

ESSS Outline

# Carers mental and physical health

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# Introduction

This summary provides an overview of evidence relating to:

*Carers mental and physical health, with additional focus on finances and employment.*

## About the evidence presented below

We searched for academic research and grey literature using a wide range of search terms including: carer, mental health, physical health, resilience, social care, carer identification, benefits, employment.

Carer health is an understudied area with a lack of robust evaluation of interventions and support services.

## Accessing resources

We have provided links to the materials referenced in the summary. Some materials are paywalled, which means they are published in academic journals and are only available with a subscription. Some of these are available through [The Knowledge Network](#) with an NHS Scotland OpenAthens username. The Knowledge Network offers accounts to everyone who helps provide health and social care in Scotland in conjunction with the NHS and Scottish Local Authorities, including many in the third and independent sectors. [You can register here](#). Where resources are identified as ‘available through document delivery’, these have been provided to the original enquirer and may be requested through NHS Scotland’s [fetch item service](#) (subject to eligibility).

Where possible we identify where evidence is published open access, which means the author has chosen to publish their work in a way that makes it freely available to the public. Some are identified as author repository copies, manuscripts, or other copies, which means the author has made a version of

the otherwise paywalled publication available to the public. Other referenced sources are pdfs and websites that are available publicly.

## Background

While funding and cuts to budgets and services continues to be an issue in social care the number of people in need of long-term care is increasing. An ageing population combined with economic austerity means an increasing reliance on family carers to support people with long term health conditions ([Al-Janabi, 2016](#)).

Most of the care in the UK is provided by family and friends. Recent polling suggests there could be around 8.8 million adult carers in the UK, up from 6.3 million in 2011 ([Carers UK, 2019a](#)), which social services and the NHS rely on to function.

The figures from England ([NHS Digital, 2016](#)) comparable across the UK show:

- 13% of carers care for 19 hours or less a week
- 15% care for between 20 and 49 hours a week
- almost 15% care for between 50 and 100 hours a week
- 36% of carers are caring for over 100 hours a week

The numbers caring for 50 or more hours or more each week are rising faster than the general carer population ([Carers UK, 2019b](#)).

The contribution of carers support to the economy is estimated at £132 billion a year ([Carers UK, 2019a](#); [Cottagiri, 2019](#)) but the health and wellbeing of carers are often not prioritised.

If a carer is working, looking after children, or having to travel long distances, then even providing a few hours of care a week can have a serious impact on their life ([Carers UK, 2019b](#)). Providing care can be hugely stressful, affecting

both mental and physical health, and resulting in social isolation and financial hardship ([Al-Janabi, 2016](#)).

A Carers UK report ([2019a](#)) found two thirds of carers focussed on the care needs of the person they care for, rather than their own needs.

## Cuts in services

More than a third of carers asked by Carers UK ([2019a](#)) had experienced a change in the amount of services that they received in the previous year because:

- care or support arranged by social services was reduced, or closed with no replacement
- the cost increased
- their personal budget no longer covers it

It's crucial to a system reliant on informal carers that both practical and financial support are available.

## Characteristics of caring

Caring is not a one size fits all concept, and the experience and effects of caring aren't the same for each group of carers. The amount and type of care that carers provide varies considerably - from providing a few hours a week shopping, collecting medication, taking someone to medical appointments, to round the clock care. Figures from NHS Digital ([2010](#)) show:

- 82% provide practical help such as preparing meals, doing laundry or shopping
- 76% keep an eye on the person they care for
- 68% keep them company
- 62% take the person they care for out
- 49% help the person they care for with financial matters

- 47% help the person they care for deal with care services and benefits
- 38% help with aspects of personal care
- 38% provide physical help

Most care for one person, but 17% are caring for two or more people:

- 40% care for their parents or parents-in-law
  - 26% care for their spouse or partner
  - 8% care for disabled children under 18
  - 5% care for adult children
  - 4% care for their grandparents
  - 7% care for another relative.
  - 9% care for a friend or neighbour
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- 58% of carers look after someone with a physical disability
  - 20% look after someone with a sensory impairment
  - 13% care for someone with a mental health problem
  - 10% care for someone with dementia.

A higher number of hours (over 20 per week) generally means care is more likely to be personal care - for example providing physical help and giving medicines. The same pattern is found for those caring for someone in their household, rather than at a distance ([Carers UK, 2019b](#)). Around half of carers are caring for someone in the same household and half care for someone living elsewhere.

Sandwich caring - people who care for an older or disabled loved one at the same time as they have young children - is growing. Data suggests that 3% of the UK general population, around 1.3 million people, have these responsibilities and are more likely to report symptoms of mental ill-health, feel less satisfied with life, and struggling financially compared with the general population ([Carers UK, 2019b](#)).

## Age

Most carers are below state pension age, and the peak age for caring is 50-64. The number of carers over the age of 65 is increasing more rapidly than the general carer population. The 2011 Census indicated that almost 178,000 under 18s have caring responsibilities, but these figures are almost certainly higher ([Carers UK, 2019b](#)).

## Gender

Women are more likely to undertake responsibility for caring, often happening at the peak of their careers, and while raising children ([Carers UK, 2019a](#)). There numbers of female carers are higher for young carers ([Barnardo's, 2017](#)) and for those providing round the clock care. Carers over 85 are more likely to be male.

Female carers were found to experience more negative health impacts than male carers. Male carers are more likely to experience less carer burden, and more work interference ([Brenna, 2016](#)).

## Race

Carers UK found that Black, Asian and Minority Ethnic carers were less likely to receive financial and practical support, often through difficulty accessing culturally appropriate information, and a lack of engagement with these communities. The Children's Society found that young carers are 1.5 times more likely to be from BAME communities and hidden from services ([Barnardo's 2017](#)).

## Disability

A 2019 survey ([Carers UK, 2019b](#)) found carers are more likely to report having a long term condition, disability or illness than non-carers. More than half of those who considered themselves to have a disability said their

financial circumstances were affecting their health. Carers with disabilities are:

- more likely to give up work to care
- less likely to be in paid work alongside caring
- more likely to be on lower incomes when working
- more likely to be the sole earner in their household
- more likely to be in debt and higher levels of debt.

## The effects of caring

Providing care, often putting someone else's needs before your own, can be challenging. Many carers experience significant physical, mental, employment and financial effects as a result of their caring role. When asked about their own wellbeing the impact of stress and anxiety on their health was the most common response from carers ([Carers Week, 2018](#)).

A Carers UK report ([2019a](#)) found carers who said they were struggling financially were more likely to say they expect their physical health to get worse, and most likely to expect their mental health to get worse, in the next two years.

Research shows providing care can be associated with poorer mental and physical health and quality of life, particularly with higher intensities of caring. Research has mainly focused on the stress associated with caring: physical and psychological strain over extended periods of time, high levels of unpredictability and uncontrollability, secondary stress in work and family relationships, and frequently requires high levels of vigilance ([Cunningham, 2019](#); [Euro Carers, 2018](#); [Farina, 2017](#)).

Carers are less likely to look after their own health and more likely to take part in harmful behaviours such as smoking and drinking ([Cottagiri, 2019](#)).

These effects differ across the groups of people being cared for and the type of carer, with women, those married, and providers of intensive care especially affected ([Bom, 2019](#)).

The Scottish Government ([2015](#)) found more than a third of carers reported caring having a negative impact on their health, and with the more care provided, the less likely the carer is to report good health.

Research by Carers Scotland found that almost half of carers with health problems reported that their conditions began after they started caring. Of those whose condition pre-dated their caring role, a quarter said their condition had worsened since becoming a carer ([Carers UK, 2019b](#)).

A UK survey of 1007 family carers found that around a third rated their health as fair or poor. Almost half had a longstanding physical complaint. A fifth reported restricting their activities because of a health problem. Worry, depression and tiredness was recorded most, with indications that smoking, alcohol and drug intake had increased as a result of caring responsibilities ([Bailey, 2019](#)). Studies from around the world show similar effects.

Intense carers (those who provide at least 20-49 hours of care a week) were more likely to be physically inactive, smoke cigarettes, gain weight, and eat unhealthily. They were more likely to self-report or have a diagnosis of depression or anxiety. Carers who had given up work to care were more likely to be smokers and have common mental disorders ([Future Care Capital, 2019](#); [Tseliou, 2019](#)).

Studies of COPD carers ([Cruz, 2017](#)) found carer burden was associated with carer-patient relationship quality, caregiving hours per week, carers' mental and emotional health and patients' physical health. Carer emotional distress was associated with disease-specific factors (such as symptoms, severity and duration) but also with carers' background characteristics, such as gender, age and educational levels.



## Positives

Although the focus is usually on the negative effects of caring, some carers do report positive aspects, finding it positive and rewarding, with improved mental health and wellbeing. Recent findings suggest that helping others may be just as beneficial to health as receiving support: caregiving makes carers feel good about themselves, gives meaning and purpose to their lives, enables them to learn new skills, improves resilience generally, and strengthens their relationships with others ([Euro Carers, 2018](#); [Farina, 2017](#); [Future Care Capital, 2019](#)).

This is dependent on the amount of care being provided and the ability to balance it with other aspects of life, and in part, on the availability of appropriate support. Analysis found that those who provide up to 4 hours per week have higher mental wellbeing scores than non-carers ([Scottish Government, 2015](#)).

This suggests that support and interventions should both reduce the negative aspects and enhance the positive aspects of caring.

## Physical health

The physical impact of caring has been studied less than mental impact, but what is often highlighted is the impact of long-term stress and anxiety, poor health behaviours and the difficulties in maintaining a healthy lifestyle, and musculoskeletal problems ([Cottagiri, 2019](#)).

Carers are more likely to have a long-standing health condition, with higher levels of arthritis, high blood pressure, and long-term back problems more common amongst carers who provide hands-on care.

Caring can be physically demanding, particularly if it means lifting the person needing care, helping them dress, wash and move around the house. Not having the necessary practical support and equipment such as hoists or stairlifts to ease the physical strain of moving and handling can lead to or

worsen injury. Half of carers ([Carers UK, 2016](#)) taking part in research said that missing out on support had an impact on their physical health.

Without the support to look after themselves, to sleep, eat and exercise properly, and to attend health appointments carers physical health problems can escalate resulting in long term injury, jeopardising their ability to provide care.

From the Scottish Government's ([2015](#)) report:

- 41% of carers said that they had a long-term condition or illness, rising in line with care hours provided
- poorer physical health is associated with old age, challenging care situations, lower socio-economic status and less informal support
- poor carer health can have lasting impacts on the carer, persisting beyond the end of caregiving
- caring may impact on an individual's ability to look after their own health
- 22% of carers aged under 25 had a long-term condition or disability, twice the rate for non-carers

More recent papers show 40% of carers reporting their physical health being affected by caring, with tiredness (35%), trouble sleeping (28%), reduced fitness (20%) and back pain (18%) the most common impacts. Carers also highlighted being unable to find time to care for themselves if they become ill. These figures increase as duration and hours of caring increase, and are generally higher for those who live in the same house as the person they care for. Women and older people were also more likely to mention an impact upon their physical health ([Alzheimers Research UK, 2019](#); [Carers UK, 2019b](#); [Cruz, 2017](#); [Future Care Capital, 2019](#)).

Back pain and back injuries are one of the most common physical ailments associated with caring, particularly in the older age group and for those caring for people with physical disabilities and long term illnesses ([Cottagiri,](#)

[2019](#); [Future Care Capital, 2019](#)). A report from Ireland ([Family Carers Ireland, 2019](#)) found around two thirds felt their back injury was caused or made worse because of their caring role.

## **Mental Health**

Caring is seen to influence emotional and mental health and is a predictor of poor mental wellbeing.

Half of all carers reported that their mental health has been affected by providing care for another person ([Future Care Capital, 2019](#)). Carers Week ([2018](#)) highlighted not getting enough sleep, providing hands on care for the person they care for, and managing financially were the three things that carers said contributed most to their stress and anxiety. Without support they can suffer from depression, stress and anxiety, strained relationships with friends and family, loneliness and isolation ([Carers UK, 2019a](#); [Cottagiri, 2019](#); [Future Care Capital, 2019](#)). The Family Carers Ireland survey ([2019](#)) saw almost half of the respondents reporting being diagnosed with depression and / or anxiety, with two thirds of these saying it was caused or made worse by their caring role.

Carers identified social isolation and loss of recreational activities as one of the greatest impacts of caring ([Alzheimers Research UK, 2019](#); [Carers UK, 2019b](#); [Cottagiri, 2019](#); [Cruz, 2017](#)). Carers are seven times more likely to say they are always or often lonely compared with the general population, and overall 80% of all carers reported having felt lonely or isolated as a result of their caring role ([Carers UK, 2019a](#)). Carers frequently lack support and often have no time or resources for social activities, with one survey showing 40% having not had a full day off from caring in over a year, and 25% in the last five years ([Carers UK, 2019b](#)).

Carers UK State of Caring ([2019a](#)) report recorded 27% of carers rating their mental health as bad or very bad, and their happiness level at 4.7 out of 10,

compared to a population average of 7.5 out of 10. There are many factors at play when it comes to the effects of caring on the carer.

The amount and duration of care increases the likelihood of experiencing mental health issues ([Brenna, 2016](#); [Cottagiri, 2019](#); [Future Care Capital, 2019](#)). Carers who provide more than 35 hours per week, particularly for those with a long-term illness such as dementia, are much more likely to have lower mental wellbeing scores and exhibit signs of possible psychiatric disorders ([Scottish Government, 2015](#)).

The type of care required also impacts, with effects on mental health most common among close family carers - parent, spouse, or child ([Future Care Capital, 2019](#)). Carers looking after disabled children under the age of 18 reported significantly poorer mental health. 36% described their mental health as bad or very bad ([Carers UK, 2019a](#)).

Carers of people with predominantly non-physical health conditions were most likely to experience mental health issues themselves, particularly if the person they are providing care for suffers from autism, addiction, or mental health conditions ([Future Care Capital, 2019](#)). Carers who care for those with mental illness often have to cope with challenging, irrational, aggressive and violent behaviour ([Alzheimers Research UK, 2019](#); [British Psychological Society, 2019](#); [Cottagiri, 2019](#)).

Young carers also come with their own challenges, particularly when providing full time care in addition to schoolwork. Previous studies show young carers are more likely than their peers to be bullied, miss school and have mental health issues. Over 50% of young carer respondents in a Barnardo's survey ([2017](#)) reported caring had impacted on their emotional and mental health.

At least half of carers expect their mental and physical health, and quality of life to get worse ([Carers UK, 2019a](#); [Carers Week, 2018](#)).

## Risk behaviours and self-care

Chronic stress may promote unhealthy behaviours such as drug and alcohol abuse, smoking, poor nutrition, and sedentary lifestyle, that are often associated with physical and mental health problems. An Australian study of women aged 50 years or more, found carers reporting higher symptoms of depression, anxiety and stress, and lower participation in health promoting and physical activities ([Mohanty, 2019](#)).

An exploratory study ([Bailey, 2019](#)) conducted with carers of people with various mental illnesses, looked at health risk behaviours in carers. It found most carers consuming inadequate fruit and vegetables, more than half engaging in inadequate amounts of physical activity, and almost a third at risk for harmful alcohol consumption. Around two-thirds were at risk for multiple behaviours.

Findings suggest carers may require risk reduction programs particularly tailored to their caring roles / context.

Carers health might be affected by:

- prioritising the health and wellbeing of the people they care for
- time, transport and financial constraints on seeking support around risky behaviours
- health professionals focussing on the health and wellbeing of the person they care for

There is inconsistency in carers being made aware of support available to look after their own physical, mental and emotional health and wellbeing including eating properly, exercising and sleep, access to health checks, flu jabs, supporting with medication and flexible appointment times.

The importance of carers talking about their experiences, taking a break where possible, the Carers Assessment, support groups, and information and signposting are frequently mentioned across the literature.

A scoping review from the United States on health-promoting self-care interventions in family carers of people with dementia found interventions helped reduce carer depression and burden, and increased quality of life, and physical activity ([Oliveira, 2019](#)).

The carers in the Future Care Capital report ([2019](#)) frequently mention limited opportunity for formal or informal respite, making self-care difficult, resulting in their own needs coming second.

## Carer identification

Providing care can take a toll on carers' health and wellbeing, finances, ability to work and relationships with family and friends. Too often carers are only identified when they are struggling to manage or are in crisis ([Carers UK, 2016](#)). Despite policy and legislation many carers are still not routinely identified and thus supported by health and social care professionals. For example, more than a third of people who care for someone with cancer have not been recognised as a carer by any health or social care professional or organisation ([Macmillan Cancer Support, 2016](#)).

Frontline professionals, such as GPs, social workers and pharmacists play a central role in ensuring carers are identified and then guided to support as early as possible in their caring journey.

### Self-identification

Many people - more than half according to Macmillan Cancer Support ([2016](#)) - do not identify themselves as a carer. For some it's often just seen as something you do. It can take years for carers to recognise themselves in that role. Parent carers, mental health carers and distance carers often take

longer than others ([Carers UK, 2016](#)), and almost a quarter take over 5 years to identify as a carer.

## Consequences

Not recognising you are carrying out a caring role can be a huge barrier to accessing support. If you do not see yourself as a carer, then you are unlikely to consider asking for a carer's assessment, applying for Carer's Allowance, or seeking advice from others who find themselves in similar circumstances. Early identification means better and earlier support for physical and mental health, access to financial support, support to stay in work, reduced isolation and loneliness, and reduced risk of burn-out ([Carers UK, 2016](#)).

The majority of carers said they missed out on financial or practical support (or both) as a result of not identifying as a carer ([Carers UK, 2016](#)). Those who identified themselves as a carer immediately or within 6 months were less likely to say they missed out on support. Missing out on support can have a significant impact across carers' lives:

- 50% said it had an impact on their physical health
- 78% suffered from stress and anxiety
- 61% said it put a strain on their relationships with friends and family
- 52% said it impacted negatively on their finances
- 42% said it caused them to give up work

## Measuring health

Measuring the effects of providing unpaid care is unfortunately an understudied area. There is a lack of tools, and standardisation within them, to measure carer burden.

A lack of consensus about what and how to measure the QoL of carers has not helped practitioners or service funders. Measures need to be appropriate for younger and older carers, type of carer and caring tasks, and be sensitive to cultural and socio-demographic differences ([Manthorpe, 2016](#)). A study on dementia carers concluded that caring often has both negative and positive consequences which need inclusion in measures and can vary by individual and over time.

A short, generic tool, community-based and across health and care, to screen for mental and physical effects on carers would support measurement ([Kudra, 2017](#)). Dow's review ([2018](#)) looked at ten instruments for measuring the quality of life of carers of people with dementia. The Carer Well-being and Support questionnaire (CWS) has the best quality evidence for the greatest number of measurement of properties and is found to be the most appropriate instrument for the assessment of quality of life in informal carers at present. The Caregiver Well-Being Scale is also worth considering. All instruments included in the review would benefit from further evaluation.

## **Wellbeing**

Despite its prevalence, the concept of wellbeing lacks a clear definition. It's often used interchangeably with quality of life. Carer wellbeing is most used in the context of mental health. But wellbeing is arguably more than just the absence of illness and should encompass both positive and negative dimensions. Cunningham ([2019](#)) argues the need for standardised and robust measurements that sees wellbeing as a multi-faceted concept to enhance research in this area.

A recent review concluded that there are serious methodological limitations in existing studies looking at negative outcomes due to caregiving, particularly if evidence is examined through a negative-impact lens only ([Totsika, 2017](#)).



The Social Care Institute for Excellence identified [nine key elements](#) of wellbeing:

- personal dignity
- emotional wellbeing
- protection from abuse or neglect
- control over everyday life
- work, education and training
- social
- domestic
- accommodation
- contribution to society

## Approaches, support and interventions

Summary Euro Carers ([2018](#)) highlighted some key factors that increase carers' life satisfaction:

- Having a high socio-economic status
- Having a good level of social and family support and being satisfied with the latter
- Ability to engage with social activities
- Having access to respite
- Being in employment

A sizable majority of carers felt that support, and increased support, in some form would be useful. Emotional support is a frequent theme. Around half of carers said that they had received some form of information or support to assist with their role as a carer. Most commonly, this was access to equipment such as stair lifts or adaptations or information on the support available to carers ([Future Care Capital, 2019](#)).

There two main approaches seen across the literature:

- formal care services for the cared-for person to reduce the level and burden of informal care
- direct support to carers, such as respite care, training, counselling and psychological support

Carers have different needs and trajectories, dependent on the person being cared for, the condition they have, and the stage they are at. What might be useful and effective for one sort of carer might not be useful or effective for another. With no 'one size fits all' approach what's likely to be effective in supporting carers mental and physical health are multicomponent interventions, with an emphasis on the psychosocial and psychoeducational, education and training ([Thomas, 2017](#); [Brimblecombe, 2018](#)).

For dementia carers what's seen to help is shared learning, and computer-delivered psychosocial support. For cancer and stroke carers it can be counselling. For young carers the most important types of service would focus on having someone to talk to, emergency / crisis planning, and mental health support ([Barnardo's, 2017](#)).

Organising accessible long-term care, providing respite care, and enabling family carers to balance work and care should be driven by social policy ([Euro Carers, 2018](#)).

## **Finances**

Many argue finances are the main dictator of the quality and choice of support and care received, and additional financial support would improve quality of life ([Farina, 2017](#)).

Family Carers Ireland ([2019](#)) found pervasive worries at the heart of carer anxiety, with three quarters worried about money, their own health and wellbeing, the lack of appropriate supports and services as well as fearful for what will happen when they die or cannot care any longer.

## Benefits

There are two main policy approaches to cash benefits. Carer's allowance, which is provided directly to the carer after successful application. And a care allowance to a person with care needs who can buy in the services of carers or use it to pay a relative to provide care ([Brimblecombe, 2018](#)).

Carers Allowance remains one of the lowest welfare benefits, though higher in Scotland than in the rest of the UK. The eligibility criteria can act as a disincentive to those who want to take up employment or work additional hours to stay within the earnings limit. Carers Allowance in England also discounts other benefits and pension, and is taxed ([Brimblecombe, 2018](#)) but does protect state pension and national insurance rights.

Carers UK ([2019a](#)) suggest that financial support for carers must be increased significantly. Carer's Allowance should be raised and increased in line with the National Living Wage, pegged at least to the equivalent of 16 hours a week so carers don't have to choose between Carer's Allowance and staying in work. Carers should also be auto enrolled in a second Carer's Pension that recognises the value of unpaid work and ensures that they do not suffer financial hardship later in life.

## Carer-proofing

One problem with carer support is that interventions often come too late, with stress treated as an inevitable side effect of caring. To support carers better, carer outcomes should be considered in healthcare decisions for long term conditions from the outset ([Al-Janabi, 2016](#)).

Health systems could reduce strain on family carers by routinely considering carers' needs alongside patients' needs in everyday healthcare decisions. New treatments and different care can equally affect carers, both positively and negatively, for example reducing physical demands or stress and anxiety, or changing lifestyles. For example, a recent study of stroke follow-up care

showed that the intervention reduced carer depression but did not affect patient outcomes ([Al-Janabi, 2016](#)).

The IMPACT mechanisms ([Al-Janabi, 2019](#)) show how health and care services can affect family carers' wellbeing, through:

- information (degree to which service delivery informs and trains family carers)
- management of care (shifts of responsibility for care between formal and family sectors)
- patient outcomes (services changing patient outcomes)
- alienation (feelings of alienation or inclusion created by service delivery)
- compliance (barriers to patients complying and engaging with services)
- timing or location (changes in the timing or location of services).

The IMPACT mechanisms may be useful in designing and evaluating services to optimise the wellbeing of carers as well as patients.

Enhanced carer proofing could complement existing interventions to support carers, such as respite care, carer support groups, and individual education and training.

## **Carer Assessment / Adult Carer Support Plan**

A Carers Assessment (or Adult Carer Support Plan in Scotland) gives carers the right to an assessment from their local authority, looking at the impact of the caring role on them and what support they might need as a result.

For various reasons, including lack of identification as being a carer, only around a third of carers have an assessment, or a review of their assessment. Carers who are providing palliative care and those looking after someone with a mental health condition were slightly more likely to have had an assessment. Parent carers are less likely.

The majority of carers in England who had been assessed / reassessed in the previous year felt that their needs were not given sufficient consideration ([Carers UK, 2019a](#)). Even with a positive experience of the assessment there is often no local services available to support them with anything raised. Cottagiri ([2019](#)) found this to be a key barrier to carers using the carers assessment. Visible positive outcomes would encourage more carers to take part in carers assessments.

Inflexibility around individual carer needs (and changing needs), lack of communication and coordination before and after the assessment was also seen to be a barrier in effectively carrying out the process.

## **Practical support**

Reducing the amount of care to be provided by informal caregivers could be achieved through interventions like respite, professional home care and assistive technology that could relieve caregivers from some of their tasks ([Cruz, 2017](#); [Bom, 2019](#)).

There has been little investigation into the accessibility and use of occupational therapy services, equipment provided for care-recipients, and manual handling training for carers.

Support equipment like grab rails, wheelchairs, stair lifts, and hoists can reduce the physical exertion required by carers and increase the patient's independence, and potentially reduce carer burden and improve physical health ([Cottagiri, 2019](#)).

Carers UK ([2019a](#)) found a fifth of carers don't buy or receive support with caring, suggesting a fairly large area of unmet need.

## **Respite**

Respite care is often seen as an important form of support for carers, providing them with time to themselves away from caring activities, to look after their own physical and mental health, and to continue providing care

safely for longer. The most common forms of respite care include day-care services, in-home respite and institutional respite. A form of longer break can be vacation breaks for carers ([Cottagiri, 2019](#)).

Despite the perception of its usefulness there has been little in the way of robust evaluation on the benefits of respite care and breaks. What there is provides useful insight into the lived experiences of carers, but the findings cannot be easily generalised.

Carers generally show satisfaction with breaks, and perceive benefits to their emotional wellbeing, but this value placed on it by carers is not reflected in research. It has been seen to reduce depression in carers ([Cottagiri, 2019](#)) and as a coping support for families with children with disabilities but some studies have shown negative effects on carers emotional wellbeing ([Brimblecombe, 2018](#)). Though they are generally seen to have a positive impact on carer wellbeing, the effects don't tend to maintain over time ([Health and Social Care Board, 2017](#)).

Further research is required to explore the specific respite needs of individuals who provide care.

Carers UK ([2019d](#)) found almost 70% of carers said that the break had a positive impact with their health and well-being improving as a result. For the 30% of carers whose break worsened / didn't have any impact on their health and well-being, this was most often because of poor quality replacement care, the break being too short or their unhappiness at returning to the caring role following the break.

A report from Alzheimers Research UK ([2019](#)) shows all carers interviewed were aware of respite care. But often a sense of duty or responsibility, not finding it appropriate or practical to leave their loved one with a friend or full-time carer, meant not using this kind of support.

Many carers have voiced their concerns over the quality of respite services. Lack of trust over the care provided or being unsatisfied with previous respite

services has caused unwillingness among carers to use respite services ([Cottagiri, 2019](#)).

Carers who hadn't been able to take a break were asked for further details ([Carers UK, 2019d](#)). 40% said that the person they care for is unwilling to accept replacement care. This echoes other research from Carers UK about worries carers have about the quality and suitability of replacement care. Cost was another issue, with 38% of carers saying that they cannot afford replacement care, and 34% even with free time they cannot afford to do any activities.

While policies ensuring ease of access to respite, such as flexibility, financial assistance, and local support ([Euro Carers, 2018](#)) are important, the services provided must be suited to the individual needs, and are well managed and professionally staffed.

## **Training and advice**

Despite the risk of physical injury, carers rarely receive training for their role. Manual handling training was the most common training need identified when Irish carers were asked what training they would like to receive ([Family Carers Ireland, 2019](#)).

Future Care Capital findings ([2019](#)) show only 13% of carers had received some form of advice or training in relation to their role as a carer - most commonly this was training in medical tasks, advice on their own mental / emotional health, and training in giving emotional support to the person cared for. Over a quarter of carers, particularly younger and middle-aged carers and those caring for long periods, indicated that some form of advice or training would be useful to them. There was also a need for advice on mental and emotional health, particularly around the stress, isolation and despondency being a carer can lead to.

## Information and communication

Recent surveys show that carers would welcome additional support from health professionals. For instance, carers are not always knowledgeable about the disease of the person they care for or have difficulties dealing with disabilities ([Euro Carers, 2018](#)). An example from COPD found carers not receiving full explanations about the disease trajectory and management strategies from health professionals led to frustration and anxiety, and feeling unprepared to care ([Cruz, 2017](#)).

Almost two thirds of people caring for someone with cancer ([Macmillan Cancer Support, 2016](#)) say they would benefit from more support. The most common types mentioned were:

- someone to talk to / emotional support
- information and advice on the support available to those who care
- advice or information on financial issues or benefits
- information about cancer and its treatment

Parent carers of children with ASD reported that receiving factual and accurate information on the disorder helped decrease their feelings of stress and anxiety around their child's behaviours ([Catalano, 2018](#)).

Good quality and timely advice and information can reduce uncertainty, social isolation and feelings of helplessness, and minimise psychological health impacts such as stress and anxiety. A lack of information and signposting from care professionals, and organisational complexity and high staff turnover can worsen carers experience ([Barnardo's, 2017](#); [Al-Janabi, 2019](#); [Cottagiri, 2019](#)).

Information needed can depend on the type and severity of illness cared for. Caring for someone with a newly diagnosed illness would require support accessing information regarding the side-effects and advantages of treatments, the physical needs of the recipient, financial support and welfare benefits they might be entitled to, how it could affect their working life, and



what support services can be accessed. But someone caring for terminally ill patients might need more information about what to expect in future, the severity of the illness, how to manage symptoms and who to contact in emergency situations ([Cottagiri, 2019](#)).

### **Joined-up services**

Carers may not be fully aware of services available to them and may find it difficult to get help from fragmented services ([Euro Carers, 2018](#)).

Daily planning of tasks and duties may be difficult for carers and cause burnout. Dealing with doctors' or social workers' appointments and organising respite care appointments can be stressful, especially when combined with personal or familial duties and employment ([Euro Carers, 2018](#)).

Integrated health and social care services, linking the voluntary and community sector with public authorities can help reduce fragmentation and improve the coordination of services, reducing carer stress and burnout. A one-stop-shop for carers and their families to get medical information and find out about what support (financial, physical, emotional and social) is available could prove beneficial to carers' wellbeing ([Al-Janabi, 2016](#); [Euro Carers, 2018](#)).

### **Case managers**

One suggested measure here is the support of a case or care manager to alleviate some of the administrative burden facing carers following an assessment of their needs and those of the person they care for. Managers can bridge the gaps between health and social care providers, and carers. Identifying carers through adequate professionals trained to support them is a key component of this ([Euro Carers, 2018](#)).

## GP's

Carers UK ([2019b](#)) found that most carers caring for at least 50 hours a week had a GP who knew about their responsibilities but didn't do anything differently to accommodate them. Very few had a GP who gave regular carers health checks or did home or telephone appointments. Over half had not been informed about how to access practical support by their GP. Where GPs didn't support carers through signposting or health checks, over half of carers reported that they let a health problem go untreated and that their mental health got worse ([Carers UK, 2019b](#)).

## Workshops, groups and counselling

Studies have shown stress management programs and cognitive behavioural therapy can reduce mental stress among carers ([Cottagiri, 2019](#)). A pilot study investigating an 8-week web-based mindfulness intervention showed improvements in levels of mindfulness, perceived stress, caregiver burden, and self-compassion ([Stjernswärd, 2017](#)). Mindfulness and acceptance and commitment therapy can change long-standing response behaviours and build personal resilience and improve mental health ([Appleton, 2019](#); [Cook, 2019](#)). Combined with training in problem-solving strategies, these have the potential to improve carers' wellbeing and increase confidence in effectively managing daily challenges ([Catalano, 2018](#)).

Cognitive Behaviour Therapy (CBT) models have been used to treat anxiety and depression, helping people develop coping strategies by working through their thoughts, feelings, and approaches to particular situations. A modern CBT approach, Acceptance and Commitment Therapy (ACT), seemed to be particularly beneficial for carers experiencing high levels of anxiety ([Kishita, 2018](#)).

Recent surveys show that carers would welcome additional psychological counselling. Counselling has proved effective to relieve carers' stress ([Euro Carers, 2018](#)).

Individual counselling and group meetings aimed at providing emotional, educational, and practical support for carers ([Brimblecombe, 2018](#); [Caton, 2019](#)) seem to offer health benefits. There is evidence on the effectiveness of mental health support groups for carers, such as Carer Peer Support Workers ([Visa, 2019](#)) and professionally facilitated, family-led support groups, psychoeducation carers support groups, and professionally facilitated, program-based support groups for people living with mental illness ([Worrall, 2018](#)).

Telehealth and online support services can also offer easier access and convenience to carers but there has been little evaluation of their efficacy ([Sin, 2018](#))

The higher quality studies of interventions are generally in the field of dementia care. Two examples highlighted by The British Psychological Society ([2019](#)):

- SHARE (Support, Health, Activities, Resources & Education) is an intervention to help couples plan for the future. It is focused on enabling the person with dementia and a key carer to work together to plan for their future with dementia. The sessions involve a range of structured discussions that enable couples to develop their understanding of dementia, think about their care values and their preferences for future care, and plan how to draw on resources as the dementia gets worse.
- START (STrAtegies for RelaTives) is a carers' psycho-educational and skills-training intervention focused on enabling carers to cope with caring. The sessions of the programme cover material which carers then put into practice at home, with support from a manual. Topics include psycho-education about dementia; carer stress and sources of emotional support; understanding and managing behaviour of the person with dementia; changing unhelpful thoughts; promoting acceptance; assertive communication;

relaxation; planning for the future; increasing pleasant activities; and maintaining the skills learnt.

## Income and employment

Caring creates financial difficulties for a significant number of carers, having less money due to reduced work and income, and an increased spending associated with caring (higher energy bills, specialist food, transport costs, care products and equipment) ([Alzheimers Research UK, 2019](#); [Carers UK, 2019b](#); [Future Care Capital, 2019](#)).

Carers who provide support for less than 10 hours a week were most likely to say that their role has not had an impact on their work life than those caring for 30 or more hours a week ([Future Care Capital, 2019](#)). The more years spent caring also increases the likelihood of being in debt ([Carers UK, 2019a](#); [Carers UK, 2019b](#)) with carers who have been caring for 15 years or more, and those who care for more than 35 hours a week are more likely to say that they are struggling to make ends meet.

### Finances

1.2 million carers (around a fifth) live in poverty in the UK, highest in the working age carer population and increasing with the number of hours of care provided ([Carers UK, 2019b](#)).

When asked how they would describe their financial situation, almost 40% of carers say that they find it difficult to make ends meet. Carers UK ([2019a](#)) found:

- 21% are or have been in debt as a result of caring
- 44% are relying on their savings
- 36% are using credit cards
- 33% are using their bank account overdraft
- 15% are falling into arrears with utility bills

- 9% are falling into arrears with their housing costs

The combination of higher costs and lower incomes can push families into financial crisis and lasting debt - 21% of UK carers are in or have been in debt as a result of caring and only 46% of UK carers can afford their bills without struggling financially ([Carers UK, 2019b](#)).

Surveys found large numbers of carers struggling to pay household bills and cutting back on essentials like food and heating ([Alzheimers Research UK, 2019](#); [Cottagiri, 2019](#)). Most have cut back on hobbies, leisure activities and seeing family and friends ([Carers UK, 2019a](#)) all of which have a negative impact on mental and physical health. Some also have to cut back on the support services that help with caring.

Carers looking after children were particularly likely to report that caring has affected their financial situation. Many parents will have to care for their child for several years and are likely to be offering full time care (60% care for 30 hours or more a week), with the resulting continuous spending for caring. They are also more likely to say they have less money due to not working ([Future Care Capital, 2019](#)).

43% of carers said their financial circumstances were affecting their health ([Carers UK, 2019b](#)).

## **Support**

The financial impact of caring is often exacerbated by delays in accessing benefits and other financial support ([Carers UK, 2019b](#)), and even when in receipt of benefits over half of carers receiving Carer's Allowance are also struggling to make ends meet. Carer's Allowance aims to help with the costs of caring, but for many the low payment level and other entitlement conditions, including an earnings limit, leaves the benefit ineffective in preventing financial hardship. Neither the Allowance nor the earnings threshold align with the national living wage, meaning that a carer can only

work for a maximum of 15 hours per week without losing the Allowance ([Carers UK, 2019a](#)).

Many carers are frustrated with the state financial support available. Those who receive carers allowance said that the amount received is minimal, particularly if they then have deductions made to other benefits as a result. Others are turned down for the allowance without understanding why given the amount of support they provide, and the impact of this on their own finances. Other issues include young carers unable to claim carer's allowance whilst attending university despite still living at home to support parents ([Future Care Capital, 2019](#)).

Carers also miss out on support due to not identifying as a carer. More than half of carers reported it impacting negatively on their finances, with almost 60% struggling to make ends meet ([Carers UK, 2016](#)).

The Future Care Capital report ([2019](#)) also notes carers applying for financial support from local authorities for things like adaptations, but only a minority being successful.

Good work-life balance and wellbeing cannot be achieved through financial support on its own. Formal care services, flexible working and poverty alleviation measures are also needed. In many cases a combination of interventions and support would be most effective ([Brimblecombe, 2018](#)).

## **Employment**

The 2011 Census found around half of the UK's carers combine work with unpaid caring responsibilities - over two million full-time and one million part-time. Recent research suggests that both the carer population and proportion of working carers has increased, with 5 million people now combining paid work and caring ([Carers UK, 2019b](#)). Part-time working is much more common amongst carers than non-carers. Carers are also more likely to stop working altogether with difficulties moving to part-time hours ([Brimblecombe, 2018](#)).

The Future Care Capital report ([2019](#)) showed over 40% of carers working life impacted by caring, with almost 20% having to stop working all together, mostly due to the stress of combining work and care, and the lack of suitable support services. Reduced and flexible working were other common approaches. All of this can be accompanied with decreased performance at work (for example, lateness, tiredness, difficulty concentrating) ([Carers UK, 2019b](#)).

Alongside this there are still a significant number of people working a full week alongside a full caring week ([Carers UK, 2019b](#)). And of those still working there are complications from having to change working patterns, accepting less qualified positions, or being unable to take on promotions ([Carers UK, 2019b](#)).

Generally, carers aged 35-49 are most likely to report an impact on their working life, and to stop working altogether. But again, effects are often dependent on circumstances and those being cared for - for example carers of people with dementia, children, or someone with autism are more likely to have to stop working ([Future Care Capital, 2019](#)).

Future Care Capital ([2019](#)) highlighted the impact emotional strain can have on resilience in the workplace, with key challenges to maintaining full time employment being appointments and accidents / fluctuations in the health and ability of the person being cared for.

The long-term impact on ability to work can be seen in a loss of skills, knowledge, experience and difficulties in / confidence to return to work when caring ends ([Brimblecombe, 2018](#); [Carers UK, 2019b](#)).

Figures estimate that 70% of carers were over £10,000 worse off as a result of reduced hours and earnings ([Carers UK, 2019b](#)). But costs from carers inability to participate fully in work go beyond the individual. For employers, there are costs associated with recruitment, retention, absenteeism, and reduced productivity. For society, costs result from lower tax revenues and

contributions, increased benefits and lost productivity and reduced contributions to GDP. It was recently estimated that the public expenditure costs of carers leaving employment in England are £2.9 billion a year ([Brimblecombe, 2018](#)).

The Department for Work and Pensions Fuller Working Lives report ([2014](#)) suggests a range of actions are needed to help more carers stay in employment: support services, income protection, flexible working practices, and better use of assistive technology. Carers UK ([2019b](#)) found what carers saw as important in workplace support: a supportive line manager / understanding employer, the ability to work flexibly, and a right to additional paid time off work to care. Workplace support however remains varied.

There are also differences in what paid support services best support remaining in work ([Brimblecombe, 2018](#)). The type of services that appear to be most effective are day services such as home care, personal assistants, day care and meals-on-wheels.

Carers UK ([2019a](#)) recommendations:

- ensure carers can balance work and care, with support to return to work alongside or after caring
- a right to paid time off work to care of at least 5-10 days
- tailored support for carers looking to return to work, including recognising the skills carers have developed through their caring role
- work with employers to include carers in health and wellbeing support at work
- recognise that good quality and affordable care services are an essential part of enabling carers to remain in or return to work alongside caring



## Care Leave

Working carers often struggle to get time off to coordinate care services or attend medical appointments, and in 2016, 70% of survey respondents had used their annual leave to care.

It is difficult to separate and assess the impact of lack of care leave on caregiving or employment. There is some evidence from Japan that it may have a positive effect on employment in combination with flexible working ([Brimblecombe, 2018](#)). However, the more intense and longer caring responsibilities are the less effective care leave is.

## Services

Half of carers ([Carers UK, 2019b](#)) stated problems accessing suitable care services as a reason they gave up work or reduced working hours. Inflexible services unable to accommodate working hours or are unreliable can make work impossible. Carers also describe being unable to find suitable care services to meet the needs of the person needing care, or find they are simply too expensive. Most working carers say they need at least one type of formal service which they are not currently receiving.

## Retirement

Only 1 in 6 carers responding to the Carers UK survey ([2019a](#)) said that their ability to plan or save for retirement had not been affected by caring. This figure decreases further as the years and weekly hours of caring increases.

Long term reduced employment and income has implications for savings, retirement and pensions. Just over 10% of carers said they retired early to care for someone ([Carers UK, 2019b](#)).

Over half of those who have yet to retire are unable to save for their retirement, higher still for those regularly using their own income or savings to pay for care or support services, and higher again for those in receipt of

carers allowance ([Carers UK, 2019a](#)). Over 20% don't know how they are going to pay for retirement, particularly those already struggling financially.

There were some notable gender differences with male carers more likely to have a workplace pension, state pension and savings to pay for their retirement.

## Conclusion

A carer's mental and physical health will have a significant impact upon their ability to provide support for the person they care for. Given the reliance on unpaid carers in health and social care the high numbers of carers who think their physical and mental health will limit or remove altogether their ability to care ([Carers Week, 2018](#)) is concerning.

There is a need for evidence-based research on all aspects of the impact of caring, and evaluation of support services for carers' mental and physical health. The needs of the growing number of former carers remain largely unreported and unresearched ([Watts, 2018](#)).

## References

Al-Janabi, H (2016) [The need to “carer proof” healthcare decisions](#) *BMJ* 2016;352:i1651 (paywall)

Al-Janabi, H (2019) [Six mechanisms behind carer wellbeing effects: A qualitative study of healthcare delivery](#) *Social Science & Medicine* Volume 235, August 2019 (open access)

Alzheimers Research UK (2019) [Dementia in the Family: The impact on carers](#) (open access)

Alzheimers Society [Carers for people with dementia struggling in silence](#) (website)

- Aoun, SM (2015) [The impact of the carer support needs assessment tool \(CSNAT\) in community palliative care using a stepped wedge cluster trial](#) *PLoS One*. 2015;10(4):e0123012 (open access)
- Appleton, P (2019) [Effects of a mindfulness-based stress reduction group programme on family carers](#) *Mental Health Practice* (paywall)
- Bailey, JM (2019) [A survey of the prevalence of modifiable health risk behaviours among carers of people with a mental illness](#). *BMC Public Health* (2019) 19:1240 (open access)
- Barnardo's (2017) [Still Hidden, Still Ignored Who cares for young carers?](#) (open access)
- Bom, J (2019) [The Impact of Informal Caregiving for Older Adults on the Health of Various Types of Caregivers: A Systematic Review](#), *The Gerontologist*, Volume 59, Issue 5, October 2019, Pages e629–e642 (open access)
- Brenna, E (2016) [Is caring for older parents detrimental to women's mental health? The role of the European North–South gradient](#) *Rev Econ Household* 14, 745–778 (open access)
- Brighton, RM (2016) [The Effect of Respite Services on Carers of Individuals With Severe Mental Illness](#) *Journal of Psychosocial Nursing and Mental Health Services* 2016;54(12): 33-38 (paywall)
- Brimblecombe, N (2018) [Review of the international evidence on support for unpaid carers](#) *Journal of Long-term Care (September)*. pp. 25-40 (open access)
- British Psychological Society (2019) [The psychological needs of families and carers of people with dementia](#) (pdf)
- Carers UK (2016) [Missing out: the identification challenge](#) (pdf)
- Carers UK (2019a) [State of Caring: A snapshot of unpaid care in the UK](#) (pdf)

- Carers UK (2019b) [Facts about carers 2019: policy brief](#) (open access)
- Carers UK (2019c) [State of Caring](#) (pdf)
- Carers UK (2019d) [Carers at breaking point: making the case for carers' breaks in England](#) (pdf)
- Carers Week (2018) [Supporting Carers to be Healthy and Connected](#) (open access)
- Catalano, D (2018) [Mental Health Interventions for Parent Carers of Children with Autistic Spectrum Disorder: Practice Guidelines from a Critical Interpretive Synthesis \(CIS\)](#) *Systematic Review. Int. J. Environ. Res. Public Health* 2018, 15, 341 (open access)
- Caton, S (2019) [Internet use for family carers of people with intellectual disabilities: A literature review and thematic synthesis](#). *Journal of Intellectual Disabilities*, 23(3), 446–468 (paywall)
- Cook, T (2019) [Mindfulness-based practices with family carers of adults with learning disability and behaviour that challenges in the UK: Participatory health research](#) *Health Expect.* 2019; 22: 802– 812 (open access)
- Cormac, I (2006) [Meeting the mental and physical healthcare needs of carers](#) *Advances in Psychiatric Treatment*, 12(3), 162-172 (open access)
- Cottagiri, SA (2019) [Key health impacts and support systems for informal carers in the UK: A thematic review](#) *J Health Soc Sci.* 2019;4(2):173-198 (open access)
- Cruz, J (2017) [Impacts of COPD on family carers and supportive interventions: a narrative review](#) *Health Soc Care Community*, 25: 11-25 (open access)
- Cunningham, NA (2019) [Understanding and Measuring the Wellbeing of Carers of People With Dementia](#) *The Gerontologist*, Volume 59, Issue 5, October 2019, Pages e552–e564 (open access)

Department for Work & Pensions (2014) [Fuller Working Lives: a framework for action](#) (website)

del-Pino-Casado, R (2019) [Sense of coherence, burden and mental health in caregiving: A systematic review and meta-analysis](#) *Journal of Affective Disorders Volume 242, 1 January 2019, Pages 14-21* (open access)

Department of Health and Social Care (2018) [Carers Action Plan 2018 - 2020: Supporting carers today](#) (website)

Dow, J (2018) [How best to assess quality of life in informal carers of people with dementia; A systematic review of existing outcome measures](#) *PLoS One. 2018;13(3):e0193398* (open access)

Euro Carers (2018) [The impact of caregiving on informal carers' mental and physical health](#) (open access)

Family Carers Ireland (2019) [Paying the Price: The Physical, Mental and Psychological Impact of Caring](#) (pdf)

Farina, N (2017) [Factors associated with the quality of life of family carers of people with dementia: A systematic review](#) *Alzheimer's & Dementia Volume 13, Issue 5, May 2017, Pages 572-581* (open access)

Future Care Capital (2019) [A Forgotten Army: Coping as a Carer](#) (website)

Health and Social Care Board (2017) [The effectiveness of short breaks in families where there are children with disabilities: A Systematic Review of the Evidence](#) (pdf)

Kishita, N (2018) [Which interventions work for dementia family carers?: An updated systematic review of randomized controlled trials of carer interventions](#) *International Psychogeriatrics, 30(11), 1679-1696* (open access)

Kudra, A (2017) [Measuring carer burden in informal carers of patients with long-term conditions](#) *British Journal of Community Nursing 2017 22:5, 230-236* (paywall)

Macmillan Cancer Support (2016) [Under Pressure: The Growing Strain on Cancer Carers](#) (pdf)

Manthorpe, J (2016) [Quality of life measures for carers for people with dementia: measurement issues, gaps in research and promising paths](#) *Research, Policy and Planning* (2016) 31(3),163-178 (open access)

McCann, TV (2015) [Carers of Parents with Mental Illness](#) *Int J Ment Health Nurs*, 24: 203-212 (open access)

Mohanty, I (2019) [A longitudinal analysis of mental and general health status of informal carers in Australia](#) *BMC Public Health* 19, 1436 (open access)

NHS Digital (2010) [Survey of Carers in Households - England, 2009-10](#) (open access)

NHS Digital (2016) [Personal Social Services Survey of Adult Carers in England](#) (open access)

O'Dwyer, ST (2016) [Suicidal ideation in family carers of people with dementia](#) *Aging & Mental Health*, 20:2, 222-230 (paywall)

Oliveira, D (2019) [Improving health-promoting self-care in family carers of people with dementia: a review of interventions](#) *Clin Interv Aging*. 2019;14:515–523. Published 2019 Mar 1 (open access)

SCIE [Impact of caring](#) (website)

Scott, JL (2016) [Caring for the carer: a systematic review of pure technology-based cognitive behavioral therapy \(TB-CBT\) interventions for dementia carers](#) *Aging & Mental Health*, 20:8, 793-803 (open access)

Scottish Government (2015) [Scotland's Carers](#) (website)

Sharma, N (2016) [Gender differences in caregiving among family - caregivers of people with mental illnesses](#) *World J Psychiatry*. 2016;6(1):7–17. Published 2016 Mar 22 (open access)

Sin, J (2018) [eHealth interventions for family carers of people with long term illness: A promising approach?](#) *Clinical Psychology Review* Volume 60, March 2018, Pages 109-125 (open access)

Stjernswärd, S (2017) [Outcome of a web-based mindfulness intervention for families living with mental illness – A feasibility study](#) *Informatics for Health and Social Care*, 42:1, 97-108 (open access)

Thomas, S (2017) [Updated meta-review of evidence on support for carers](#) *Health Serv Deliv Res*2017;5(12) (pdf)

Totsika, V (2017) [Informal caregivers of people with an intellectual disability in England: health, quality of life and impact of caring](#) *Health Soc Care Community*, 25: 951-961 (paywall)

Tseliou, F (2019) [Do carers care for themselves? A population-based study.](#) *International Journal of Population Data Science* (2019) 4:3:054 (paywall)

University College London (2018) [The Emotional Wellbeing Of Older Carers](#) (pdf)

Visa, B (2019) [Mental health carers' experiences of an Australian Carer Peer Support program: Tailoring supports to carers' needs.](#) *Health Soc Care Community*. 2019; 27: 729– 739 (open access)

Watts, J (2018) [Being a former carer: impacts on health and wellbeing](#) *Illness, Crisis and Loss*, 26(4) pp. 330–345 (pdf)

Williams, A (2017) [Gender and sex differences in carers' health, burden and work outcomes: Canadian carers of community-dwelling older people with multiple chronic conditions.](#) *International Journal of Care and Caring*. 1. 331-349 (open access)

Williams, F (2019) [Interventions for reducing levels of burden amongst informal carers of persons with dementia in the community. A systematic](#)

[review and meta-analysis of randomised controlled trials](#) Aging & Mental Health, 23:12, 1629-1642 (open access)

Worrall, H (2018) [The effectiveness of support groups: a literature review](#) Mental Health and Social Inclusion, Vol. 22 No. 2, pp. 85-93 (paywall)



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