Short breaks for carers: a scoping review

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Foreword

We know, and have known from the earliest developments in community care, just how important it is for unpaid carers to have the opportunity of regular breaks from their caring responsibilities. Our own research at Shared Care Scotland has shown powerfully how breaks from caring helps carers have a life of their own to the benefit of their own health and well-being. However, there is still much we have to learn about what works and why? For different groups of carers, we should have a better understanding of what makes for a successful break. And, while short term outcomes may be obvious, we are less clear about how access to meaningful breaks might support sustainable caring relationships in the longer term. There is also much we can learn from the development of self-directed short breaks, and assistive technology.

If we are to explore these and other questions further, the first step is to build a picture of what we know already. Shared Care Scotland, working alongside the UK Short Breaks Research & Practice Development Group, has commissioned Bangor University to map and summarise all the research undertaken into short breaks. This has been a challenging undertaking that had to be narrowed down as the scale of the task became clear. Nonetheless, this resulting report is a significant step towards achieving a more complete picture of the evidence for short breaks which we hope will support further efforts to improve policy and practice in this area, and highlight where new research is needed.

Our grateful thanks to all those who contributed to this scoping review and especially to the authors, Louise Prendergast and Diane Seddon at Bangor University.

Don Williamson
Shared Care Scotland

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Overview

The purpose of this scoping review is to better understand the research evidence about short breaks for carers (sometimes called respite care) and what this research tells us about the impact of short breaks for carers.

By reviewing the available evidence and identifying gaps in the research literature, this scoping review shall support the work of a newly established UK Research and Practice Development Group on Meaningful Short Breaks for Carers, helping to shape its research vision. The Group, which has support from academic and practice colleagues across the four United Kingdom regions, shall take forward research and practice on meaningful short breaks for carers that promotes interdependent caring relationships and benefits both carers and people with complex support needs.

This short report provides an overview of the findings. A summary table (Appendix 1) presents further details, outlining key findings and recommendations for practice development from the existing body of published research, as well as gaps in the evidence base. This report focuses on carers supporting older adults, including people with dementia. Where appropriate the experiences of parent carers are highlighted to illustrate similarities and differences in carer support needs and their experiences of short breaks provision.

Background

Carers are a heterogeneous group ranging from young people supporting a parent or sibling, parents caring for a child with a disability, people supporting adults with a physical and/or learning disability and those providing end of life palliative care. Increasingly, research recognises that caring relationships are complex and dynamic and can be reciprocal in nature (Seddon and Robinson 2015). Many carers provide 50 hours or more care each week (Carers UK 2018). Yet, only 16% of carers recently surveyed by Carers UK (2018) said they receive or buy a break from caring and one fifth refused support due to concerns over the quality of the care and the nature of

the break offered. 72% of carers surveyed in the State of Caring study (Carers UK 2018) reported mental ill health as a result of caring and 61% experienced physical ill health. There are increasing demands being placed on older carers; two and a quarter million (2,299,200) people aged 65 years and over provided care in 2015/16, a 16.6% increase from five years previously. Of these, 404,000 were age 80 years and over, providing 12.7 million hours of care in 2015/6, an increase of 12.7% from 2009/10 (Age UK 2017). The support which carers provide is estimated to be worth around £132 billion per year (Carers UK 2018).

Legislation emphasises the importance of developing alternative ways to promote the wellbeing of carers and people with complex health and social care needs. Carers frequently cite access to breaks as one of three factors that could make a positive difference to their lives and support positive wellbeing outcomes (Carers UK 2017 & 2018). Supporting interdependent caring relationships through the provision of meaningful short breaks is a priority for social care policy and practice across the UK regions and seen as essential to preventing a carer crisis or breakdown in the caring relationship.

Policy recognises the importance of supporting people to achieve *what matters to them*, and as such, care and support must be individualised and person-centred to help people to maximise their personal wellbeing outcomes (Care Act [England] 2014; Social Services and Wellbeing Act [Wales] 2014 and Carers [Scotland] Act 2016). *Re-thinking Respite* (Rochira 2018) called for a fundamental shift in the way respite care is conceptualised and delivered, with opportunities for a short break taken together and/or apart and support for family and personal relationships, so that the carer and supported person can live as ‘ordinary life’ as possible. Across the UK, considerable resource is spent on traditional respite care provision that often fails to deliver meaningful outcomes (Rochira 2018). Whilst there have been moves across the UK regions to develop and deliver alternative types of short breaks provision, considerable change is needed to enable individuals to sustain and maintain wellbeing in line with *what matters* to them.

Scoping review method

Scoping reviews capture a broad range of evidence and knowledge from a wide variety of sources. They are particularly effective in prioritising future research areas and informing policy and practice development. Arksey and O'Malley's (2005) framework guided this review. Their five-stage approach involves:

1. Identifying the research question(s)
2. Identifying relevant studies
3. Study selection
4. Charting the data
5. Collating, summarising and reporting results

Defining the carer population

For the purpose of this review, carers are defined as people who care for family members, friends or neighbours on an unpaid basis. The initial search included carers involved in supporting children and adults with a broad range of acute and chronic conditions. Following initial screening, it was decided to focus the review on older adults, including those with dementia, due to the high volume of literature.

Defining short breaks

Shared Care Scotland's short breaks definition underpins the Scoping Review. A short break is defined as any form of service or assistance, which enables the carer(s) to have sufficient and regular periods away from their caring routines or responsibilities, with the purpose to support the caring relationship and promote the health and well-being of the carer, the supported person and other family members affected by the caring situation. Breaks from caring could therefore be:

- For short or extended periods
- Take place during the day or overnight
- Involve the person with support needs having a break away from home allowing the carer time for themselves
- Allow the carer a break away with replacement care in place
- Take the form of the carer and the person they care for having their break together, with assistance if necessary, providing a break from the demands of their daily caring routines

(Shared Care Scotland Position Statement, 2017)

Review questions

The primary review questions were:

1. What does research tell us about the impact of short breaks for carers?
2. What are the gaps in the existing research literature?

Identifying relevant studies

The national and international evidence base on short breaks for carers was searched and included:

- Peer review articles using qualitative, quantitative or mixed methods approaches
- English language publications from 2000 onwards
- Grey literature
- Policy and practice literature published by devolved UK administrations

Articles were identified from searching databases and grey literature (see Table One below).

Table 1. Overview of the literature search

SOURCE	NUMBER OF RETRIEVALS
Academic databases	
Science direct (medicine, nursing & health professions; social sciences and psychology)	61
Proquest Applied Social Sciences Index and Abstracts	165
PsycInfo	293
CinahlPlus	145
Web of science (includes web of science core, biosis, medline, scielo)	647
Cochrane Library	1
Social care online	72
Pubmed	328
Other sources	
CAREN (Carer Research and Knowledge Exchange Network)	10
Open Grey Government department websites	6 8
Other including IRIS, Carers Scotland. IRIS (shared care deposit information) Carers UK via websites	27
Google Scholar	91
Articles recommended by others – (organisations: ARCH and NIHR)	38
TOTAL	**1892**

Citations were imported into the bibliographic management software Mendeley and duplicates removed. Literature was included if there was reference to an outcome from short breaks or respite care for carers. In particular, the focus was on locating research that evidenced the contribution of short breaks in achieving the following carer generated outcomes (Miller and Barrie, 2018):

- Health and well-being (of the carer)
- A life of their own
- Positive relationships with the supported person
- Choices in caring, including limits
- Satisfaction in caring

Outcomes refer to the changes or benefits for carers (and those they support) following a short break.

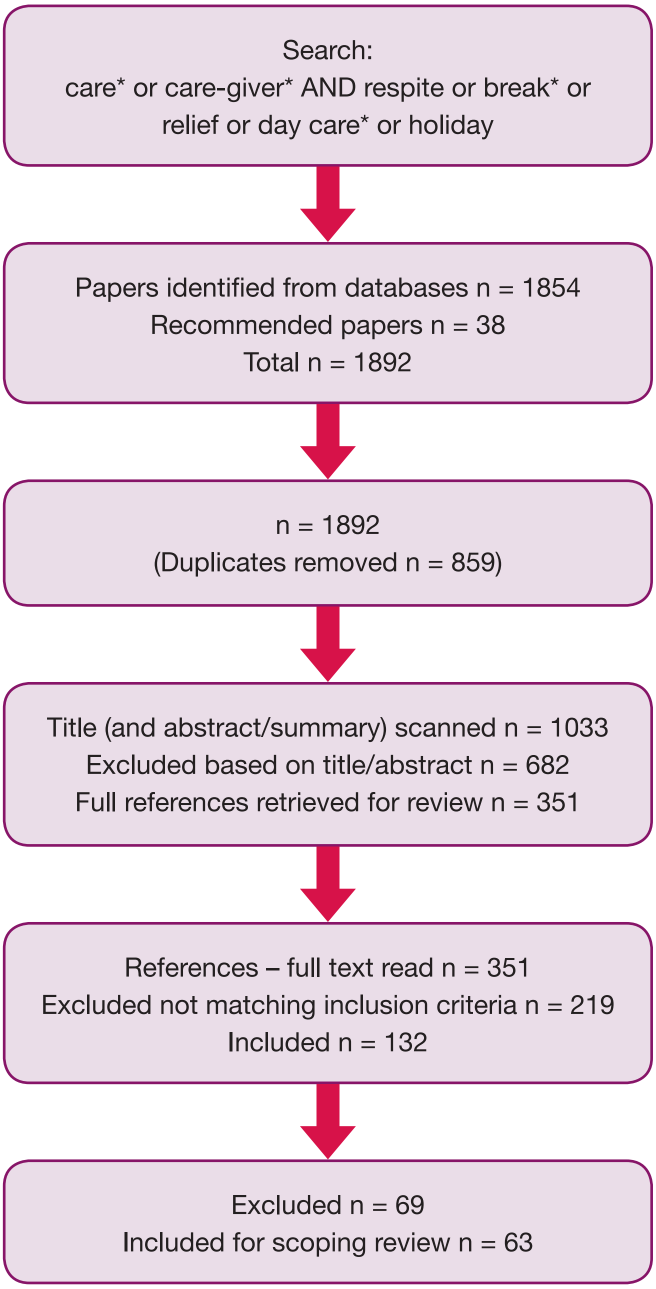
Overview of search results

A total of 1,854 papers were initially identified from the search, with a further 38 from the annotated bibliography of respite and crisis care studies (ARCH) and others (total n=1,892). 859 duplicates were removed. 1,033 papers were then scanned by title and abstract by the lead reviewer (LP). Following exclusions (n=682) the number of full references retrieved for the review was 351 (see Figure One overleaf). These references were then categorised into different carer groups, (see Table Two below).

Table 2. Literature categorised according to carer groups

	NUMBER OF REFERENCES
Older adults	53
Dementia	73
Alzheimer's	6
Total adults	**132**
Children	93
General	62
Mental illness or learning disabilities	19
Palliative/end of life	10
Other	35
Overall total	**351**

Figure 1. Overview of search results



Narrative review

A narrative synthesis was completed. The following information was included firstly in an Excel chart and then collated in a summary table that includes:

- Author(s), year of publication, country
- Carer group
- Aims of study
- Methods
- Outcome measures (where specified)
- Key findings
- Gaps identified and/or recommendations made

The summary table (Appendix 1) presents an overview of the main areas of interest and helps to identify gaps in the evidence base. The terms used in the summary table, for example, carer, caregiver, older dependent, patient, cared for and care recipient are those used in the original research. This reflects the lack of consistent terminology across studies, both nationally and internationally, and the limitations of frequently used terms. For example, caring is often described in unidirectional ways and terms such as cared for and care *recipient* are reductive.

Note: The summary table presents information on carers for older adults, including dementia, only. Some additional literature relating to the experiences of parents caring for a child with a disability is included in the report and the full citation appears in the list of references.

Summary of key findings

Various types of short breaks are identified in the literature, including traditional day-care, residential care and in-home respite, along with alternative breaks provided by host family support arrangements, supported holidays (taken together and apart), access to leisure and arts facilities, the provision of equipment (for example, a bicycle), the provision of space (for example, a shed) and technologies (for example, telecare). A broad range of terms are used to describe short breaks, including respite care and restorative care.

Notably, most studies evaluating the impact of short breaks focus on traditional day and residential respite care services rather than the more alternative types of support that have developed in recent years. This highlights a significant gap in our current understanding of short breaks provision and the role of alternative short breaks in enabling carers and those they support to achieve positive wellbeing outcomes. Evaluating the impact of these breaks, from a range of perspectives, is a priority for future research and practice development.

Findings from the scoping review are presented below, summarising what the literature tells us about the impact of short breaks, identifying key factors that are critical in effecting positive outcomes and exploring areas for future research.

What research tells us about the impact of short breaks for carers – carer health and well-being

A good deal of the research identified for inclusion in this scoping review describes the impact of short breaks on carer health and wellbeing. It highlights both the positive and negative impacts arising from short breaks as well as the importance of personalisation in shaping health and wellbeing outcomes.

Impact of short breaks on carer health and wellbeing – positive outcomes

Being a carer can be physically and emotionally tiring (Shared Care Scotland 2012). Research confirms that short breaks provide relief from caring (Ashworth and Baker 2000, Berglund and Johansson 2013, Rochira 2018), leaving carers feeling invigorated (Neville and Byrne 2007, Berglund and Johansson 2013). Shaw et al's (2009) systematic review of respite care provision for frail older people identifies various positive outcomes relating to health and wellbeing including improved carer morale. Meanwhile, Victor's (2009) systematic review of UK interventions for carers concludes that short breaks lead to improvements in carer emotional well-being, with feelings of normality, freedom, peace of mind and relief, albeit tempered by a sense of anxiety, sadness and guilt.

We identified eighteen studies (looking at carers for older adults including those with dementia) where validated outcome measures were used to assess the impact of short breaks on carers' physical and emotional health and their perceived sense of wellbeing (see Appendix 2).

Using stress hormone cortisol measures to assess the impact of short breaks on carer stress, Klein et al (2016) report that frequent use of day care services is associated with a reduction in carer stress, whilst Leggett et al (2016), also using stress hormone cortisol measures, conclude that adult day care services have a protective or restorative effect on the carer, helping them to manage stressors associated with the caring role. The authors emphasise the public health benefits of short breaks for carers involved in supporting someone living with dementia.

Assessing carer stress and overload, using the CES-D Depression Scale, Måvall and Thorslund (2007) report day care has a more positive outcome on carers who are less worried, overloaded and burdened at base line, than carers with a high score for negative and difficult feelings. Liu et al (2018) note that breaks afforded by frequent use of day care services decrease carer related stress, as measured using the Daily Inventory of Stressful Events Measure (DISE) and potentially confer physiological benefits to chronically stressed carers, with more time to participate in other activities and exposure to non-care related activities. It is interesting to note that findings from the Måvall and Thorslund (2007) study suggest that day care needs to be targeted effectively and offered in a timely way otherwise it has limited impact, whilst the findings from Liu et al's (2018) work suggests that day care does confer benefits for carers who report chronic stress levels.

In their three month research comparing *users* with *non-users* of day care, Gaugler et al (2003) report adult day care services *might* have positive effects on carer health and co-residing relatives with dementia, specifically the opportunity to engage in social activities whilst attending day care can help to reduce behavioural difficulties in the supported person and potentially this can reduce carer stress.

Research confirms that short breaks enhance carers' sense of resilience and perceived well-being, alleviating some of the physical and emotional stressors associated with caring (Zarit et al 2014, Vandepitte et al 2016). Carers illustrate how essential short breaks are to supporting wellbeing outcomes:

> *I don't know what I'd have done without them.*
> (Greenwood et al 2012, 6).

> *It has been just been a life saver for me.*
> (Roberts and Struckmeyer 2018, 7).

A sense of *retrospective necessity* is evident in carer accounts of short breaks provision. Carers highlight the impact short breaks have upon their wellbeing and ability to cope with their caring responsibilities. Throughout the literature, carers speculate on how they previously coped without a break and the benefit that might have been obtained had the short break provision been available earlier:

> *I initially found myself thinking, I'm the only person… the only one who can't do this, who can't get it right. But then, I began to realise that actually I was normal...they [the day center staff] helped me realise that it was normal to need a break...and after I accepted their offer...I could finally see that it works.*
> (Phillipson and Jones 2012, 11–12).

Some carers reflect on how short breaks enable them to continue caring; they only recognise this *retrospectively*. This may be because carers view short breaks as intended primarily for the benefit of the person they support rather than to benefit themselves. Some carers admit difficulties in coping with their caring responsibilities prior to accessing a break. They are embarrassed or reluctant to admit to needing help and recognise the necessity of the break *only afterwards* (Dundee Carers Centre 2014).

Studies report improvements in carers' emotional wellbeing by taking short breaks, having been very tired and rundown before their break and often citing that they need time to relax away from the demands of the caring role (Laing 2013). Research by O'Connell et al (2012) reports that four fifths of carers experience lower stress levels after a short break. In contrast, other studies report short breaks deliver *only* positive physical *but not* positive emotional outcomes (King and Parsons 2005), whilst others conclude that *any* positive benefits accruing from a break soon dissipate (McNally 2013).

Bell and Litherland (2013) evaluated five Shared Lives Plus Schemes across the South West of England over a two-year period. They describe the supported person (with dementia) as engaged in family life and activities and the carer reporting health benefits from having a break. Similarly, Wilz and Fink-Heitz (2008) explore assisted holidays – a short break for couples where one person is living with dementia. Most couples rate this short break as helpful and rejuvenating, reporting significant improvements in physical health, although the reported effect on depression is non-significant. A report by Dementia Adventure (2017), a charity enabling persons living with dementia to get outdoors, highlights improved health and well-being outcomes both for the carer and person living with dementia, an increased sense of resilience and reduced sense of isolation and loneliness.

Carers report that the opportunity to attend to basic self-care needs means their physical health often improves during short break periods (Salin and Åstedt 2007). In relation to residential breaks, carers can experience better sleep, feel a sense of assurance as well as knowing that, for the supported person, medical conditions could be identified during their stay (Lee et al 2007, Shared Care Scotland 2010).

Impact of short breaks on carer health and wellbeing – the importance of personalisation

Research confirms that positive health and wellbeing outcomes for carers and the individuals they support are linked to the provision of *personalised* short breaks. For example, Washington and Tachman (2017) report on a houseguest programme delivered by masters level social work students providing a personalised education workshop for the carer and visit plans tailored to carers' individual preferences. Positive carer outcomes are related to the tailored activities provided, rapport and reciprocity between the students and the family dyad.

Impact of short breaks on carer health and wellbeing – some negative outcomes

Alongside the positive health outcomes, research confirms that some carers taking short breaks report feelings of guilt, anxiety, emptiness and loneliness, particularly when the break takes the form of residential respite care (Salin and Åstedt, 2007, Shared Care Scotland 2012, Roberts and Struckmeyer 2018), as well as sadness at being separated (Victor 2009). This is captured by Roberts and Struckmeyer (2018, 8):

> *…. I just feel guilty, I'm not gonna lie.*

Strang (2001) reports on carers' sense of guilt, including the carer quoted below, who cancelled a pre-arranged break because of this:

> *….guilt. I didn't sleep that night hardly any at all and in the morning I got up and ….cancelled.*
> (Strang 2001, 78–79).

Some carers perceive a break as an admission of failure (Ashworth and Baker 2000), letting the supported person down and an abrogation of their caring responsibilities (Strang 2001, Bamford et al 2009, Greenwood et al 2012). Frequent visits to residential short break establishments, made by some carers, can make it difficult for them to relax and heighten their sense of stress. This is captured in the work by Salin et al (2009):

> *The lack of satisfaction expressed by spouse carers may have had to do with their making such frequent visits to the institution during respite care, which made it impossible for them to get the rest they needed.*
> (Salin et al 2009, 499).

Research suggests that these negative effects may be mitigated when carers are supported, either by family, friends or professionals, to accept their need for a short break as legitimate (de la Cuesta-Benjumea 2010, Phillipson and Jones 2012, Laing 2013) and appreciate its preventative effects (McDonald and Macleod 2016).

The logistics of arranging a short break can present a series of challenges for carers that can temporarily increase stress levels. For example, getting the supported person ready to take a break, transportation issues and settling in at a residential facility can be stressful (Bontinen and Perry 2001, McDonald and Macleod 2016). On returning home from residential based breaks, some carers report a deterioration in the physical and or cognitive functioning of the supported person and an increased burden of caring (King and Parsons 2005, Neville and Byrne 2008). Arksey et al (2004) call for more in-home short breaks provision to mitigate these effects. Whilst endorsing this call, Dundee Carers Centre (2014) emphasise that in-home provision must be personalised and culturally sensitive.

They cite examples of BME carers having to undertake additional work before taking a break, such as preparing appropriate family meals to cover the period they are away, which can exacerbate carer burden.

Impact of short breaks on carer health and wellbeing – the wider literature

Looking at the wider research literature, similar findings are reported in studies about the experiences of parents caring for a child with a disability, though the literature suggests that the positive outcomes for parents are often less tangible than the positive outcomes for their child (McConkey 2011). Spruin et al (2018) note the emotional health and wellbeing benefits for parent carers during and after the short break period. McConkey et al (2004) conclude that residential short breaks for parents supporting children with multiple disabilities provide rest, relaxation and uninterrupted sleep, whilst Wilkie and Barr (2008) and Collins et al (2014) highlight renewed energy levels amongst parents and the restorative outcomes arising from a short break. As with carers supporting older adults, parent carers also reflect on the *retrospective necessity* of short breaks, including those participating in focus group discussions convened by Shared Care Scotland in 2012:

> *...it does help you cope... you know, shortness of temper, you know, frustration... and the thing, when you have had respite and then don't have it, I can then look back and say 'my God, that really saved our life', and I mean that literally, you know, saved our family and everything.*
> (Shared Care Scotland 2012, 17).

Others suggest that short breaks have the potential to positively affect parent and child wellbeing and reduce parental stress, though it is sometimes difficult to determine whether changes in parental wellbeing are attributable to the short break per se or to other variables such as child maturation (Robertson et al 2011). The importance of *personalised* short breaks is highlighted by parents supporting a child with multiple disabilities (McConkey et al 2004, McConkey 2011), in particular, the preference for leisure and holiday breaks (McConkey and Adams 2001). However, for some parent carers taking a break can impact negatively on their perceived ability to cope with their caring responsibilities and their sense of resilience. This is captured in the interview work by Shared Care Scotland in 2012:

> *Well when you have to cope all the time you just do, but if you suddenly don't have to cope, you suddenly relax and all your coping mechanisms kind of go away, and then when he comes back I kind of go to pieces because I can't cope because I have left it behind, so I have to readjust, it takes me about another week to readjust and it's really hard.*
> (Shared Care Scotland, 2012, 23).

What research tells us about the impact of short breaks for carers – a life of their own

Supporting a life alongside caring is a key policy priority across the UK regions. Research confirms that short breaks present carers with opportunities to take time away from the 'caring world' to pursue personal interests and activities that are often taken for granted, such as socialising or going for a walk (Ashworth and Baker 2000, Gottlieb and Johnson 2000, Strang 2001, Schacke and Zank 2006, Victor 2009). Phillipson and Jones (2012, 10) capture this:

> *I feel it frees me up, even to talk on the phone or read, or do a crossword [...].*

Thinking and relating to others in ways not linked to the caring role affords carers space to temporarily 'disconnect' from being a carer and focus on other roles, for example, as a grandmother, a wife, a mother, or a friend, and to re-connect with other family members/significant others (de la Cuesta-Benjumea, 2011, Shared Care Scotland 2012). Laing (2013, 31) captures this:

> *I remembered that I still have some life. For a few days I wasn't just a carer or a mum or a wife.*

For some carers, short breaks afford opportunities to undertake routine domestic chores and mundane tasks, including going shopping and meeting basic self-care needs (such as sleeping and attending their own medical appointments) rather than pursuing outside interests or spending time with friends and family (Ashworth and Baker 2000, Gottlieb and Johnson 2000, Bontinen and Perry 2001, Bamford et al 2009, Greenwood et al 2012, O'Connell et al 2012, Berglund and Johansson 2013). This can be a source of frustration for carers as the following quote illustrates:

> *I am somewhat annoyed with having to spend so much time on housework.*
> (Carer, cited in Lund et al 2009, 119).

Chen and Huang (2011) describe how carers in Taiwan use short breaks to complete housework. Similarly, Salin and Åstedt, (2007) suggest that cleaning the supported person's room at the start of a residential short break is a symbolic gesture representing a break from the caring role.

Employing a batch of measures that include the Caregiver Burden Inventory, CES-D Depression Scale and Caregiving Appraisal Instrument, Lund et al (2009) explore the use of respite time with 52 family carers who avail of adult day care services. They conclude that carer wellbeing outcomes are influenced by carers' level of satisfaction with *how they spend their respite time* and *how consistent they are in engaging with favoured activities*, for example, hobbies and restorative activities. Those carers who are very satisfied with their use of time have significantly lower depression scores than those who are not satisfied. Carers reporting inconsistency between their desired versus actual respite activities and also dissatisfaction with their use of time report higher levels of depression and carer burden and less satisfaction in the caring role. However, the authors note it is important to consider that carers who are depressed from the outset are less able to use their respite time satisfactorily.

McNally's (2013) study of temporary residential respite also highlights that short breaks have the most positive impact on wellbeing, albeit temporary, when carers are able to engage in creative and absorbing social activities rather than complete practical and mundane tasks. Similar conclusions are drawn by Pienaar and Reynolds (2015) and O'Shea et al (2017), who argue that the way carers use the time afforded by a short break has a significant effect on carer outcomes. A satisfactory use of time pursing interests or being with family and friends is associated with positive outcomes and improved caregiver wellbeing.

Research completed by Shared Care Scotland (2012, 14) draws similar conclusions. For example a parent caring for her young son reports:

> *It's wonderful because I just feel as though I'm living again, instead of just being a total carer.*

Presenting findings from their mixed method study looking at parental preferences for short breaks provision, McConkey et al (2004) report that parents value breaks that enable them to do things they could not otherwise do. Time for oneself is also identified as important by older parents whose adult son or daughter has intellectual disabilities (McConkey and McCullough 2006). However, it is important to note that time away from caring can be occupied by other demands for parent carers, including responsibilities for other children (McConkey 2011).

What research tells us about the impact of short breaks for carers – positive relationships with the supported person

Research confirms that short breaks play a key role in supporting positive caring relationships and enabling carers to continue caring (Ashworth and Baker 2000, Schacke and Zank 2006, Victor 2009, Shared Care Scotland 2012, Berglund and Johansson 2013, Downes 2013, Dalton et al 2018, Rochira 2018). Affording much needed space, short breaks enable carers to positively frame their relationship with the supported person, their caring role and their achievements (Roberts, and Struckmeyer 2018). Following a break, carers report renewed vigour and commitment to the caring role. Laing's (2013, 31) evaluation of the Time to Live strand of the Creative Breaks Programme in Scotland captures this:

> *it enabled them to return to their caring role with renewed energy, enthusiasm and ability.*

The nature and quality of the pre-existing relationship is of course important.

Following their evaluation of the Shared Lives Project, Bell and Litherland (2013) conclude that short breaks can help support improvements in relationships when someone is living with dementia.

Carers reflect on the importance of their short break experience both for themselves and for the continuation of the caring relationship:

> *It keeps him out of full time care because I think otherwise I would be suicidal*
> (Shared Care Scotland 2012, 11).

Parent carers report similar outcomes. For example, Collins et al (2014) note that short breaks can make the difference between parents feeling able to cope and continue in their caring role and they enable them to care for their other children. Similarly, Robertson et al (2010) note that short breaks support families to get along better and relieve family stress. McConkey (2011) notes improved family functioning and coping following a short break.

What research tells us about the impact of short breaks for carers – choices in caring

There is limited research looking at the ways short breaks provision might impact on carer choices, including limits to the caring role. Whilst some studies suggest that short breaks play a key role in supporting continued caring and delaying admission to nursing or residential care (Pickard 2004, Arksey et al 2004, Shared Care Scotland 2012, Dundee Carers Centre 2014) there is too little research to draw firm conclusions. For example, Mason et al's (2007) systematic review, looking at different models of respite care, concludes there is no reliable evidence that short break interventions influence choices about caring, including preventing or delaying entry to nursing or residential care. This is an important area for future research and practice development.

What research tells us about the impact of short breaks for carers – satisfaction in caring

There is very limited evidence looking at the impact of short breaks on carer satisfaction with the caring role. This is an important area for future research and development as levels of carer satisfaction are known to be closely associated with a willingness and ability to continue in the caring role.

Research concludes that short breaks can contribute to carer satisfaction if they offer some type of educational experience and an opportunity to learn from other carers (Gitlin et al 2006, Phillipson and Jones 2012, Dalton et al 2018). This in turn can facilitate carer confidence and a greater sense of overall satisfaction in their caring role. Gitlin et al (2006) report on a day care plus service that offers support and education to carers and enhances carer confidence in managing complex behaviours. Additionally, carers utilising this short break day care facility report an enhanced sense of wellbeing, reduction in depressive symptoms and a decreased sense of carer burden.

What research tells us about the impact of short breaks for carers – the quality of the short break experience

The quality of the short break experience for the supported person, in particular, the opportunity for safe and meaningful engagement, is critically important in determining outcomes (de Jong and Boersma 2009, Shared Care Scotland 2012, McDonald and Macleod 2016). Research confirms that short breaks have greater physical, psychological and psychosocial benefit when they are appraised, by the carer, as a positive experience for the supported person (O'Shea et al 2017). Indeed, research suggests this lessens carers' sense of guilt (Stirling et al 2014).

Where there are concerns over the quality of the break experience, carers continue to carry the stress of caring during a short break, remain home, or, in the case of in-home respite, leave the house for only a short period of time (Carretero et al 2007, Neville and Byrne 2007, Bamford et al 2009, Greenwood et al, 2012, Berglund and Johansson, 2013, Dundee Carers Centre 2014). Perpetual worrying about the supported person and, in the case of residential breaks, an expectation of frequent visits can negate positive outcomes (Salin and Åstedt, 2007, Salin et al 2009). De la Cuesta-Benjumea (2010) concludes that carers are the 'referee of standards of care' and the responsibility of care is only relinquished when carers have confidence in the quality of the short breaks provision.

Research identifies key characteristics of traditional residential short breaks provision that are important in determining positive wellbeing outcomes for carers and those they support – further details are presented in the summary table (Appendix 1). It seems likely that some of these characteristics are also pertinent to alternative short breaks provision, such as supported holidays. Key characteristics include appropriate levels of staff expertise, personalisation of care and support, opportunities for additional medical care and interventions to address behavioural problems (de Jong and Boersma 2009, Victor 2009, McDonald and Macleod 2016, Vandepitte et al 2016). The importance of enjoyable and stimulating activities, opportunities to interact with others, staff friendliness, empathy, respect and a safe environment are highlighted (Arksey et al 2004, Bamford et al 2009, Greenwood et al 2012, Berglund and Johansson 2013, Stirling et al 2014, O'Shea et al 2017). Short breaks are appraised as positive when they include stimulation and activities for the supported person, particularly activities which the carer feels they could not themselves provide (Bontinen and Perry 2001) and, in the context of dementia care, when specialist dementia nurses provide tailored information and advice to carers (Phillipson and Jones 2012). A positive short break environment is one that enables the supported person to 'be themselves':

> *[…] For just a moment he was a person of value*
> (carer, quoted in de Jong and Boersma, 2009, 275).

The Dementia Adventure Impact Report (2017) highlights the importance of enabling people living with dementia to get outdoors, take positive risks and try new things. The organisation report this type of short break confers benefits associated with the outdoor environment, to the carer and supported person, improving carer wellbeing and helping to sustain positive caring relationships.

Similar findings are reported in the wider literature. For example, McConkey and McCullough (2006) highlight the benefits of holiday breaks for adults with intellectual disabilities, such as getting away from home, fun activities and new experiences. McConkey et al 2004 note similar short break benefits for children with disabilities, such as social interaction, a change of environment, a break from routine and fun activities. The authors also highlight opportunities to develop skills that enable some children to become more independent. Following their mixed method study of short breaks and respite services in England, Welch et al (2014) conclude that breaks provide opportunities for children to access the outdoors and be creative. Fewer conduct and hyperactivity problems are noted after taking a short break (Spruin et al 2018).

It is important to recognise that residential breaks can be a worrying time for carers and be mindful of the need to take steps to mitigate carer anxieties (Salin and Åstedt 2007). Where breaks are taken apart, staff updates about older adults and activities they undertake are appreciated by carers (Bamford et al 2009, de Jong and Boersma, 2009). Similarly, parent carers, whose children take residential short breaks, highlight the importance of staff feedback (McConkey et al 2004) which can help to address worries about standards of care and parental ambivalence and emotional conflict (McConkey 2011, Robertson et al 2011). Research concludes that a break alone is insufficient to reduce the stressors that some parent carers experience; it is when trusted relationships with break providers are forged that parents experience most benefit (McConkey 2011). Building and sustaining positive relationships with providers and helping families to plan for the future is key (McConkey 2011). An evaluation of Action for Children Services in Cardiff, Edinburgh and Glasgow affirms the benefits of staff sharing their expertise and experience with parent carers whose children have developmental disabilities and severely challenging behaviour (McConkey 2011). The importance of personalised short breaks, matching short breaks to the needs and preferences of families, is key (McConkey and Adams 2001).

Duration of short breaks

The duration of the short break is an important consideration. Research confirms this is linked to carer reported outcomes, with longer breaks (of more than 24 hours) having a greater positive effect for carers than shorter ones (Shaw et al 2009). Research by Dundee Carers Centre (2014) suggests that a period of less than half a day is not considered a short break. Pienaar and Reynold's (2015) work supports this. They report on a creative art and leisure programme for carers with the supported person cared for nearby. The four 90 minute sessions are considered 'not long enough' by carers, with some expressing sadness when the programme ends. Having said this, research confirms that carers have modest expectations about the frequency and duration of breaks. This is captured by a parent carer:

> *I am not looking for massive amounts…but it would be really nice if three or four times a year I could have one or two overnights where I could plan to do something like go away for the weekend*
> (Shared Care Scotland 2012,23).

Carers from BME backgrounds are less likely to have a break than carers from other ethnic groups (Arksey et al 2004) and feel that they have limited choices (Shared Care Scotland 2012). Research has emphasised the need to recognise the heterogeneity of the carer population, in particular, language and culture (Shaw et al 2007, Shared Care Scotland 2012) and be mindful of family boundaries and traditions (Dundee Carers Centre 2014).

What research tells us about the impact of short breaks for carers – the importance of choice and flexibility

An evaluation of the Scottish Short Breaks Fund projects notes that personalisation and choice, for both the carer and the supported person, are crucial in affecting outcomes (Scottish Government 2011). The importance of choice in short breaks provision to address varied needs and preferences is also highlighted by Shared Care Scotland (2010). For example, some carers express a wish for a family holiday, rather than the break that is offered. Shared Care Scotland (2010) emphasise that the optimal type of short break varies considerably, dependent on personal choice, from a few hours, a few days or longer. Some carers prefer a break with the supported person, others without, some in their own home, others in an external location. Some carers may favour more than one type of break, for example, combining holidays and sitting services.

Whilst there is very limited evaluation of alternative short breaks provision in the research literature, there is evidence such breaks are appraised positively by carers. Assisted vacations are positively evaluated by carers and the person they support, in particular, the opportunities for social activities and continuous exchange of experiences with other carers (Wilz and Fink-Heitz, 2008). Dundee Carers Centre (2014) highlight the benefits of taking breaks with other carers, noting opportunities for mutual support and mentoring. Through their mapping of short breaks provision, they highlight the need for more holiday type breaks.

Research confirms the need for greater flexibility in short breaks provision, with traditional forms of support being expensive and lacking responsiveness to the needs and preferences of carers and the individuals they support (O’Connell et al 2012, Rochira 2018). In the case of dementia, different types of short break may be required along the dementia care pathway to effectively meet the wellbeing outcomes for carers and those living with dementia (Rochira 2018). Work by Shared Care Scotland (2010) highlights an over reliance on traditional forms of short breaks, despite other options better suited to the needs and wishes of the carer and supported person. Whilst some local authorities have tried to move away from ‘traditional’ overnight short breaks, there is mixed success and challenges to address. For example, older people are noted as being “risk averse” and traditionally least likely to use self-directed support and non-traditional short break options. Dundee Carers Centre (2014) notes the importance of self-directed support in facilitating the provision of personalised and more creative breaks. They suggest there is much to be learned from the culture and practice of the learning disability field, where carer short break needs are more widely recognised.

Research concludes that breaks are predominantly *provision* rather than *person* centred. This is highlighted in the following quotes from carers contributing to the *Rethinking Respite* study (Rochira 2018):

> *And it's not individual people's care – it's just about containing people and that's why people don't want to go.*
> (Rochira 2018, 28).
>
> *They're not looking at it logically and it's not person centred.*
> (Rochira 2018, 28).
>
> *[Respite is] rigid and off-the-shelf…They need to tailor the service – not off-the-shelf [services] like we are little dolls.*
> (Rochira 2018, 33).

Rurality presents challenges, in particular, the limited availability of accessible services, lack of opportunities to take breaks together and transportation issues. *Respitality* in Scotland is cited as a creative solution to breaks provision. Reviewing breaks provision in the Scottish Highlands, McDonald and Macleod (2016) call for an expansion of *respitality* services in partnership with the tourist sector. Similar calls have been made to look at alternative types of shorter term provision, for example, the expansion of Dementia Cafes that provide meaningful engagement for people living with dementia and their carers (Dalton et al 2018) and creative arts and leisure interventions that seek to promote the wellbeing of caring dyads (Pienaar and Reynolds 2015).

What are the gaps in the existing research literature?

This scoping review has identified a broad range of interesting and informative literature. However, there remain significant gaps in our understanding of the impact of short breaks provision, particularly the impact of alternative short breaks that move away from traditional service models. Further research is needed, across the UK regions, to explore:

- The ways short breaks might contribute to the delivery of improvements against national priorities for carers and those they support
- The extent to which carers enhanced rights under recent legislation are effectively translated into practice in respect to their short break needs

There are exciting opportunities for research-informed practice development. Some broad areas for future research development activity are set out below and are clustered around three key themes:

- Understanding *what matters* – capturing and evidencing short break needs
- Capturing *what matters* – outcomes from short breaks
- Commissioning, delivering and scaling up alternative short breaks provision to reflect *what matters* to carers

Whilst future research will vary in design and scale, as well as suitability for open and responsive funding calls, some observations relating to research methods and study design are presented.

Understanding what matters – capturing and evidencing short break needs

Understanding *what matters* to carers and those they support is key to taking forward research and practice development activity, in particular, what constitutes a meaningful short break, the hallmarks of impactful provision and key features of the caring experience that shape short break preferences.

Research must look at current carer assessment and support planning processes and explore, from carer and practitioner perspectives, the sensitivity and effectiveness of these in identifying, capturing and evidencing carer short break needs. This includes opportunities for carer self-identification of their short break needs. Qualitative research might also explore how dialogue between practitioners and carers during a carer assessment could potentially help to legitimise carers' need for a short break and relieve some of the associated anxieties and feelings of guilt. This research may sit within a wider programme of work around assessments and support planning as co-produced conversations to generate shared understanding and promote positive wellbeing outcomes. Drawing upon the existing evidence base about outcome focused carer assessments and support planning (Seddon et al 2010, Cook and Miller 2012, Seddon and Robinson 2015, McBride et al 2017) could help to inform future approaches to identifying and capturing short break needs.

Review is key to effective assessment and care management and responsiveness to changing needs. Mixed methods research is needed to understand how review processes report on the outcomes from short breaks and how this information might inform the future planning and commissioning of short breaks provision.

Capturing what matters – outcomes from short breaks

Whilst there are descriptive accounts of alternative short breaks provision in the published literature there is very limited research exploring or measuring the outcomes arising from this type of breaks provision. How best to capture or measure outcomes, both qualitatively and quantitatively, is a methodological challenge. This might include the development of an appropriate suite of validated measures (see below).

There are important lessons to be learned from existing work looking at personal outcomes, for example, the *Meaningful and Measurable* action inquiry project (Miller and Barrie 2016). This project explores how best to capture and use personal outcomes data, considers the quality of interactions needed to generate robust outcomes data, captures emergent good practice in recording outcomes and highlights the difference made by focusing on outcomes in practice.

Whilst capturing health and wellbeing outcomes is important, future research must consider a broader range of outcomes, in particular, the role of short breaks in supporting carers to have a life of their own, the impact on carer sense of satisfaction in the caring role, the ways in which short breaks do or do not influence choices about caring (including limits and decisions about care home placement) and outcomes for the wider family. In the context of parents caring for a child with a disability, it is important to explore the impact of short breaks on siblings.

Ways to maximise positive outcomes arising from short breaks is an important area for future research. This might include ways to reduce carer anxiety prior to and during the break period and support for carers who feel lonely and isolated during the short break period. Allied to this, it is important to understand more about carers' use of time during short breaks and how this influences outcomes. For example, the opportunity to undertake mundane tasks versus pursuing personal interests and other roles. Drawing on Chappell et al's (2001) distinction between *internal* and *external* respite provision might prove helpful. External provision refers to a complete disengagement from practical and physical caring activities, whilst internal provision refers to mental or physical stimulus with all-encompassing activities for the mind or body such as reading, hobbies or television as well as *stolen moments* away from caring.

Little is known about the ways in which short breaks may be effectively combined with other interventions. For example, the impact of combining a short break with opportunities for counselling or training and education around key issues, such as coping skills, relaxation techniques, behavioural management, sleep management and meeting self-care needs. Understanding the barriers and facilitators to achieving wellbeing outcomes during a short break is also important, in particular the importance of:

- Supporting carers to identify the outcomes that are important to them and working from that understanding
- Establishing relationships with a trusted support worker

The impact of different types of alternative short breaks in realising outcomes is an important area for future research and development, including breaks taken together and breaks taken apart, breaks taken in the home, breaks taken away from the home. This may also include the benefits (or otherwise) of taking breaks with other carers. The optimum length of break is also important as are strategies to maintain positive outcomes following a short break.

Commissioning, delivering and scaling up alternative short breaks provision to reflect what matters to carers

It is important to be mindful of the changing policy and practice context, in particular, the move towards personalisation and self-directed support. Re-thinking the role of commissioners as facilitators of change, helping to bring together providers, people with complex care needs and their carers to shape the future development of short breaks provision is key. It is critical to co-creating a future vision for short breaks that reflect jointly produced, mutually valued outcomes.

The evolution of commissioning and procurement arrangements required to support the delivery of short breaks provision is an important area for future research and development. Reflecting the complex, inter-sectoral nature of short breaks provision, research is needed to identify ways to effectively commission and deliver alternative, meaningful short breaks in the future that reflect what matters to carers, including through:

- Social enterprise services
- Social tourism/respitality
- Social prescribing, linking individuals to non-clinical community-based support such as sport, leisure and arts facilities
- Individual direct payments and self-directed support
- Pooling of direct payments, with other people in similar circumstances, to enable new provision to be established

Research must address the barriers and facilitators associated with diffusing into practice alternative approaches to the commissioning and delivery of short breaks provision, including new partnerships with sectors such as hospitality, leisure and arts. Taking into account the emerging landscape of new providers, research should build upon work completed in Scotland (McDonald and Macleod 2016) to explore the challenges of delivering personalised, culturally sensitive breaks to an increasingly diverse population, including those living in remote rural areas of the UK. This includes upscaling, future sustainability and capacity issues and how these might be addressed against a backdrop of rising demand and declining public budgets.

Research methods and study design

There are number of important considerations that need to be borne in mind when planning and designing research around short breaks provision.

Future research must capture the heterogeneity of the carer population and effectively articulate the views of people with complex support needs. Findings from this scoping review highlight that the outcomes of short breaks are closely tied to the quality of the short break experience, yet the perspective of the supported person is often missing from studies (Arksey et al 2004, Bamford et al 2009, O'Shea et al 2017). It is crucial that this perspective is reflected, alongside the perspectives of carers and practitioners, not least because the outcomes for the person with complex care needs also influence the outcomes for the carer, as reflected in the research reported above. This may present challenges where cognitive impairments or learning difficulties are present but these challenges are not insurmountable for experienced researchers with appropriate expertise. Capturing the perspectives of other family members, which may include siblings and spouses to understand how short breaks affect them, is also important and will help to address gaps in the existing evidence base.

As an under researched field, there are considerable opportunities for quantitative, qualitative and mixed methods studies. This includes cross-sectional research designs that capture short break experiences at a single point in time and longitudinal research to explore short break needs, impact and provision over a longer period of time. Longitudinal work with carers and people with a broad range of chronic health conditions might be particularly informative, with a focus on how short break needs might change over time and the contributing factors. Drawing on some of the seminal theoretical and conceptual work around caring, for example, the *caring career* (Pearlin and Aneshensel 1994) and the *carers as experts model* (Nolan et al 1996) might offer some useful insights into understanding how short break needs evolve and change over time.

Observational research, for example, observing (with explicit consent) assisted holiday programmes, may yield interesting insights that are difficult to capture using other methods. Such techniques may capture the inter-dependent and rewarding aspects of some caring relationships and 'in the moment' benefits that may or may not contribute towards lasting impacts.

There are exciting opportunities to undertake large-scale trials in order to compare short break outcomes arising from traditional versus alternative break types. This might include comparisons of traditional day and residential respite care provision, with in-home respite and more alternative breaks, such as supported holidays. Intervention studies might also compare the impact of alternative short breaks for different carer groups. Clearly there are a broad range of comparators, including but not restricted to:

- Carers supporting individuals with different conditions
- Carers supporting adults and those supporting children and young people
- Carers from different ethnic backgrounds
- Co-resident and non-resident carers
- Adult carers and young carers

Capturing outcomes from short breaks presents a challenge. Work to develop and validate a suite of *carer generated* measures to reflect health, wellbeing and resilience outcomes, alongside social and relational outcomes is a priority. There are limitations to current measures in use. For instance, although measuring symptoms like depression is important not all carers experience significant symptoms of depression. In longitudinal studies, measures that have low endorsement at baseline (i.e. no problem indicated) will not capture the impact of short break interventions as there is no room to score significantly better on the measure (i.e. there are floor/ceiling effects).

Reporting research findings with a view to informing practice development can present challenges. Researchers need to think carefully about dissemination strategies. Alongside traditional academic peer-reviewed papers, they must devise more creative and impactful ways of conveying key messages to commissioners and providers (for example, podcasts that relay first-hand experiences of short breaks) and target these messages effectively.

Conclusion

This scoping review has identified research literature, published from 2000 onwards, that reports on outcomes of short breaks for carers, with a particular focus on carer health and wellbeing, a life alongside caring, relationships with the supported person, choices in caring and satisfaction in caring. It concludes that a good deal of research has looked at traditional day and respite care provision to the neglect of more alternative types of provision that have developed in recent years.

Broad areas for future research development have been identified. Whilst the scoping review has concentrated mainly on carers for older adults, including those with dementia, the heterogeneity of the carer population is recognised as is the importance of researching and evaluating short breaks provision from a range of different perspectives.

References

Age UK (2017) Older carers left to fill the gap as our social care system crumbles https://www.ageuk.org.uk/latest-news/articles/2017/december/older-carers-fill-the-gap/

Arksey, H. and O'Malley, L. (2005) Scoping studies: towards a methodological framework. *International Journal of Social Research Methodology* 8, 19-32.

Arksey, H. Jackson, K., Croucher, K., Weatherly, H. Golder, S., Hare, P., Newbronner, E., and Baldwin, S. (2004) Review of Respite Services and Short-term Breaks for Carers for People with Dementia. *Report for the National Co-ordinating Centre for NHS Service Delivery and Organisation R&D*.

Ashworth, M and Baker, M (2000) Time and space: carers' views about respite care. *Health and Social Care in the Community* 8, 1, 50–56.

Bamford, C., Arksey, H., Poole, M., Kirkley, C., Hughes, J., Corber, L., and Bond, L. (2009) Person- and carer-centred respite care for people with dementia: developing methods of evaluating the effectiveness of different methods: report for the National Institute for Health Research Service Delivery and Organisation programme. *Southampton: National Institute for Health Research.*

Bell, J. and Litherland, R. (2013) *Shared Lives and Dementia*. Final Report of the National Shared Lives Dementia Project. Shared Lives South West http://sharedlivessw.org.uk/wp-content/uploads/2013/09/exec-summary.pdf

Berglund, A.L. and Johansson, I. (2013) Family caregivers' daily life caring for a spouse and utilizing respite care in the community. *Nordic Journal of Nursing Research and Clinical Studies /Vård i Norden*, 33, 1, 30–34.

Bontinen, P. and Perry, J. (2001) Evaluation of a weekend respite program for persons with Alzheimer disease. *Canadian Journal of Nursing Research* 33, 1, 81–95.

Care (England) Act (2014) http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted

Carers (Scotland) Act (2016) https://www2.gov.scot/Topics/Health/Support-Social-Care/Unpaid-Carers/Implementation/Carers-scotland-act-2016

Carers UK (2017) *State of Caring 2017*, Carers UK.

Carers UK (2018) *State of Caring 2018,* Carers UK.

Carretero, S., Garcés, J., Ródenas, F. (2007) Evaluation of the home help service and its impact on the informal caregiver's burden of dependent elders. *International Journal of Geriatric Psychiatry* 22, 782–749.

Chappell, N. L., Reid, R.C. and Dow, E. (2001) Respite reconsidered – A typology of meanings based on the caregiver's point of view. *Journal of Aging Studies* 15, 2, 201–216.

Chen, T.F. and Huang, L.H. (2011) Caregiver Efficacy and Efficacy Determinants for Elderly Care Recipients Who Accept Home Respite Care in Taiwan. *Journal of Nursing Research*, 18, 1, 18–25.

Collins, M., Langer, S., Welch, V., Wells, E., Hatton, C., Robertson, J., and Emerson, E. (2014) A break from caring for a disabled child: parent perceptions of the uses and benefits of short break provision in England. *British Journal of Social Work*, 44(5), 1180–1196.

Cook, A., and Miller, E. (2012) Talking Points Personal Outcomes Approach: A Practical Guide. Joint Improvement Team. Scotland. Retrieved from https://personaloutcomes.files. wordpress.com/2014/03/talking-points-summary-briefing-21-june-2012.pdf <https://personaloutcomes.files.wordpress.com/2014/03/talking-points-summary-briefing-21-june-2012.pdf>

Dalton, J., Thomas, S., Harden, M., Eastwood, A., and Parker, G. (2018) Updated meta-review of evidence on support for carers. *Journal of Health Services Research and Policy*, 23, 3, 196–207.

de la Cuesta-Benjumea, C. (2010) The legitimacy of rest: conditions for the relief of burden in advanced dementia care-giving. *Journal of Advanced Nursing* 66, 5, 988–998.

de la Cuesta-Benjumea, C. (2011) Strategies for the relief of burden in advanced dementia care-giving *Journal of Advanced Nursing* 67, 8, 1790–1799.

de Jong, J. D. and Boersma, F. (2009) Dutch psychogeriatric day-care centers : a qualitative study of the needs and wishes of carers. *International Psychogeriatrics*, 21, 268–277.

Dementia Adventure (2017) Dementia Adventure Impact Report https://dementiaadventure.co.uk/wp-content/uploads/2018/02/Dementia-Adventure-2017-Impact-Report.pdf

Downes, S. (2013) The Eden Principles in dementia respite care: carers' experience. *Quality in Ageing and Older Adults*, 14, 2, 105–115.

Dundee Carers Centre (2014) Short Break (Respite Care) Provision in Dundee – now and in the future. https://lx.iriss.org.uk/sites/default/files/resources/short-break-provision-in-dundee-now-and-in-the-future-draft-final-report-october-21-v4.pdf

Gaugler, J., Jarrott, S., Zarit, S., Stephens, M. and Townsend, A. (2003) Respite for Dementia Caregivers: The Effects of Adult Day Service Use on Caregiving Hours and Care Demands *International Psychogeriatrics* 15, 1, 27–58.

Gitlin, L.N., Reever, K., Dennis, M.P., Mathieu, E., Hauck,W.W. (2006) Enhancing Quality of Life of Families Who Use Adult Day Services: Short- and Long-Term Effects of the Adult Day Services Plus Program, *The Gerontologist*, Volume 46, Issue 5, 630–639.

Gottlieb, B. H., and Johnson, J. (2000) Respite programs for caregivers of persons with dementia: A review with practice implications. *Aging and Mental Health*, 4(2), 119–129.

Greenwood, N., Habibi, R., and Mackenzie, A. (2012) Respite: carers' experiences and perceptions of respite at home. BMC Geriatrics, 12, 42.

Holm, S., and Ziguras, S. (2003) The host-homes program: an innovative model of respite for carers of people with dementia *Australasian Journal on Ageing* 22, 3, 2003.

King, A., and Parsons, M. (2005) An evaluation of two respite models for older people and their informal caregivers *The New Zealand Journal* 118, 1214.

Klein, L. C., Kim, K., Almeida, D. M., Femia, E. E., Rovine, M. J., and Zarit, S. H. (2016) Anticipating an easier day: Effects of adult day services on daily cortisol and stress. *Gerontologist*, 56(2), 303–312.

Laing, A. (2013) *Evaluation of Time to Live Short Breaks Fund* (Supported by Scottish Government) Evaluation of Time to Live strand of the Creative Breaks programme from October 2012–September 2013.

Leggett, A. N., Liu, Y., Klein, L. C., and Zarit, S. H. (2016) Sleep duration and the cortisol awakening response in dementia caregivers utilizing adult day services. *Health Psychology*, 35(5), 465–473.

Lee, D., Morgan, K., and Lindesay, J. (2007) Effect of institutional respite care on the sleep of people with dementia and their primary caregivers *Journal of the American Geriatrics Society*, 55(2), 252–258.

Liu, Y., Almeida, D M., Rovine, M. J., and Zarit, S. H. (2018) Modelling Cortisol Daily Rhythms of Family Caregivers of Individuals with Dementia: Daily Stressors and Adult Day Services Use. *Journals of Gerontology – Series B Psychological Sciences and Social Sciences*, 73, 3, 457–467.

Lund, D. A., Utz, R., Caserta, M. S., and Wright, S. D. (2009) Examining What Caregivers Do During Respite Time to Make Respite More Effective. *Journal of Applied Gerontology* 28, 1, 109–131.

Mason, A., Weatherly, H., Spilsbury, K., and Arksey, H. (2007) Community-based respite care for frail older people and their carers. *Health Technology Assessment*, 11, 15, 1–157.

Måvall, L., and Thorslund, M. (2007) Does day care also provide care for the caregiver? *Archives of Gerontology and Geriatrics*, 45, 2, 137–150.

McBride, T., Miller E., and Dewar, B. (2017) "I know who I am; the real me, and that will come back:" The importance of relational practice in improving outcomes for carers of people with dementia, Illness, Crisis and Loss, online version: http://journals.sagepub.com/doi/abs/10.1177/1054137317700061

McConkey, R. (2011) *Working Outside the Box: An Evaluation of Short Breaks and Intensive Support Services to Families and Disabled Young People whose Behaviour is Severely Challenging*. Summary Report for Action for Children.

McConkey, R., and Adams, L. (2000) Matching short break services for children with learning disabilities to family needs and preferences. *Child: Care, Health and Development*, 26, 5, 429–444.

McConkey, R. and McCullough, J. (2006) Holiday Breaks for Adults with Intellectual Disabilities Living with Older Carers. *Journal of Social Work*, 6, 1, 65–79.

McConkey, R., Truesdale, M., and Conliffe, C. (2004) The Features of Short-Break Residential Services Valued by Families Who Have Children with Multiple Disabilities. *Journal of Social Work,* 4, 1, 61–75.

McDonald, A., and Macleod, D. (2016) A Review of Respite/ Short Break Provision for adult Carers of Adults in the Highland Partnership Area Key Findings and Main Recommendations https://lx.iriss.org.uk/sites/default/files/respite_review_key_findings_and_main_recommendations_february_2016.pdf

McNally, L (2013) T*he Psychosocial and Physical Effects of Respite Care on Informal, Spousal Caregivers* PhD thesis, University of London.

Miller, E. and Barrie, K. (2016) *Learning from the Meaningful and Measurable project: Strengthening links between identity, action and decision-making*. Healthcare Improvement Scotland.

Miller, E. and Barrie, K. (2018) *Personal outcomes, person-centred working and personalisation* http://ssscnews.uk.com/wp-content/uploads/PersonCentredThinking_SummaryReport.pdf

Neville C.C., and. Byrne G .J. (2007) Staff and home caregiver expectations of residential respite care for older people. *Collegian* 14, 2, 27–31.

Neville, C. C., and Byrne, G. J. A. (2008) Effect of a residential respite admission for older people on regional Queensland family carers. *Collegian*, 15, 4, 159–164.

Nicoll, M., Ashwroth, M. and McNally, L. (2002) Satisfaction with respite care : a pilot study. *Health and Social Care in the Community*, 10, 6, 479–484.

Nolan, M., Grant, G. and Keady, J. (1996) *Understanding Family Care: A Multidimensional Model of Caring and Coping*. Open University Press. Maidenhead.

O'Connell, B., Hawkins, M., Ostaszkiewicz, J., Millar (2012) Carers' perspectives of respite care in Australia: An evaluative study. *Contemporary Nurse,* 41(1), 111–119.

O' Shea, E., Timmons, S., O' Shea E, Fox. S. and Irving. K (2017) Key stakeholders' experiences of respite services for people with dementia and their perspectives on respite service development: a qualitative systematic review. *BMC Geriatrics,* 17, 1, 282. http://doi.org/10.1186/s12877-017-0676-0.

Pearlin, L., and Aneshensel C. (1994) Caregiving: The unexpected career. *Social Justice Research*, 7(4):373–390.

Phillipson, L., and Jones, S. C. (2012) Use of Day Centers for Respite by Help-Seeking Caregivers of Individuals with Dementia. *Journal of Gerontological Nursing*, 38, 4, 24–34.

Pickard, L. (2004) *The effectiveness and cost-effectiveness of support and services to informal carers of older people* Literature Review for Audit Commissioning, London School of Economics, 1–90. https://www.pssru.ac.uk/pub/dp2014.pdf

Pienaar, L., and Reynolds, F. (2015) 'A respite thing': A qualitative study of a creative arts leisure programme for family caregivers of people with dementia.' *Health Psychology Open*, 2, 1.

Roberts, E., and Struckmeyer, K. M. (2018) *The Impact of Respite Programming on Caregiver Resilience in Dementia Care: A Qualitative Examination of Family Caregiver Perspectives*. INQUIRY: The Journal of Health Care Organization, Provision, and Financing, 55, 004695801775150. http://doi.org/10.1177/0046958017751507.

Robertson, J., Hatton, C., Wells, E., Collins, M., Langer, S., Welch, V., and Emerson, E. (2011) The Impacts of short break provision on families with a disabled child: An international literature review. *Health and Social Care in the Community*, 19, 4, 337–371.

Rochira, S., (2018) Older people's commissioner for Wales, Rethinking Respite for People Affected by Dementia Older Peoples' Commissioner Office http://www.olderpeoplewales.com/en/reviews/respite.aspx

Salin and Åstedt (2007) Women's views of caring for family members. *Journal of Gerontological Nursing* 33, 9, 37–45.

Salin, S., Kaunonen, M., and Åstedt-Kurki, P. (2009) Informal carers of older family members: how they manage and what support they receive from respite care. *Journal of Clinical Nursing*, 18, 4, 492–501.

Schacke, C., and Zank, S. R. (2006) Measuring the Effectiveness of Adult Day Care as a Facility to Support Family Caregivers of Dementia Patients. *The Journal of Applied Gerontology*, 25, 1, 65–81.

Scottish Government (2011) Short breaks fund Evaluation of round 1 projects https://lx.iriss.org.uk/sites/default/files/resources/sbf_round_1_evaluation_-_shared_care_scotland.pdf

Seddon, D. and Robinson, C. (2015) Carer assessment: continuing tensions and dilemmas for social care practice. *Journal of Health and Social care in the Community*, 23 (1):14–22, Special Edition.

Seddon, D., Robinson, C., Tommis, Y., Woods, B., Perry, J. and Russell, I. (2010) A study of the Carers Strategy 2000: Supporting Carers in Wales, *British Journal of Social Work*, 40 (5): 1470–1487.

Shared Care Scotland (2010) '*It's about time: An overview of short break (respite care) planning and provision in Scotland*' Report by Reid-Howe Associates Ltd for Shared Care Scotland https://lx.iriss.org.uk/sites/default/files/resources/its_about_time_report_nov_2010.pdf

Shared Care Scotland, (2012) *Rest assured: A study of unpaid carers' experiences of short breaks* https://www.iriss.org.uk/resources/reports/rest-assured-study-unpaid-carers-experiences-short-breaks-survey-data.

Shaw C., McNamara R., Abrams K., Cannings-John R., Hood K., Longo M., Myles S., O'Mahony S., Roe B., Williams K. (2009) Systematic review of respite care in the frail elderly. *Health Technology Assessment* (20): 1–224.

Social Services and Wellbeing Act (Wales) http://www.legislation.gov.uk/anaw/2014/4/contents

Spruin, E., Abbott, N., and Holt, N. (2018) Examining the Experiences of a Short Break Scheme amongst Adolescents with Disabilities (Service Users) and their Parents. *International Journal of Disability, Development and Education*, 65, 2, 148–162.

Stirling, C. M., Dwan, C. A., and McKenzie, A. R. (2014) Why carers use adult day respite: a mixed method case study. *BMC Health Services Research*, 14, 1, 245.

Strang, R. (2001) Family caregiver respite and leisure: a feminist perspective *Scandinavian Journal of Caring* 2001 15, 74–8.

Tretteteig, S., Vatne, S., and Rokstad, A. M. M. (2016) The influence of day care centres for people with dementia on family caregivers: an integrative review of the literature. *Aging and Mental Health*, 20, 5, 450–462.

Vandepitte, S., Van Den Noortgate, N., Putman, K. Verhaeghe, S., Verdonck, C., and Annemans, L. (2016) Effectiveness of respite care in supporting informal caregivers of persons with dementia: a systematic review. *International Journal of Geriatric Psychiatry* 31, 12, 1277–1288.

Victor, E. (2009) *A Systematic Review of Interventions for Carers in the UK : Outcomes and Explanatory Evidence*. London: The Princess Royal Trust for Carers, (January), 1–168.

Washington, T. R., and Tachman, J. A. (2017) Gerontological Social Work Student-Delivered Respite: A Community-University Partnership Pilot Program. *Journal of Gerontological Social Work*, 60, 1, 48–67.

Welch, V., Collins, M., Hatton, C., Emerson, E., Robertson, J., Wells, E., and Langer S. (2014) Short Break and Respite Services for Disabled Children in England: Comparing Children's and Parents' Perspectives of their Impact on Children. *Children and Society*, 28, 6, 478–494.

Wilkie, B. and Barr, O. (2008) The Experiences of Parents of Children with an Intellectual Disability Who Use Respite Care Services. *Learning Disability Practice*, 11, 30–36.

Wilz, G., and Fink-Heitz, M. (2008) Assisted vacations for men with dementia and their caregiving spouses: Evaluation of health-related effects. *Gerontologist*, 48, 1, 115–120.

Zarit, S., Kim, K., Femia, E., Almeida D. and Klein, L. (2014) The effects of adult day services on family caregivers' daily stress, affect, and health: Outcomes from the daily stress and health (DaSH) study. *Gerontologist*, 54, 4, 570–579.

Appendix 1. Summary table

Reference and research location	Carer group and break type	Study aims	Method(s)	Outcome measures	Key findings relating to carer outcomes	Recommendations and knowledge gaps
Arksey, H., Jackson, K., Croucher, K., Weatherly, H., Golder, S., Hare, P., Newbronner, E., and Baldwin, S. (2004) International. *Review of Respite Services and Short-term Breaks for Carers for People with Dementia. Report for the National Co-ordinating Centre for NHS Service Delivery and Organisation.*	Carers of people with dementia. Various types of respite care.	To identify services available to carers, their effectiveness, identify best practice and areas for further research.	International literature review and consultation with representatives from national bodies and carers.	None.	Day-care: some studies showed improvement to carer health and wellbeing and delayed entry to a care home. Home respite: high carer satisfaction related to the perceived quality of care. Individuals able to maintain routines, roles and sense of self. Host family respite: little evidence available. Institutional/overnight respite: difficult to organise, concerns about standard of care leading to carer guilt.	Need to measure the impact of respite care on quality of life, health and wellbeing and long-term cost effectiveness. Future research to look at different short breaks, carer groups, cultures and stage of illness. Comparative and longitudinal studies needed.
Ashworth, M., and Baker, M. (2000) UK. *Time and space: carers' views about respite care. Journal of Health and Social Care in the Community 8, 1, 50–56.*	Carers of older adults. Various types of respite care.	To understand carers' experiences of respite care.	Qualitative research. Semi – structured interviews with carers (n=23).	None.	Carers report sense of freedom, normality and physical and emotional temporary relief. Accepting respite care also seen as an admission of failure. Concerns with quality of care and whether it is appropriate to ethnic and cultural needs. Home sitting viewed positively.	Only those receiving respite care were included. It is important to capture the perspective(s) of those who do not use respite/breaks services to understand why.
Bamford, C., Arksey, H., Poole, M., Kirkley, C., Hughes, J., Corber, L., and Bond, L. (2009) UK. *Person- and carer-centred respite care for people with dementia: developing methods of evaluating the effectiveness of different methods.* *Report for the National Institute for Health Research Service Delivery and Organisation Programme.*	Dementia carers. Various models of respite and short breaks.	To identify and describe the range of respite care/short breaks from the perspectives of carers and service providers.	International literature review, (update of Arksey 2004) telephone surveys, focus groups and interviews with PWD and carers, frontline staff and managers, and comparative case studies. Over 350 measures reviewed. Measures initially appeared relevant, further examination indicated a poor match with the components of person-centred care.	Measures identified and assessed against set of standard criteria for judging the quality of structure, process and outcome measures (Fitzpatrick et al., 1998a; Fitzpatrick et al., 1998b).	Carers report sense of guilt and anxiety. However, respite provides a break and time for appointments and chores.	Methodological difficulties evaluating services due to lack of appropriate outcome measures. Could develop new tools for evaluation from perspective of PWD, carers and front-line staff. National mapping exercise to highlight innovation and conditions needed for successful replication.
Bell, J. and Litherland, R. (2013) England, UK. *Shared Lives and Dementia.* Shared Lives South West.	Carers of people with dementia Shared Lives Plus (formerly Adult Placement Scheme).	To evaluate a Shared Lives project, including peoples' experiences, hopes, expectations, and concerns.	Information collected from 46 people over 2 years at five sites. Short open-ended questionnaires before (baseline), during and end of placement from people with dementia (n=5) family carers (n=14) and Shared Lives carers (n=29).	None.	Baseline: carers, hoping for normality, an opportunity for a life away from caring and a better relationship with the PWD. During break: PWD stimulated, happy/satisfied, carer had a good break and well-needed rest. Positive relationship with the Shared Lives family important in shaping outcomes. Concerns: House inappropriate for PWD and long time to match PWD to Shared Lives Carer.	Research needed to identify longer-term savings as an early intervention service. Local authorities and independent organisations must invest in local schemes to enable skill development, experience and capacity to deliver services and support for staff carers.

Reference and research location	Carer group and break type	Study aims	Method(s)	Outcome measures	Key findings relating to carer outcomes	Recommendations and knowledge gaps
Berglund, A. L. and Johansson, I. (2013) Sweden. *Family caregivers' daily life caring for a spouse and utilizing respite care in the community.* *Nordic Journal of Nursing Research and Clinical Studies /Vård i Norden, 33(1), 30–34.*	Spousal carers (age over 65) of people with neurological disorders cared for at home for more than 6 months (including dementia). Residential respite care.	To show how family caregivers experience daily life when they care for a spouse at home and when their spouse is in residential respite care.	Qualitative interviews with family caregivers.	None.	Carers report relief, relaxation, worry, guilt and shame. Recovery from role of family caregiver (self-care and rest) dependent on care quality. Socialising with others with similar experiences positive. Gain energy for further caring at home – physical and mental rest and recovery. Workload builds during care period. Balance two different roles –caregiver and spouse.	Early education from professionals and support from family and friends. Individually adapted support and follow-up from caring staff. Knowledge and experiences of caregivers should be followed up. Family caregivers need opportunities for self-care.
Bontinen, P. and Perry, J. (2001) Canada. *Evaluation of a weekend respite program for persons with Alzheimer's Disease.* *Canadian Journal of Nursing Research 33, 1, 81–95.*	Family caregivers of people with dementia. Adult day programme, extended to increase options as an overnight respite service.	To explore family caregivers' experiences of day care service.	Qualitative evaluation. Data from 19 caregivers.	None.	Short breaks provide opportunities for self-care, family and social relationships, other activities, relaxing and a good night's sleep. Difficult to capture temporary relief from stress and worry or responsibility of caregiving. Relief tied to knowing the PWD was safe and well. Caregivers used respite to fulfil own needs yet expressed concern about the wellbeing of the PWD. Safety and comfort of the family member- positive social and physical stimulation for PWD is important.	Traditional quantitative approaches to evaluating respite may be inappropriate – they may not capture the complex feelings of relief associated with respite.
Carretero, S., Garcés, J., Ródenas, F. (2007) Spain. *Evaluation of the home help service and its impact on the informal caregiver's burden of dependent elders.* *International Journal of Geriatric Psychiatry 22, 782–749.*	Informal carers (older dependents). Home Help Service (HHS).	To examine characteristics of HHS and effectiveness in reducing the burden of informal care of dependent people.	Experimental design and field study – users and non-users of HHS (n=269). User and caregiver satisfaction of assistance and user and caregiver's quality of life before HHS and with HHS.	Quantitative measures on subjective assessment of the HHS, evaluation of personal relationship, and assessment of caregiver's quality of life using the Zarit Burden Interview.	Low coverage and frequency of care, little diversity and professional training of workers. User and carer satisfaction reported with HHS and associated with an increase in quality of life for both groups. Personal care services but no psychological care for caregiver.	Positive appraisal maybe due to fear of service being withdrawn or, content with minimum service. Need to explore the wider context of caregiver's burden for appropriate psychosocial interventions.
Chappell, N. L., Reid, R.C. and Dow, E. (2001) Canada. *Respite reconsidered – A typology of meanings based on the caregiver's point of view.* *Journal of Aging Studies, 15 (2), 201–216.*	Carers of older adults with a diversity of conditions including forms of dementia. Various forms of respite.	To understand carer's meanings and experiences of respite and examine if these differ according to social and demographic variables.	In-depth qualitative interviews with caregivers (n=14). Focus group with 5 caregivers. Structured interviews with open ended questions, with n=241 caregivers.	Andrews and Withey's Life Satisfaction Scale (1976), Rosenberg's Self Esteem Scale (1965), Zari caregiver Burden Inventory (1980). Pearlin, Leierman, Menagan and Mullann's (1981) Social Support Scale.	Stolen moments: activities taken in the day shopping, part of the routine (reading, or change of scenery). Connections: social activity – connections with 'the world out there' a break in and of themselves. Relief: from constant responsibility, caregiver is out of touch with the care receiver and able to push all worries aside, for a while. Mental or physical stimulus, physical and mental boost engage mind or body in an all-encompassing manner e.g. reading or even watching television totally absorbing, taking courses or pursuing hobbies, involvement in work, committees.	Over 60% of caregivers defined a break in ways different to policymakers and professionals. Policy and practice must grasp what a break means to carers. Many reforms based on perspectives of decision-makers, policymakers, and service providers. Redefine respite as an outcome rather than service. Recognise emotional aspects of caring (not only task). Need longitudinal research focusing on respite as outcome and profile carers over time.

Reference and research location	Carer group and break type	Study aims	Method(s)	Outcome measures	Key findings relating to carer outcomes	Recommendations and knowledge gaps
Chen, T.-F., and Huang, L.-H. (2011) Taiwan. *Caregiver Efficacy and Efficacy Determinants for Elderly Care Recipients Who Accept Home Respite Care in Taiwan.* *Journal of Nursing Research, 18(1), 18–25.*	Caregivers of older adults. Home respite care.	To understand caregiver efficacy and efficacy determinants.	Questionnaires to caregivers (n=137, 84.5% response rate n= 117).	Elderly care recipient data: Efficacy scales: life quality guidelines (Chia and Li 1999, WHOQOL Group, Zhan 1992), self-rated depression scale (SDS). Subscales of physiological health, psychological condition, social relationships, care task, family role.	Respite care gave an important break to carers, improved the psychological health of the carer, but did not relieve pressure. Carers used respite care to do housework. Caregiver also used respite to look after their own physiological health. A fear of isolation using respite, many felt isolated when they did use it, not spending time interacting with others. Carers relied on information from other caregivers about services available.	The needs of carers must be recognised when developing future policies and programs. Respite care is a relatively new concept and needs to be promoted, through existing community based networks and mass media to increase caregiver awareness and use of service.
Dalton, J., Thomas, S., Harden, M., Eastwood, A. and Parker, G, (2018) International. *Updated meta-review of evidence on support for carers.* *Journal of Health Services Research and Policy, 23, 3, 196–207.*	Carers, including for PWD. Various respite.	To explore the evidence on interventions specifically designed to support carers.	Systematic review of high quality evaluations of interventions, including respite care, in supporting carers of ill, disabled, or older adults. 61 reviews included.	None.	Effective support for carers of PWD includes opportunities to share and learn from others and reframe thinking about dementia. Psychosocial interventions may have a positive impact on depression and anxiety, subjective burden and stress.	Primary research needed, exploring what type of respite is best and for whom. Need to know more about the outcomes that carers think are valuable.
de la Cuesta-Benjumea, C. (2010) Spain. *The legitimacy of rest: conditions for the relief of burden in advanced dementia care-giving.* *Journal of Advanced caring, 66, 5, 988–998.*	Female carers/ relatives of people with advanced dementia. Various respite services.	To identify the conditions that relieve burden for female caregivers of relatives with advanced dementia.	Qualitative semi-structured interviews with 23 female carers of people with advanced dementia.	None.	Centrality of cared for – their needs prioritised over carers. Trust issues: carers have greater confidence in substitute care from cohabiting relatives, spouses, parents and offspring; they know are ‘going to be watchful’. Caregivers keep an eye over hired care until they feel comfortable. Caregivers are referees of standards of care. They need support and acknowledgement from others for their legitimacy to rest.	Future research to explore conditions that favour the relief of burden within other cultural and caregiver groups. Relief of caregivers’ burden should be central to policy with aims to remove exploitative situations of women (duty and natural), detrimental to family life.
de la Cuesta-Benjumea, C. (2011) Spain. *Strategies for the relief of burden in advanced dementia care-giving.* *Journal of Advanced Nursing 67, 8, 1790–1799.*	Female carers/ relatives of people with advanced dementia. Various respite services.	Uncovering the strategies that women caregivers of relatives with advanced dementia use to rest from care-giving.	Qualitative semi structured interviews with 23 women long term carers of people with advanced dementia.	None.	Caregivers rest is doing, thinking and relating to others in different ways than those linked to care-giving. Respite affords the opportunity to ‘disconnect’ from being a caregiver, having physical, social and symbolic spaces, to become someone different, act upon other identities and connect with a different world.	Research needed with a more diverse sample to include male caregivers, caregivers from different countries and socioeconomic background and with caregivers who do not co-reside with their relative and those caring for relatives with different chronic conditions.

Reference and research location	Carer group and break type	Study aims	Method(s)	Outcome measures	Key findings relating to carer outcomes	Recommendations and knowledge gaps
de Jong, J. D. and Boersma, F. (2009) The Netherlands. *Dutch psychogeriatric day-care centers : a qualitative study of the needs and wishes of carers.* *International Psychogeriatrics, 21(2009), 268–277.*	Family caregivers of people with dementia. Day care facilities.	To explore the needs and wishes of informal caregivers of people with dementia attending psychogeriatric day care.	Qualitative, exploratory study, based on interviews with family caregivers and professional focus groups.	None.	Notes carer confidence in shared, tailored care. Highlights carer need for education and information about dementia during short break.	Share knowledge about dementia with the caregivers. Underutilisation of professional resources and services point to need for proactive approach by professionals if caregivers do not actively seek advice.
Dementia Adventure (2017) UK. *Impact Report.*	Carers and people living with dementia.	Impact report. Dementia Adventure (DA) "Evidence led charity to enable people living with dementia get outdoors, connect with nature, themselves and their community, and retain a sense of adventure in their lives."	Asking detailed questions of beneficiaries before and after the holiday.	None.	Activities enable positive outcomes for PWD and carers. Carers report improved well-being, reduced isolation and loneliness, improved health and healthier living and increased resilience. Positive experience for PWD: increased confidence to go outdoors and try new things.	Findings need validating through larger studies; it suggests that emotional wellbeing is the biggest benefit of being part of a DA holiday.
Downes, S. (2013) Australia. *The Eden Principles in dementia respite care: carers' experience.* *Quality in Ageing and Older Adults, 14, 2, 105–115.*	Carers of PWD. Day respite centre.	Hawthorn House – a respite centre open 6 days a week to give respite care to carers and a one week extended stay for 2 people with dementia.	Quantitative and qualitative methods. Questionnaires and semi-structured interviews to assess carer's health and perceptions of services. Dementia care mapping over 12 months. 34 carers (63% of total number using respite) participated.	GHQ-12 standard 12 item questionnaire. Zarit Burden Interview (ZBI) 12-caregiver stress or burden, personal and role strain factor modified 'Eden survey'. Quality of life and services.	Authors report a 80% reduction in carer stress. Respite commonly described as feeling like home, and a 'happy place'. Somewhere to go if carer needs help. Importance of a break for the carer (overnight or day care at the house) – own space, own spare time, relief, enabling them to care for longer.	Further research proposed for 6 monthly intervals to study long-term quality of life effects of 'Eden principles'.
Dundee Carers Centre (2014) Scotland, UK. *Short Break (respite Care) Provision in Dundee – now and in the future Dundee* *Carers Centre. Report on behalf of the Dundee Partnership.*	Mixed group of carers (adults). Short breaks and respite.	To investigate the current and future provision of Short Breaks/Respite for adults in Dundee.	Review of research of carers' experiences taking short breaks, consultations with carers. Mapping existing provision and future demand for short breaks in Dundee, interviews with providers, workshop with stakeholder groups.	None.	All carers valued short breaks They would like more holiday breaks, with or without cared for. Open to residential breaks with other carers for mutual support, to explore new ideas. Strong culture of carers looking after themselves, modest requests for support – even when struggling. Over 60s: breaks a significant positive contribution to resilience and health well-being. Respite at home to be 'like an alternative family member' providing it. Needs to be regular, flexible, feel familiar and fit with the person's preferences, interests and characteristics. Proactive /activity focused –a sitter service too passive and unengaging. Short breaks can create additional work for BME carers who prepare family meals to cover time they are away.	Need for a new framework to support and encourage connectedness and sustainable growth. New forms of short break provision are emerging making increasing personalisation and self-directed support possible. Providers expect to expand and diversify services. Recognise a creative approach is needed.

Reference and research location	Carer group and break type	Study aims	Method(s)	Outcome measures	Key findings relating to carer outcomes	Recommendations and knowledge gaps
Gaugler, J., Jarrott, S., Zarit, S., Stephens, M. and Townsend, A. (2003) USA. *Respite for Dementia Caregivers: The Effects of Adult Day Service Use on Caregiving Hours and Care Demands* *International Psychogeriatrics 15, 1, 27–58.*	Carers of people with dementia. Adult Day Care Services (ADCS).	Does the use of ADCS reduce caregiving hours, behaviour problems and caregiver perceptions of care recipient impairment?	Quasi – experimental comparison of carers using and not using adult day care centres. Interviews at baseline, 3 months (n= 169/231) and 1 year (n=231/140).	Role captivity measure (Pearlin et al 1990), Psychological wellbeing (depression scale (Radloff, 1977).	ADSCs may exert positive psychological effects on caregivers and residing elderly relatives, including people with dementia. Social activities offer stimulation (music, arts) and may reduce behavioural problems (but not stem cognitive decline).	Research needed exploring how adult day programs provide direct and observable benefits to persons with dementia.
Gitlin, L.N., Reever, K., Dennis, M.P., Mathieu, E., and Hauck,W.W. (2006) USA. *Enhancing Quality of Life of Families Who Use Adult Day Services: Short- and Long-Term Effects of the Adult Day Services Plus Program.* *The Gerontologist, Volume 46, Issue 5, 630–639.*	Family caregivers of frail older adults (including people with dementia). Adult day services (programme- based on Pearlin, Mullan, Semple, and Skaff's (1990) stress process model).	To examine the short- and long-term effects of Adult Day Services Plus (ADS Plus).	Quasi-experimental design, to recruit 129 caregivers from three adult day centres. Two centres offered adult day services and ADS Plus (n=67); the third center (n=62) offered only routine adult day services. ADS Plus involved a staff social worker who provided care management and support to family caregivers through face-to-face and telephone contact. Education, counselling and referral services were offered for 12 months.	Caregiver Depression: CES-D 10-item version. Caregiver Burden Zarit Burden Interview. Memory and Problem Behaviours and Self Stress in caregiving role, Zarit and Zarit (1990) 24-item Memory and Problem Behaviors scale, Perceived Change in Well-Being Perceived Change Index (Gitlin et al., 2003). Time for Healthy Behaviors Checklist.	Immediate benefits for carers: reduction in depressive symptoms, increased confidence in managing troublesome behaviours and enhanced overall well-being. Fewer nursing home placements for families in ADS Plus than for those receiving ADS only.	ADS Plus has social validity. Families evaluated the program as supportive and invaluable, a critical "safety net." Further research is needed to explore the role of day care services in preventing or delaying admission to care homes.
Gottlieb, B. H., and Johnson, J. (2000) Canada. *Respite programs for caregivers of persons with dementia: A review with practice implications.* *Aging and Mental Health, 4(2), 119–129.*	Family caregivers of persons with dementia. Centre based (day) respite care.	Critical review of articles: role and impact of centre-based respite programs for caregivers of people with dementia, timing and duration of their use by family caregivers; impacts on the mental health and wellbeing of caregivers.	Review of the literature since the late 1980s.	None.	Respite late on at near crisis point, usually between two and four-and-a-half years into caregiving. Day programmes are short-term `time-out' experiences, carers use time to do chores. Two different objectives of caregivers: sustaining themselves in the caregiving role (role endurance) versus	Outreach programmes needed to allay caregivers' fears of losing control and that it does not mean long-term placement, nor failure to cope as a caregiver. Supplementary interventions for staff to encourage better use of carer respite time and augment respite care with other interventions.

Reference and research location	Carer group and break type	Study aims	Method(s)	Outcome measures	Key findings relating to carer outcomes	Recommendations and knowledge gaps
Greenwood, N., Habibi, R., and Mackenzie, A. (2012) UK. *Respite: carers' experiences and perceptions of respite at home.* *BMC Geriatrics, 12, 42.*	Carers caring for someone over 60. Respite at home.	To investigate carers' experiences of in-home respite, their perceptions of care workers and impact of respite on themselves and their cared for.	Qualitative – semi-structured interviews with 12 carers receiving 4 hourly respite.	None.	Carers report, guilt leaving the cared for. Tension and guilt dissipated only when full confidence in the care worker – a gradual process. Centrality of cared for. Trust before considering and accepting respite. Respite used to do mundane, everyday tasks.	Outcome scales may not be meaningful for all carers. Research that allows participants to describe outcomes relevant to them is more likely to highlight positive benefits than quantitative research. Mixed methods research may help understand why qualitative and quantitative findings sometimes conflict.
Holm, S., and Ziguras, S. (2003) Australia. *The host-homes program: an innovative model of respite for carers of people with dementia.* *Australasian Journal on Ageing 22, 3, 2003.*	Carers of older people with dementia. Host home respite in care worker's home.	To investigate the operation of community respite 'host-home' program, pilot respite care projects.	Interviews with staff, care recipients (dementia) and carers. Information from written records such as funding submissions.	None.	Carer perspectives: positive. Confidence in having a break due to perceived care quality, homely setting. Suitable for behaviour or confidence issues. Supported person 'good to get out of the house' socialise in a casual setting. Staff perspectives: personalised flexible service.	Smaller group responds to individual needs. Culturally relevant as host home shared cultural background – suggest partnership between ethno-specific agencies and respite services. Potential for expansion but must ensure cost shifting not onto staff.
King, A., and Parsons, M. (2005) New Zealand *An evaluation of two respite models for older people and their informal caregivers.* *The New Zealand Journal Vol 118 No 1214.*	Care givers of older persons. Home-based respite, respite facility, support services, or a combination of all three.	Evaluation of two models of respite relief care.	Scorecard, semi-structured interviews (n=2 older people and their carers) and postal surveys directed to clients (utilising respite care) and staff members involved (n= 21 older people, 36 carers).	Evaluation tool used was balanced scorecard (Leggat and Leatt 1997) based on five key perspectives: customer, financial, innovation and learning, internal business, and community.	Caregivers from two respite models reported that the break was insufficient. One caregiver stated the respite gave a break 'physically' but not 'mentally'. Caregivers report the older person's condition deteriorated after staying at the respite facility. Staff believed respite services provide caregivers with a break to help alleviate stress. Since changing respite models to enable the caregiver to have more control in decision-making, the amount of older people receiving home-based respite has dramatically increased.	Comments made how respite facilities could be more responsive to the needs of the older person; several caregivers were concerned with the care received at the respite facility. Continuity of care is critical.
Klein, L. C., Kim, K., Almeida, D. M., Femia, E. E., Rovine, M. J., and Zarit, S. H. (2016) USA. *Anticipating an easier day: Effects of adult day services on daily cortisol and stress.* *The Gerontologist, 56, 2, 303–312.*	Family caregivers of individuals with dementia. Adult day services.	Do adult day services (ADS), lead to improved regulation of the stress hormone, cortisol and what are the implications for carer health and well-being.	Within-subject treatment design to compare caregivers' diurnal cortisol responses on days they received the intervention (ADS) and days they did not. Interviews over eight consecutive days and five saliva samples on each of those days. 158 caregivers.	Salivary cortisol awakening response (CAR) and cortisol area under the curve with respect to ground (AUC-G).	The more days that caregivers use ADS, the more relief they show in diurnal cortisol levels. Care-related stressors lower on ADS days. Caregivers agreed they look forward to their relative attending ADS. Anticipation of time away, as well as relief from stressors.	ADS improves caregiver's cortisol regulation, which could enhance long-term health outcomes. Focus on a single biomarker limits understanding of biological responses to stress. Further studies needed to evaluate ADS exposure effects and additional health outcome measures.

Reference and research location	Carer group and break type	Study aims	Method(s)	Outcome measures	Key findings relating to carer outcomes	Recommendations and knowledge gaps
Laing, A. (2013) Scotland. *Evaluation of Time to Live strand of the Creative Breaks programme from October 2012–September 2013.*	Short Breaks Fund – a grant making programme to support the development of short break services and to support carers and their families to arrange their own breaks.	To review and contrast Creative Breaks funded projects.	Telephone interviews with a representative from each project; analysis of mid-term and end of Grant Reports.	None.	Improvement in carer's mental and emotional wellbeing when taking short breaks, as well as renewed energy and enthusiasm. Carers felt their work as carer and need to be 'cared for' was recognised. Flexibility for carer to define a good break is important.	Future evaluations to speak directly to carers to find out directly what works and what doesn't: participatory, action research methods might be helpful.
Leggett, A. N., Liu, Y., Klein, L. C., and Zarit, S. H. (2016) USA. *Sleep duration and the cortisol awakening response in dementia caregivers utilizing adult day services.* *Health Psychology, 35(5), 465–473.*	Family caregivers of people with dementia. Adult day-care centre.	Is sleep duration moderated by ADS use?	158 caregivers from DaSH study (daily experiences and stress of primary, family caregivers for PWD who attend ADS at least two days a week). Saliva collection, baseline interview, daily diaries over 8 days.	Cortisol levels and Cortisol Awakening Response (CAR) Sleep duration. Overnight care-related stressors assessed using the Daily Record of Behaviour Depressive symptoms: Non-Specific Psychological Distress Scale.	A protective or restorative effect of ADS use on daily cortisol by providing a predictable amount of time away from constant caregiving demands. Respite intervention helps to normalize this chronic stress response and may have key public health benefit.	Further investigate mechanisms through which ADS can moderate associations between sleep and cortisol regulation. Providing caregivers who experience chronic stress with respite or a mechanism to reduce stressor exposure may reduce burden, allostatic load and poor health outcomes.
Lee, D., Morgan, K., and Lindesay, J. (2007) UK. *Effect of institutional respite care on the sleep of people with dementia and their primary caregivers.* *Journal of the American Geriatrics Society, 55(2), 252–258.*	Carers of people with dementia. Institutional respite care.	To evaluate sleep–wake patterns of people with dementia and their caregivers before, during, and after 2-week periods of institutional respite care.	Questionnaire assessments, baseline and throughout study caregiver and PWD, 33 dyads completed the full protocol. 2-week period of institutional respite care, sleep outcomes for carers and PWD 6 weeks of continuous wrist actigraphy, daily sleep diaries.	Sleep activity: actigraphic measures. Quality of life (Medical Outcomes Study 36-item Short Form survey) and quality of sleep (Pittsburgh Sleep Quality Index) Epworth Sleepiness Scale.	Carers: respite periods are associated with significant increases in total sleep time per night, time in bed and improvements in subjective sleep quality. PWD: respite associated with significant increases in sleep onset latency, reductions in total sleep time per night and weakening of the circadian activity rhythm.	Carers sleep disturbance reversed during periods of respite care, but worsens already disturbed sleep patterns for PWD. Respite care and future research should target sleep management.

Reference and research location	Carer group and break type	Study aims	Method(s)	Outcome measures	Key findings relating to carer outcomes	Recommendations and knowledge gaps
Liu, Y., Almeida, D. M., Rovine, M. J., and Zarit, S. H. (2018) USA. *Modelling Cortisol Daily Rhythms of Family Caregivers of Individuals with Dementia: Daily Stressors and Adult Day Services Use.* *Journals of Gerontology – Series B Psychological Sciences and Social Sciences, 73(3), 457–467.*	Caregivers of people with dementia. Adult day services.	Diurnal cortisol trajectory and associations with the adult day services (ADS) use, among family caregivers who experienced high levels of daily stress.	165 caregivers from the Daily Health and Health study (DaSH) 8 days of daily telephone interviews, provide five saliva samples each day.	Care-related measured using the Daily Record of Behaviour (DRB). Non-care stressors measured using the Daily Inventory of Stressful Events (DISE; Almeida et al., 2002). Using five items drawn from the DISE (Sin et al., 2014), caregivers reported occurrences of positive experiences during past 24 hours.	Daily stress exposure among dementia caregivers is associated with increased cortisol levels at certain times of the day (i.e., before bed). Daily ADS use was associated with more robust CAR, which could benefit chronically stressed caregivers physiologically. ADS use provides some caregiving respite and decreases care-related stressor exposures (Zarit et al., 2014), opens up opportunities for caregivers to engage in a full life, which may have increased the exposures to other non-care stressors such as work demands as well as positive experiences.	Findings could be used to argue for increasing affordability of ADS and other respite programs, through expansion of coverage of lower income people under "dual eligible" programs (Medicare and Medicaid) and more broadly by inclusion of ADS under Medicare.
Lund, D. A., Utz, R., Caserta, M. S., and Wright, S. D. (2009) USA. *Examining What Caregivers Do During Respite Time to Make Respite More Effective.* *Journal of Applied Gerontology 28, 1, 109–131.*	Family caregivers of adults (50 or older). Adult day services.	To understand caregivers' desired and actual use of respite time, satisfaction with respite time use, and caregiver outcomes (burden, depression, and satisfaction with caregiving).	Time use form (time log) 22 desired activities and actual activities and time spent over the week. In home interview with the caregiver one week later. 52 caregivers participated (57% response rate).	'Yesterday Interview' (Moss and Lawton). 'Caregiver Burden Inventory' (Novak and Guest, 1989). Depression CES-D Radloff, 1977. Satisfaction with caregiving measured by a subscale of Caregiving Appraisal Instrument Lawton et al. (1989).	Three most-desired activities: time with family, housework, rest and relaxation to spend 2 to 3 of their respite hours per week on each of these three activities. Caregivers spent on average the same amount of time they had desired in nearly 14 of the 19 activities assessed on the time log. Caregivers very satisfied with respite time had significantly lower depression scores than those who were not.	Interventions need to be more individualized in order to be effective. Important to be culturally sensitivity to ethnic and racial differences among care-givers. Future research: longitudinal work needed to assess diverse forms of respite services and populations. Need for more creative designs and better translational research.
Maayan, N., and Lee, H. (2014) International. *Respite care for people with dementia and their carers.* *Cochrane Database of Systematic Reviews, (1).*	Carers of people with dementia Various types of respite care.	To assess benefits and harms of respite care for people with dementia and their caregivers and the effect of respite care on rates of care home admission.	Systematic review of literature reporting on randomised control trials comparing respite care with a controlled intervention for PWD.	None.	Four studies included. One did not report data that could be analysed, three were small and short time only. No evidence of benefits or adverse effects of carers of PWD using respite care. Results of studies not pooled, as so few studies and outcomes measured in different ways. All the studies reported outcomes for the caregiver, only one reported outcomes for the person with dementia.	Methodologically sound research that includes key stakeholder perspectives is needed before firm conclusions can be drawn.

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Mason, A., Weatherly, H., Spilsbury, K., and Arksey, H. (2007) International. Community-based respite care for frail older people and their carers *Health Technology Assessment, 11(15) 1–157.*	Older people, (frailty, disability, cancer or dementia). Various types of respite care.	To review the evidence for different models of community-based respite care for frail older people and their carers.	Systematic review: searches 1980–2005. 22 primary studies included.	None.	Some evidence that respite for carers may have small positive effect in terms of burden and mental or physical health. Carers generally very satisfied with respite. No reliable evidence found that respite either benefits or adversely affects care recipients, or delays entry to residential care.	Clarify objectives of respite services, how services are provided and how outcomes are measured. Further research to focus on different groups of older people and carers, or be sizable enough for subgroup analysis. Measures must aim to target outcomes relevant to carers and older people, as there will be joint and separate interests and aspirations. Pilot studies needed to inform full-scale studies of respite in the UK using a range of methodological approaches due to the complex and intersectoral nature of respite care.
Måvall, L., and Thorslund, M. (2007) Sweden. *Does day care also provide care for the caregiver?* *Archives of Gerontology and Geriatrics, 45 2, 137–150.*	Caregivers of people with dementia. Day care.	To investigate if day care is an effective form of respite for the caregivers of relatives with dementia.	Interviews (multiple choice) with caregiver after day 5 of day care visit and follow up interview 4 months after attendance. Co-residing and non-residing (CR and NCR). 51 caregivers.	Caregiver overload scale of 7 items, including 4 developed by Pearlin et al. (1990) and 3 developed for Jarrott et al., (1998).	Caregiver satisfaction with day care determined by complex factors: characteristics of the individuals, their social and living environments. Greatest benefit to caregivers who experience less worry, overload and role captivity from the start. An easy decision to discontinue day care where care recipient was not happy at day care and caregiver experienced preparations as burdensome.	Day care cannot be independent from other types of formal care, needs to be integrated with other services.
McDonald, A and Macleod, D (2016) Scotland, UK. *A Review of Respite/ Short Break Provision for adult Carers of Adults in the Highland Partnership Area Key Findings and Main Recommendations.*	Carers of adults. Respite/short break services.	Review of respite for Adult Carers of Adults (aged 16+).	Conversations and feedback reports with carers and staff employed in carer support organisations, health and social care workforce, respite providers.	None.	Respite often equated with residential respite. Lack of accessible, core residential respite services in the Highland region. Importance of listening and being listened too. Importance of building a relationship with support workers emphasised. Doing the shopping or going for a cup of tea is just living, not respite. Very few establishments have 2 beds to enable couples to receive respite together.	More work needed – conversations with stakeholders to develop way forward. Carers must be involved as equal partners. Engage with people who are being cared-for. Need to pilot and evaluate different forms of respite. Respitality being introduced across Scotland; Highlands have a large number of tourist businesses and could further pilot work in this area.

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McNally, L (2013) UK. *The Psychosocial and Physical Effects of Respite Care on Informal, Spousal Caregivers.* *PhD thesis, London University.*	Spousal Caregivers. Residential respite.	To examine the short-term effects of a single episode of residential respite care on carers' self-reported well-being, salivary cortisol and care recipients' level of dependency.	112 spousal carers (57 controls, 55 respite).	Self-reports of well-being and depression: CES-D, adapted Caregiver Burden Scale, The Montgomery-Borgatta Caregiver Burden Scale. Author developed scale to measure social activity of carer 12-item checklist of social events to estimate the number of times they had engaged in each activity listed in the last seven days. Levels of salivary cortisol.	Respite care gave significant and positive effects on carer's self-reported well-being, but for most these outcomes these were short lived. The effects of respite were evident one week after the end of the break from caring, but not three weeks after. Effect on physical symptoms was longest lasting effect of respite. Respite had a more positive impact when carers were able to increase their social activity during the respite period. Cortisol was higher among the respite group than among control maybe due to anticipation of return of cared for, undertaking chores during respite.	Interventions need to be aimed at increasing social activity, running alongside respite provision. Future research to assess the optimum length of time for respite that supports positive carer outcomes.
Neville C.C., and. Byrne G .J. (2007) Australia. *Staff and home caregiver expectations of residential respite care for older people.* *Collegian (Royal College of Nursing, Australia), 14(2), 27–31.*	Residential respite care. Carers of older adults.	To identify the value of residential respite care and reasons for and expectations of use.	Interviews with carers (n=100) and staff (n=25). Open ended questions, prior to and 1 week into admission.	None.	Disruptive behaviour a strong reason for seeking respite care–mostly wandering. Need for a physical and emotional break. Recipient's psychological wellbeing paramount in carers' expectations of care – their happiness, enjoyment and opportunities to socialise with others. Not overly high expectations of care. If residential care demonstrated therapeutic effects, caregivers may use the service more.	Open-ended questions used as no suitable valid and reliable scales for examining these issues were available. This is a key area for research development.
Neville, C. C., and Byrne, G. J. (2008) Australia. *Effect of a residential respite admission for older people on regional Queensland family carers.* *Collegian, 15(4), 159–164.*	Family carers of older people. Residential respite care.	To determine the effect of a residential respite care (RRC) admission for older people on family carers.	Repeated measures, prospective design. The participants were 100 family carers who were studied before and after the RRC admission.	General health questionnaire GQH-28 (to detect psychological distress – disruptions in normal functioning. Caregiving Hassles Scale (CHS) (to assess daily hassles)	60% of RRC recipients (n = 100) admitted to give the carer a break from their caring role and responsibilities. Family carers of older people who had dementia and hearing problems recorded high burden scores. Reduction in psychological distress or burden does not persist after a period of RRC – e.g. due to persons readjustment to home environment. Perceived mental and physical deterioration may lead to increased burden on return.	Further research to examine what is happening to the family carer and the older person during RRC. Trial interventions for family carers such as educational programs and self-care strategies (e.g. massage and meditation) to see if improvements can be made for the outcomes of RRC. Carers considering RRC need to be informed of potential increased burden.

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Nicoll, M., Ashworth, M. and McNally, L. (2002) UK. *Satisfaction with respite care : a pilot study.* *Journal of Health and Social Care in the Community, 10(6), 479–484.*	Carers of people with dementia. Various types of respite care.	To investigate perceived social support and carer satisfaction from respite care (house sitting, residential care and day care).	Questionnaires to 144 carers (26 suitable responses).	Social Support Survey (Sherbourne and Stewart 1991), 13- item Carer Strain Scale (Gilleard et al. 1984). Geriatric Depression Scale (Brink and Yesavage 1982).	Social support important in carer's satisfaction with respite care. Benefit to carer and patient correlated significantly with number in the carer's support network. Respite benefited carers more than patients. Those unsupported by friends and relatives are less satisfied with respite care.	Likely that isolated carer will experience less benefit from respite care, further work needed to determine the precise benefit of a social network and how best to support the isolated carer.
O'Connell, B., Hawkins, M., Ostaszkiewicz, J., and Millar, L. (2012) Australia. *Carers' perspectives of respite care in Australia: An evaluative study.* *Contemporary Nurse, 41(1), 111–119.*	Carers of people with dementia. Various types of respite care.	To examine carers' experiences and views of respite care.	Survey. Self-reported, reply mailed survey package (62 carers, low response rate (21%)	None.	Carers usually accessed respite for assistance to relieve burden of care and to attend basic needs, maintain their health care, shopping, social, chore associated with daily living. Lower stress levels after using respite and health improved since using respite care. Inflexibility of service a problem.	Providers need to recognise limitations of current provision and develop strategies to diversify range of support available.
O' Shea, E. O., Timmons, SE. O., Fox, S., and Irving, K. (2017) International. *Key stakeholders' experiences of respite services for people with dementia and their perspectives on respite service development: a qualitative systematic review.* *BMC Geriatrics, 17(1), 282.*	People with dementia. Respite services.	To understand key stakeholders' experiences of respite services for people with dementia, with a view to informing respite service development	Systematic review of qualitative studies. 23 papers reviewed (1980–2016).	None.	Broad agreement around key areas for service development across range of stakeholders (flexible and responsive person-centred care, meaningful activity for people with dementia, enhanced client-service communication and informational support). Organisational tension evident between frontline staff and management in respite services, hindering the cultural change necessary to facilitate service development in line with peoples' needs and preferences.	Future research to explore the development of alternative/modified 'respite' service models, which have greater capacity to be flexible and responsive to the needs of caring dyads. The perspectives of people with dementia must be included in qualitative research in this area.
Phillipson, L., and Jones, S. C. (2012) Australia. *Use of Day Centers for Respite by Help-Seeking Caregivers of Individuals with Dementia.* *Journal of Gerontological Nursing, 38(4), 24–34.*	Caregivers of people with dementia. Day centre.	To illuminate and understand day centre use from the perspective of help-seeking caregivers.	Qualitative approach. Focus groups, individual interviews and interviews dyads (two participants and interviewer). Semi-structured discussion guide.	None.	Carers' perceived beneficial outcomes for the PWD: improved life, social interaction, mental stimulation away from the home. This provided peace of mind for carers to attend to their social and practical needs, other family members or friends. Education: carers briefly observe staff managing spouse's behaviour. Accepting need for a break from caring as 'normal' (staff helped with this) and legitimate.	Day centres need to be promoted as a break for the carer with benefits to supported person. Nurses working with carers may need to promote use as normative. Carers' perceptions of care enhanced when nurses possess specialist dementia skills and provide education and support for family caregivers.
Pickard, L. (2004) UK. The effectiveness and cost-effectiveness of support and services to informal carers of older people. *Literature Review for Audit Commissioning, London School of Economics, 1–90.*	Carers of older people. Various respite care services.	To identify services with positive outcomes for carers, under which conditions, and identify cost effectiveness and access issues.	Literature Review.	Reviewed measures used in studies reported.	Day care, home help and institutional respite care may delay admission to a care home, have positive outcomes for carers and be cost effective. May be ambivalence in its use by older people. Lack of evidence to evaluate effectiveness of in home respite care despite this being valued by older people and carers.	None described.

Reference and research location	Carer group and break type	Study aims	Method(s)	Outcome measures	Key findings relating to carer outcomes	Recommendations and knowledge gaps
Pienaar, L., and Reynolds, F. (2015) UK. *A respite thing: A qualitative study of a creative arts leisure programme for family caregivers of people with dementia.* *Health Psychology Open, 2(1).*	Family caregivers of people with dementia. Creative arts group.	To explore the meanings of impact of a creative arts group on carers for PWD.	Qualitative research to explore the meanings of a creative arts leisure intervention for caregivers of family members with dementia.	None.	Creative arts leisure interventions may offer a meaningful form of brief respite to caregivers of people with dementia. PWD were nearby and engaged in a meaningful activity. Intervention too short.	Further research is needed into the long-term benefits of creative arts groups for promoting carer well-being.
Roberts, E., and Struckmeyer, K. M. (2018) USA. *The Impact of Respite Programming on Caregiver Resilience in Dementia Care: A Qualitative Examination of Family Caregiver Perspectives.* *INQUIRY: The Journal of Health Care Organization, Provision, and Financing, 55.*	Carers of people with dementia. Adult day care.	Which factors contribute to resilience in caregiving? How does awareness of respite impact resilience outcomes and how has this translated to improved outcomes for the care recipient?	Qualitative research. Semi structured interviews with 33 family caregivers of individuals with dementia.	None.	Family Dynamics: guilt for wanting relief from their caregiving duties. Isolation with caring. Seeking respite: many heard by chance. Adult day care positive responses, trustworthy, opportunity to get out, do chores. Potentially boring for PWD, finance issues for some. Resilience for carer. Wish for respect and dignity for supported person.	Restructure and augment funding for respite. Create opportunities for individualised programmes. A cohesive framework of social systems for a well-integrated care plan to give resilience across the trajectory of care. Accessible educational resources for carers. Further study of specific demographic groups of caregivers (disease progression, age).
Rochira, S. (2018) Wales, UK. *Rethinking Respite for People Affected by Dementia. Report by Older People's Commissioner for Wales Office.*	Carers of people with dementia. Various types of short breaks.	Exploring respite, to provide evidence of how respite can be positively transformed.	Qualitative research with over 120 individuals affected by dementia (carers and people living with dementia). Literature review, focus groups and call for good practice examples.	None.	No agreed definition or consensus on outcomes. Language used to describe breaks from caring imply burden. Carers report guilt and challenges in accessing services.	Rethink language used to describe breaks/respite.
Salin, S. and Åstedt-Kurki, P. (2007) Finland. *Women's views of caring for family members.* *Journal of Gerontological Nursing, 33, 9, 37–45.*	Wife and daughter informal carers of an older relative. Respite services of a residential home.	To describe the life situation of informal caregivers who use a respite service regularly.	Qualitative interviews with carers (N= 17). Data analysed using inductive content analysis.	None.	Relationship between caregiver and care recipient influences the caregiver's ability to recover during respite. Warm relationship: both welcomed respite, wanted to stay together at home for as long as possible. Relationship of imprisonment a day to day struggle. Respite relief. Doing things of personal interest without schedules, travelling, meeting friends, hobbies, relaxed outing, peaceful time at home, self-care. Many felt their health was better during respite. Cleaning room at start of respite symbolic. Unexpected guilt, free time emptiness and loneliness. Perpetual worrying, anxiety about the care quality.	Need to consider family history and tailor provision accordingly. Nurses should ask appropriate questions and encourage both caregiver and care recipient to retain their own individuality despite the relationship of dependence. Future research should study respite nurses and their relationships with family caregivers.

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Salin, S., Kaunonen, M., and Åstedt-Kurki, P. (2009) Finland. *Informal carers of older family members: how they manage and what support they receive from respite care.* *Journal of Clinical Nursing, 18(4), 492–501.*	Informal carers who regularly use respite care. Various forms of respite.	How do informal carers describe the support they receive from respite care?	Two part structured questionnaire, including an open ended question (n= 143 response rate 46.3%) majority age 80 or over (67%) cared for, over half PWD.	Carers' Assessment of Managing Index CAMI (Nolan et al.1995) and an index developed by the researchers (Likert –type scale)	Most carers felt invigorated during respite care. Lack of satisfaction by spouse carers may be due to frequent visits to respite service. Most felt they and supported person were welcomed but nurses knew little of home situation and little time to discuss aims and objectives of the respite care period. Nurses remained distant and unknown to them. Information to continue care at home inadequate.	Important to analyse meaning of the caring relationship so support can be tailored more effectively. Nurses and informal carers should see each other as partners in cooperation with a common goal, i.e. well-being of older people and the entire family, and should include collaboration with all members of the multi-professional team, e.g. meals-on-wheels, district nurse and doctor, with regular meetings, even when there is no crisis.
Schacke, C., and Zank, S. R. (2006) Germany. *Measuring the Effectiveness of Adult Day Care as a Facility to Support Family Caregivers of Dementia Patients.* *The Journal of Applied Gerontology, 25 (1), 65–81.*	Family caregivers of people with dementia. Adult day care.	Reporting on findings from an evaluation of adult day care.	Comparison of longitudinal changes (over 9 months) in caregiving stress in adult day care users (treatment group) n = 37 (n = 18) with non-day users (control group) n = 40 (n = 19) Qualitative semi-structured Interviews.	Multidimensional caregiving stress measure developed for this study (validity tested with Burden Interview Zarit 1990). Theoretical considerations: Pearlin et al (1990) stress process model of caregiving.	Use of day care alleviated care-related stress. Enables family, employment and caregiving responsibilities and gives opportunity for caregiver participation in social and recreational activities.	Important to recognise the multidimensional nature of carer stress. Researchers need to identify specific intervention factors, work closely with practitioners and be explicit in the outcome criteria used.
Scottish Government (2011) Scotland, UK. *Short breaks fund: Evaluation of round 1 projects. Report.*	Short breaks provision for adult and young carers.	To consider what these projects have achieved, capture the challenges and prioritise areas for future development.	Case studies, analysis of End of Grant Reports, the original applications and grant assessments, and 10 interviews. A meeting with a National Carer Organisation Short Breaks Fund Oversight Group For many carer groups – older/ PWD.	None.	Funded projects worked to support the delivery of personalisation, choice and relevance. The breaks were designed around the needs of the carer and the person they care for. This mutuality was essential in the delivery of successful breaks. Carers benefitted from improved physical and mental health, more able to live a life outside caring and more able to sustain their caring role. Many carers were nervous about leaving a family member in someone else's care.	Organisations need to be encouraged to not just work with their existing client groups but to reach out to those in their communities who need support, and from this prioritise those most in need of a short break. This Fund has benefitted a lot of carers, but many more are not accessing or benefitting from short breaks. The Fund should consider how to stimulate new and alternative services that can help to deliver long-term solutions around supporting carers to access short breaks.

Reference and research location	Carer group and break type	Study aims	Method(s)	Outcome measures	Key findings relating to carer outcomes	Recommendations and knowledge gaps
Shared Care Scotland (2010) Scotland, UK. *It's about time: An overview of short break (respite care) planning and provision in Scotland.'* *Report by Reid-Howe Associates Ltd for Shared Care Scotland.*	Carers of adults. Various types of respite care/ short breaks.	Map out the landscape of respite care and short break provision for adults in Scotland; identify good practice in the planning, commissioning and design of respite care and short break services; understand challenges and solutions.	Literature review. Interviews with individuals covering all 32 local authority areas. Interviews with representatives of 9 NHS Boards. A survey of statistical information (16 responses). Views of stakeholders in the public sector, a number of carers' and other organisations.	None.	Main forms of provision in-home short breaks, residential care home and day centres. Increases in use of telecare. Break considered unsuitable if supported person would be unhappy. "Best" type of short break varied, personal choices: a few hours, few days and, in some cases, with or without supported person. Variations in the desired frequency of breaks. Preferences dependent on intensity of care provided. Older people least likely to use self-directed support to manage their care, or engage with non-traditional options. Early-onset dementia may fall outside general eligibility criteria. Some local authorities tried to move away from "traditional" overnight short breaks. Need for a clearer understanding of the benefits and costs of short breaks and clear cost-benefit framework to support assessment processes. Many clients who might benefit from a short break were unable to access one as needs not assessed as critical or substantial. Variability in the knowledge and understanding of individual assessors about short break options.	Research needed to investigate carer satisfaction with assessment process, local authorities' use of different criteria and managing scarce resources. Approaches to measuring or identifying unmet need were limited.
Shared Care Scotland (2012) Scotland, UK. *Rest assured. A study of unpaid carers' experiences of short breaks. Report.*	Unpaid carers. Various types of respite/short breaks.	To understand the benefits of short breaks, good practice in planning and provision, areas for improvement and evidence of carer outcomes.	Scotland-wide survey (1,210 responses) distributed through carer organisations, four focus groups involving 36 carers and 13 interviews.	None.	Short breaks helped alleviate physical and emotional demands of caring to sustain the caring relationship and prevent admission to residential care. BME and older adults less likely to avail of alternative short breaks provision. Mixed views on lengths of breaks. Improvements needed: accessibility, information, improved planning process, flexibility, emergency respite, appropriate and alternative short breaks, support to address physical, financial and mental impact of caring, recognise language/ cultural needs.	Carers suggestions for improvement: early intervention rather than crisis point, increased choice, flexibility, frequency and length of short breaks. Carers also highlighted the importance of information and culturally suitable services. A single point of contact and dates secured well in advance is important. Measuring the reach and impact of short breaks and meeting the challenges and opportunities presented by Self-directed Support is important.

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Shared Care Scotland (2016) Scotland, UK. *Strategic Review of the Short Breaks Fund. Final Report. (2016)*	All carer groups. Evaluation of short breaks fund.	How the fund could achieve maximum future impact and what lessons could be learned from the past 5 years.	Desk based research – review reports and publications, national policy and action plans. Internal and external workshops with stakeholders, consultations with organisations and focus groups with carers.	None.	Short breaks enable carers to enjoy 'me time', recharge batteries and provide space to do other activities. They can help to reduce isolation and re-build social connections with friends and other family members. However, carers can experience guilt and stigma. Many carers view a short break as a luxury. In relation to short breaks, choice and flexibility of what, when and where are critical aspects in meeting carer needs. Short breaks don't need to be exceptional things – sometimes simple things make the big difference. Supported person has the opportunity to try new activities that are engaging and stimulating.	Need to continue innovating and explore and demonstrate diverse forms of short breaks that have impact. Feedback from stakeholders suggests the events and workshops to share knowledge, learning, updates relating to policy are valued and good practice.
Shared Lives Plus (2018) Wales, UK. *The State of Shared Lives in Wales 2018. Report.*	Various carers for older adults.	Report on Shared Lives services in Wales.	Statistics and description of Shared Lives in Wales.	None.	Schemes are offering short-break and day support as a flexible option so that older people can maintain independence using a direct payment or the person's own money. Increases choice for older people with dementia and people facing health challenges, improves timely hospital discharges and prevents readmissions. Shared Lives helps carer and those they support to 'recharge their batteries'.	Research is needed, that involves carers and people using Shared Lives, to assess the impact of Shared Lives on independence and wellbeing. Work with local third sector and voluntary organisations to promote and develop Shared Lives services.
Shaw, C., McNamara, R., Abrams K., Cannings-John, R., Hood, K., Longo, M., Myles, S., O'Mahony, S., Roe B., and Williams, K. (2009) International. *Systematic review of respite care in the frail elderly.* *Health Technology Assessment (20): 1–224.*	Carers of frail elderly.	To assess the effectiveness of breaks in improving the wellbeing of informal carers of frail and disabled older people living in the community, to identify carer needs and highlight barriers to the uptake of respite services.	Systematic review. Meta-analysis of quantitative studies and thematic analysis of qualitative studies. 104 quantitative papers, 70 qualitative papers.	Systematic Review reflected on outcome measures used in other studies.	No effect of respite on anxiety, but positive effects on morale, anger and hostility. Single-group studies suggest quality of life was worse after respite use, with increased rates of institutionalisation after respite use. Uptake influenced by carer attitudes to caring and respite provision, caregiving relationship; knowledge and availability of services; acceptability and impact of respite care, hassles in use of and quality of respite care; appropriateness and flexibility. Carers expressed need for information, early support, a diverse range of break services that provide meaningful stimulation and reliable transport.	Consider short- and long-term outcomes using mixed methods research. Research to address optimum time for provision of respite for relief from burden; evaluate interventions to break down barriers to respite use. Explore the meaning of a 'mental break' and how interventions may help carers achieve this.
Stirling, C. M., Dwan, C. A., and McKenzie, A. R. (2014) Tasmania. *Why carers use adult day respite: a mixed method case study.* *BMC Health Services Research, 14(1), 245.*	Carers of mostly older adults (including PWD). Adult day care respite service.	Explores carers' expectations and experiences of day respite, and the levels of trust in care-recipients' care.	Mixed method case study (qualitative and quantitative data). Survey data adapted from existing tools.	Outcomes based on Maslow's hierarchy of needs and psychological contract theory.	Carers need to feel confident that respite delivers benefits, e.g. meaningful and enjoyable activities, belongingness and love and esteem. Perceived benefits for supported person: interest in friends, daily activities, physically active.	None reported.

Reference and research location	Carer group and break type	Study aims	Method(s)	Outcome measures	Key findings relating to carer outcomes	Recommendations and knowledge gaps
Strang, R. (2001) Canada. *Family caregiver respite and leisure: a feminist perspective.* *Scandinavian Journal of Caring 2001 15, 74–8.*	Female carers of people with dementia. Various types of respite.	Exploring the experience of respite for family carers of people with dementia.	Qualitative methods. Interviews and narrative vignettes with 8 female carers.	None.	Carers report sense of freedom, identity/roles away from the caregiving world and 'having your own self'. Carers also report guilt and concerns for welfare of the supported person. Women internalise gendered expectations.	Need to explore links between respite and leisure in the context of 'the ethic of care' within a feminist framework and recognise age, socio-economic status and concept of carer entitlement.
Tretteteig, S., Vatne, S., and Rokstad, A. M. M. (2016) Norway. *The influence of day care centres for people with dementia on family caregivers: an integrative review of the literature.* *Aging and Mental Health, 20, (5), 450–462.*	Family caregivers of people with dementia. Day care centres.	To provide an extended understanding of the influence of Day Care Centres on family caregivers (FCs).	Integrative review including 19 studies: qualitative (n = 2), quantitative non-randomised (n = 8), quantitative descriptive studies (n = 7), and with mixed-method design (n = 2).	None.	Main outcome in several studies was the decrease of stress and care demands, associated with the provision of day care, might lead to the postponement of nursing home placement.	The limited standardisation of DCCs according to content and quality of treatment, structure, and organisation is a challenge for research, and in the running of a clinical evaluation of the service. There is a need for an increased focus on the qualitative content of the DCC as both a respite and a support service, taking the diversity of FC and PWD needs into consideration.
Vandepitte, S., Van Den Noortgate, N., Putman, K. Verhaeghe, S., Verdonck, C., and Annemans, L. (2016) International. *Effectiveness of respite care in supporting informal caregivers of persons with dementia: a systematic review.* *International Journal of Geriatric Psychiatry 31, 12, 1277–1288.*	Caregivers of persons with dementia. Various forms of respite.	To investigate the effectiveness of different types of respite care in supporting informal carers	Systematic review of literature - quantitatively controlled or uncontrolled trials. 17 studies included.	None.	Day care the most investigated type of respite care, with positive outcomes for carer and PWD. It can reduce burden on caregiver and address behavioural problems of PWD. It may improve sleep quality. Only one study looking at community based respite care programme – high satisfaction and preference for this type of break.	Lack of evidence for the effectiveness of respite. Need new intervention studies measuring effectiveness and cost-effectiveness of respite care, especially in-home respite programs.
Victor, E. (2009) UK. *A Systematic Review of Interventions for Carers in the UK : Outcomes and Explanatory Evidence. London: The Princess Royal Trust for Carers.*	Carers of ill, disabled or frail family members. Various respite Interventions.	What is known about the outcomes of interventions for carers, the explanatory evidence about how interventions support carers and the contextual factors that influence outcomes?	Systematic review of interventions directly targeted at carers, 107 studies post 1990. UK based research.	None.	Few quantitative studies report significant positive impact on carers. Qualitative studies more likely to report benefits. Qualitative studies generally reported breaks enable carers to have a rest and experience physical and emotional relief, do everyday jobs, pursue social activities and interests and employment. Some qualitative evidence carers felt breaks facilitated a sense of normality, freedom, peace of mind and relief, whilst also anxiety, sadness at being separated. Qualitative evidence breaks enabled some to continue in caring role who would otherwise have sought other options. Little robust quantitative evidence of improvements to emotional well-being.	Future research should measure outcomes and consider explanatory mechanisms and contextual factors. Comparative research to consider the relative value of different short break types. Consider outcomes for person receiving care and how this may influence use of short breaks and benefits gained by carers.

Reference and research location	Carer group and break type	Study aims	Method(s)	Outcome measures	Key findings relating to carer outcomes	Recommendations and knowledge gaps
Washington, T. R., and Tachman, J. A. (2017) USA. *Gerontological Social Work Student-Delivered Respite: A Community-University Partnership Pilot Program.* *Journal of Gerontological Social Work, 60 (1), 48–67.*	Carers of people with dementia. Houseguest respite programme.	To examine caregivers' experiences in houseguest respite programme, a home based caregiver intervention delivered by masters level students.	Semi structured interviews with caregiver and supported person (n=7). Thematic analysis producing themes relating to houseguest programme	None.	Carers identified lack of respite from caring, little information on strategies and few supportive services, social isolation and exhaustion. Pre houseguest: socialisation limited, lack of physical activity. Post houseguest: entertained supported person, music and activities, positive feelings and calmness, tailored activities. Good for students as they had personal experience.	Future work should look at the effect of houseguest programme on burden of caregivers, quality of life (caregivers and PWD) and behaviour of care recipients. Lack of diversity in sample. More research recognising diversity of carers' experiences.
Wilz, G., and Fink-Heitz, M. (2008) Germany. *Assisted vacations for men with dementia and their caregiving spouses: Evaluation of health-related effects.* *Gerontologist, 48 (1), 115–120.*	Spousal caregivers of men with dementia (moderate to severe). One week assisted vacation in hotel/rehab clinic (shared activity for caregiver and care recipient).	To determine the effectiveness of care-assisted vacations in reducing caregivers' susceptibility to depression and physical complaints.	Pilot study quasi-experimental, two-group (intervention vs waiting list condition), repeated measures design 2004 to 2005. 18 couples in intervention, 11 in waiting list control. Interviewed 3 months after first interview.	Subjective physical health of participants: Giessen Subjective Complaints List (GBB-24; Brähler, Schumacher, and Scheer, 1995). Depression: Beck Depression Inventory (Beck, Steer, and Garbin, 1988).	Directly after taking a break there were significant improvements in the intervention group – a reduction in physical complaints and emotional stress. Majority assessed assisted vacation as helpful and rejuvenating. Positive evaluation of social activities and continuous exchange of experiences with other caregivers.	Future research with larger sample sizes could confirm the effects – here, only caregiving wives of men with dementia. Larger sample size could give insight into effects for different levels of dementia.
Zarit, S., Kim, K., Femia, E., Almeida D. and Klein, L. (2014) USA. *The effects of adult day services on family caregivers' daily stress, affect, and health: Outcomes from the daily stress and health (DaSH) study.* *The Gerontologist, 54 (4), 570–579.*	Carers of PWD. Adult Day Services.	To examine the effects of use of ADS by carers of PWD.	173 caregivers interviewed.	Daily psychological distress using adapted inventory from the Non-Specific Psychological Distress Scale (Kessler et al., 2002; Mroczek and Kolarz, 1998), care related stressors BPSD, non-specific psychological distress scale, and daily health symptoms.	Care related stress decreased on ADS days. Carers reacted to non-care stressors with less depressive effect than on non-ADS days. ADS may allow caregivers to manage challenges without the build-up of tension leading to anger or depression and haver positive implications on long term health.	Need to consider the multiple dimensions of caregivers' daily experiences for understanding their wellbeing.

Appendix 2. Studies using validated outcome measures

Author	Short break type	Validated measure/s used
Gaugler et al (2003)	Home help service	Role captivity measure (Pearlin et al 1990), psychological wellbeing (depression scale (Radloff, 1977), the Zarit burden interview.
Klein et al, (2016) and Legget et al (2016)	Adult day care	Stress hormone cortisol measures.
Lee et al (2007)	Institutional respite care	Sleep activity (Pittsburgh Sleep Quality Index) Epworth Sleepiness Scale actigraphic measures, and Quality of life (Medical Outcomes Study 36-item Short Form survey).
Nicoll et al, (2002)	Various respite care services	Medical Outcomes Social Support Survey (Sherbourne & Stewart 1991), 13- item Carer Strain Scale (Gilleard et al. 1984). Geriatric Depression Scale (Brink & Yesavage 1982).
Lund et al (2009)	Adult day care	Activities from ‘Yesterday Interview’ (Moss and Lawton) ‘Caregiver Burden Inventory’ (Novak & Guest, 1989). Depression measured using CES-D Radloff, 1977. Caregiving Appraisal Instrument developed by Lawton, Kleban, et al. (1989).
Måvall L., & Thorslund, M. (2007)	Adult day care	Depression, somatic problems and psychological wellbeing. Caregivers’ self-perceived levels of role captivity and worry (physical and psychological strain (CES-D; Radloff, 1977). Items developed jointly for American study (Jarrott et al., 1998). Caregiver overload scale of seven items, including four developed by Pearlin et al. (1990), three developed for study and Jarrott et al., (1998).
Neville, C. C., & Byrne, G. J. A. (2008)	Residential respite for older people	General health questionnaire GQH-28 to detect psychological distress – disruptions in normal functioning and Caregiving Hassles Scale (CHS)
Downes 2013)	Adult day care	GHQ-12 wellbeing including anxiety, depression, loss of confidence and self-esteem. Zarit Burden Interview (ZBI) 12-item to measure caregiver stress or burden, personal and role strain factor modified ‘Eden survey’.
Zarit (2014)	Adult day care	Daily psychological distress adapted inventory from Non-Specific Psychological Distress Scale (Kessler et al., 2002; Mroczek & Kolarz, 1998), care related stressors BPSD, non-specific psychological distress scale, and daily health symptoms.
Salin et al (2009)	Various respite care services	Carers’ Assessment of Managing Index CAMI (Nolan et al.1995) and an index developed by the researchers (Likert –type scale).
Chen T.-F., & Huang, L.-H. (2011)	Home respite care	Life quality guidelines (Chia and Li 1999, WHOQOL Group, Zhan 1992), self-rated depression scale (SDS). Subscales of physiological health, psychological condition, social relationships, care task, family role.
Chappell, N. L., Reid, R. C., & Dow, E. (2001	Various respite care services	Andrews and Withey’s Life Satisfaction Scale (1976), Rosenberg’s Self Esteem Scale (1965), Zari caregiver Burden Inventory (1980). Pearlin, Leierman, Menagan and Mullann’s (1981) Social Support Scale.
Schacke, C. & Zank, S. R. (2006),	Adult day care	Multidimensional caregiving stress measure developed for study (validity tested with Burden Interview Zarit 1990). Theoretical considerations: Pearlin et al (1990) stress process model of caregiving.
Lui et al (2018)	Adult day care	Care-related stressors Daily Record of Behaviour (DRB) and non-care stressors measured the Daily Inventory of Stressful Events (DISE; Almeida, Wethington, & Kessler, 2002), and cortisol levels in saliva,
Gitlin et al (2006)	Adult day care	Caregiver Depression: CES-D, 10-item version. Caregiver Burden Zarit Burden Interview. Zarit and Zarit (1990) 24-item Memory and Problem Behaviors scale, Perceived Change Index (Gitlin et al., 2003). Time for Healthy Behaviors Checklist, six items from the National Institutes of Health multisite Resources for Enhancing Alzheimer’s Caregiver Health (REACH II) initiative.
Wilz, G. & Fink-Heitz, M. (2008)	One week assisted vacation in a hotel/ rehab clinical as a shared activity	Subjective physical health of participants, Giessen Subjective Complaints List (GBB-24; Brähler, Schumacher, & Scheer, 1995). Depression: Beck Depression Inventory (Beck, Steer, & Garbin, 1988).
McNally L (2013)	Residential respite care	Self-reports of well-being and depression: CES-D, adapted Caregiver Burden Scale, The Montgomery-Borgatta Caregiver Burden Scale. Author’s own 12-item checklist of carer social activity listed. Levels of salivary cortisol.

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