reduction of carer stress and build carer confidence.(Carers UK,2017).

The use of simple technology devices in the home to help monitor and support the cared for person – fall detectors, home/voice-activated technology, mobile phone apps does offer some benefits for carers in relation to reassurance and peace of mind. But feedback from carers indicates technology offers limited respite, is not a substitute for hands-on care and does not constitute a real break.

- The survey reveals carers most used form of technology is a mobile phone to maintain the regular contact whilst away on a carer break although this can be double-edged ***“It’s not a break if you are constantly in touch with the person you look after.”***
- 44% of Carers UK survey respondents said that they did not believe technology would enable them to take a break.
- ***“Technology doesn’t help. My house is hardwired with every technology you could think of. I need a person to take over for a little while.”***
- A review on use of assistive technology among carers of older adults found that whilst carers report that assistive technologies decrease the burden of caring some have concerns that using technologies can also add to it. Further research is needed to understand the limitations of assistive technologies (Marasinghe,2016)

Models of carers’ breaks and respite

The standard offer – traditional respite/breaks based on fixed days/hours - does not meet the needs of many carers who need choice, flexibility and a range of options.

The 2017 NICE consultation on adult carer support reported over a quarter of local councils reducing the capacity of their short break services whilst 1 in 10 carers in the

State of Caring report for 2017 stated that they relied on a day centre for a break (Carers UK,2017). The scaling back of day services reflects a policy shift to the development of more personalised and integrated forms of support, but to be effective this requires the availability of a range of alternative models of provision otherwise the burden of filling the gap continues to fall upon informal carers. For those who care for people with multiple/complex needs, the availability of high quality, accessible residential respite is still critical.

- There is a tension between cost-effectiveness and what is valued by carers with a need to develop more robust evaluative models (Larkin,2019).
- Focusing on what people can do (i.e asset-based approaches) produces a more dynamic model of support than conventional day centres (Henwood,2018)
- The development of carer-friendly communities can reduce the demands for formal respite services and create opportunities for reaching carers who have little or no contact with formal services (Carers UK,2016)
- The Shared Lives model of community-based care is relatively new but evaluative studies show evidence of positive impacts on wellbeing for family carers which these include improved wellbeing, increased ability to cope with the pressure of caring for a relative reducing likelihood of carer breakdown and reduced feelings of social isolation (Shared Lives,2017)
- There is a preference among carers for more flexible at-home respite care rather than residential placements which some carers find too institutional. Carers say more accessible and affordable sitting services would greatly improve their lives. (NICE,2017).
- Relationship-centred breaks, for example using “respite” type provision which offer social and recreational activities shared by carer and cared for person show evidence of carer value.
- Learning from carers and co-producing services with them is essential to facilitating carer take-up and positive outcomes.

Implications for commissioning practice

Research on carer breaks shows that there is a need rethink the whole concept of respite, to review and reframe existing services, to develop more creative solutions and provide a range of breaks in a mix of settings tailored to different carer needs which are culturally and age appropriate.

Routes to respite/breaks are not always clear to carers, current options do not deliver the flexibility, quality and choice needed and money may be being spent on commissioning services which are underused and/or do not deliver meaningful outcomes.

- There is a need for more preventative and early intervention alternative respite care and breaks to prevent carer crisis and breakdown (Vecchio,2018)
- Preventive support for carers is crucial in helping health and social care transform. Despite some ‘inconclusive’ research in the area, there is enough of a logic model to suggest that cost effective interventions can and should be made ‘up-stream’ to minimise carer distress and avoidable physical and mental ill health caused by prolonged caring without appropriate help. (Anfilogoff,2018)

- The style of support and the manner in which it is provided can be crucial (Henwood,2018)
- Commissioners should encourage the use strength/asset-based approaches exploring what is on offer locally in terms of community assets and local business opportunities. Small charities and social enterprises may be put off by formal tendering processes but able to offer more tailored, innovative support (LGA, 2018)
- Monitoring and reporting on commissioned services are often not focused on appropriate metrics or outcomes and based on short term funding. Commissioning models of support within longer timeframes gives organisations more opportunity to examine effectiveness and scale up successful initiatives (Henwood, 2018)
- The pricing approach offered by traditional providers of respite care appears not to take into account the “true” cost of delivering a respite service. Although cost comparisons between traditional and community-based services are challenging the costs of Shared Lives are generally in-line with, and in some cases more affordable than traditional respite and day care provision and provide an important option for commissioners (Cordis Bright,2018)

Workforce training

- Building up trust and a positive relationship between carers and service providers is vital to the success of respite services. Understanding the provision of respite from the perspective of service providers needs more exploration and there may be need for more staff training in this area for commissioners, providers and social workers. Care staff are a key component of respite services success and critical in the facilitation of carers feeling able to temporarily “hand over” care and share responsibility.
- A US study of a respite training programme for respite providers staff showed that formal training for respite resulted in improved outcomes for carers (Ackermann,2018).
- Carers also need support from providers and care staff with around feelings of guilt and being able to talk about respite needs with the person they care for and wider family. Carers value empathy, emotional support and feeling able to discuss concerns and be listened to (Neville,2015)
- Effective information-sharing between carers and care staff when the cared for person is unable to represent themselves is crucial. Providers and staff need to take a proactive, flexible approach to engaging and working with carers over the entire period they are using services (McSwiggan,2017)
- Organisational tension between frontline staff and management in the delivery of respite services has been identified as hindering cultural change in terms of the development of alternative community models which have greater capacity to respond to the needs of the individual carer/cared-for relationship (O’Shea,2017).

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