



Unpaid care



Increasing numbers of people are living with complex health needs and disabilities and require help with everyday activities. These people are often cared for, informally and unpaid, by family, friends, and neighbours. This POSTnote outlines the prevalence of unpaid care across the UK, examines its impact on carers, the support available to them and the barriers in accessing this support.

Background

People can be cared for by family, friends or neighbours without payment (unpaid or informal care), or through services, such as care homes or home visits, that they or their local authority pay for (formal or paid care).¹ The UK Government defines unpaid care as a private arrangement whereby someone cares for a family member, friend, or neighbour. This may be because of long-term physical or mental ill health or disability, or care needs relating to old age.² Unpaid care can include caring for children,³ although most unpaid care is provided by children and spouses.^{4,5} Carers are different to paid care workers who care for people as part of their paid employment, such as care assistants, nurses or support workers.^{2,6}

Carers provide a range of support including personal care, emotional support, help with practical tasks such as shopping, and reminding or giving medication.^{4,7} An estimated 6.5 million people were providing unpaid care in the UK in 2011 (around 10% of the population).⁸ Research by the charity Carers UK reports that three in five people are expected to need to provide care at some point in their lives.⁹ The demand for care is likely to continue to increase

Overview

- Around 6.5 million carers in the UK provide care worth an estimated £57 billion to £100 billion per year. The number varies across the UK with a higher proportion of carers in Wales and Northern Ireland.
- Providing unpaid care can affect carers' education, employment, relationships, household finances, health and well-being. Effects on carers tend to worsen with the more care provided.
- Support for carers can be provided by a range of organisations, such as employers and governments, and it can include financial, employment-related, respite care, and emotional and social support. Some carers, such as those from ethnic minorities, can find it difficult to access support.
- Respite breaks, training, and counselling can improve carers' mental health and reduce stress.

as the population ages and people's care needs become more complex.¹⁰⁻¹⁴

It is difficult to put a value on unpaid care and estimates range from £57 billion to over £100 billion per year.^{15,16} The National Audit Office found that the value of unpaid care provided in 2015/16 significantly outweighed that of the formal care provided by local government and the NHS and is comparable to national spending on health care.¹⁷ It is unclear to what extent the availability and accessibility of publicly funded formal care affects the demand for unpaid care. Some studies suggest that unpaid carers' can reduce demand on formal care,¹⁸ however others suggest that it increases it.^{19,20}

Prevalence of unpaid care across the UK

Many carers do not self-identify as a carer and may not be aware of the support that they can access.²¹ Studies have shown that carers often under-report the level of support they provide compared with responses from care recipients.²² Figures on the number of carers, and hours spent caring, are thus likely to be underestimates.

Demographic characteristics of carers

The prevalence of carers varies across the UK. Wales and Northern Ireland (NI) have higher levels of unpaid carers (12% of people in Wales and NI provide unpaid care) than England (10%) and Scotland (9%).²³ This varies regionally within each country with levels of care associated with rural areas, socio-economically deprived areas, those with a higher concentration of older people, and areas with a higher prevalence of poor health.^{4,8,24-28}

The 2017 [House of Commons Library briefing on Carers](#) provides more information about carers' employment, incomes, earnings and health and wellbeing. Data from the 2011 Census show that, across the UK:

- **Gender.** Women represent 51% of the population but make up 58% of carers.²⁹ However, of those aged 85 years or over, 12% of men and 5% of women provided unpaid care.^{30,31} On average, time spent caring for adults, by people over 50 years, increased between 2000 and 2015.³
- **Ethnicity.** People from the White ethnic group make up the largest proportion (94%) of carers, as they do as an overall proportion of the population (87%).³² However, further work is needed to look at whether this is shaped by the age structure and health of different ethnic populations. The proportion of people providing care, and its amount, varied amongst ethnic groups. For example, in England, Wales and Scotland, White British/Scottish, Irish, and Gypsy or Irish Traveller people were among the highest providers of unpaid care (in terms of hours of care provided). People of Chinese, White and Black African (only England and Wales), and African (only Scotland), were among the lowest providers of unpaid care.^{33,34}
- **Age.** Most carers are aged between 50–64 years. People aged 65 and over make up a higher proportion of carers (19%) than they do the population as a whole (12%).³⁵⁻³⁷
- **Amount of care provided.** Most carers provide between 1 and 19 hours of unpaid care per week.³⁸ Around 25% of carers provide more than 50 hours per week, and 15% provide 20–49 hours per week.³⁸

Other data show that:

- Most carers care for just one person (83%), although they may also look after children or grandchildren.^{39,40}
- Over half (58%) of carers care for someone with a physical disability, 20% care for someone with a sensory impairment, 13% care for someone with a mental health condition, and 10% care for someone with dementia.³⁹

There are concerns that there may not be sufficient numbers of unpaid carers in the future to meet demand, particularly from older people.⁵ Factors such as increasing female employment, fewer children, and higher divorce rates amongst men over 60 years may affect the future availability of children to provide unpaid care.^{28,41-43}

The impact of unpaid caregiving

Carers report many positive effects of caring including improvements in psychological well-being, personal fulfilment and physical health.^{44,45} However, in general,

research shows that providing unpaid care is associated with negative impacts on carers' education, employment, household finances, health and wellbeing, and personal and social relationships. It is difficult to isolate the effect of caring on particular outcomes such as health, and data often rely of self-reporting rather than objective measures. Measuring the impact of caregiving on people who provide care is difficult as effects will vary depending on the:

- demographic and socio-economic characteristics of the carer,
- relationship between the carer and the person they care for, and
- type, amount (number of hours per week), and duration (length of time caring) of care provided.

Education

In 2011, there were 177,918 young unpaid carers (5 to 17 years-old) in England and Wales. This is an increase of almost 19% since 2001.⁴⁶ Research has shown a link between providing care and low qualification levels, low attendance at school, and higher reports of bullying.

- Young carers tend to have lower levels of educational attainment than non-carers, and attainment decreases as more hours of care are provided.⁴⁷ The think tank, the New Policy Institute, found that in 2013/14, 70% of working-age people caring for 20 hours or more per week did not have qualifications higher than GCSE level compared to 48% of non-carers.⁴⁸
- Just over half (55%) of parents of young carers (aged 5–17 years) reported their child had been absent from school at least a few times in the previous year compared to one-third of parents of non-young carers.⁴⁹
- 68% of young carers report being bullied at school,^{50,51} compared with 48% of all children and young people.⁵²

Employment

Survey data from 2017 report that 50% of unpaid carers are in employment, 33% work full-time, and 17% work part-time. A quarter of carers are retired and a fifth are economically inactive. Men who provide care are more likely to be in full-time employment and women are more likely to be work part-time.³⁰ Several studies have shown that caring negatively impacts employment.⁵³⁻⁵⁸ Impacts vary by:

- the amount of time spent providing care, with more time caring associated with lower employment levels;⁵³⁻⁵⁹
- the type of care provided (such as personal care), for example carers that live with the person they care for are less likely to be in employment;^{55,60} and
- the gender and health of the carer and the employment status of their partner. For example, men providing more than 50 hours of care per week are more likely to reduce their working hours than women, suggesting that women may either juggle intensive care commitments alongside work or leave work altogether.^{59,61,62}

In 2015–16, an estimated 345,000 unpaid carers aged 16–64 years in England, predominantly women, left employment to provide care. This is estimated to cost around £2.9 billion a year in public expenditure from lost tax revenue and providing benefits to people who have left their

jobs.⁶³ For those who have left work to take on a caring role, a lack of skills and confidence can hinder their ability to get back into employment.^{64,65}

Finance

Being a carer can lead to additional financial costs, such as an increase in household bills and additional transport costs, such as hospital parking charges.⁸¹ It is estimated to cost up to three times as much to raise a child with a disability than it does a child without any disability.⁸² One study estimates that carers would need to be compensated by between £190 and £357 per week in order to reach the same standard of living as non-carers.⁸³ A 2014 Carers UK survey found that 30% of carers experienced a decrease of £20,000 or more a year in their household income because caring had led them to give up work, reduce their hours or take lower paid work.^{29,84,85}

Health and Well-being

Carers' health and well-being have been consistently linked to their quality of life.⁸⁶ Carers themselves may have social care needs and multiple long-term conditions.⁸⁷ The evidence on the links between caregiving and health and well-being is mixed, with studies variously reporting positive, negative or no effects, depending on the nature of care provided and the period over which it was studied. Beneficial effects of caring include improvements in psychological well-being and physical health.^{44,45} However, several studies in the UK have found that the mental and physical health of carers deteriorates incrementally with increasing hours of care provided.⁸⁸⁻⁹⁶ One study found that carers that live with the person they care for report worse health compared with those that do not.⁹⁷

Relationships

Providing care can have a negative impact on personal and social relationships.⁴ Caregiving can strain personal relationships, particularly when care is provided by a partner or spouse.^{98,99} Carers report feeling lonely, isolated and depressed.¹⁰⁰⁻¹⁰³ A 2014 survey by Carers UK found that over half (57%) of carers said they had lost touch with friends and family as a result of caring.¹⁰⁴ Carers of people with mental health conditions can experience stigma or prejudice against the person that they care for that can cause stress. Lack of support or understanding from friends and family may also be upsetting to the carer.¹⁰⁵

Providing support to carers

Support for carers can be indirect (supporting the people being cared for) or direct (supporting carers themselves). Support can be provided by governments (through the benefits system for example), employers, health and social care services, charities, schools, friends and family, or paid for privately. A 2016–17 NHS survey reported that over 70% of adult carers were extremely, very or quite satisfied with the support services they had received.³⁹

Social care is a devolved policy area and policies for carers differ across the UK (Box 1). In all UK countries, local

authorities have a duty to identify carers and carers have the right to request an assessment of their support needs.²⁹ NHS data in England for 2015–16 show that a third of carers in contact with their local authority (131,000) did not receive a review or assessment during the year.¹⁰⁶

Types of support can include:

- financial support,
- employment support,
- respite care (temporary provision of care by people other than the primary caregiver, such as day centres),
- education and training (for example, on nutrition or using hoists and other mobility equipment), and
- emotional and social support, such as counselling.¹⁰⁷

Box 1: Policies to support carers across the UK

England

- The Care Act 2014 sets out how people's care and support needs should be met and introduces carers' right to an assessment.^{29,66} A 2016 review by the Carers Trust found that although some carers were receiving good support, more could be done to raise carers' awareness of their rights and ensure a consistently high standard of assessments.⁶⁷
- In June 2018, the Government published an action plan for carers setting out a 2-year programme of work to support unpaid carers, ahead of the forthcoming social care Green Paper that is expected in autumn 2018. The measures include: a new scheme to improve employment support for carers, a new Carer Innovations Fund to promote creative and innovative ways to support carers, and funding for a review of best practice in identifying young carers and access to support.⁶⁸ Better practical support for families and carers is expected to be one of "the seven key principles" underpinning the forthcoming Green Paper on social care for older people.^{69,70}

Scotland

- The Carers (Scotland) Act 2016 sets out a range of measures intended to improve the support given to carers. It gives carers the right to a plan that identifies their needs and provides them with information about support available, and puts a duty on local authorities to support carers whose identified needs meet local eligibility criteria. Local authorities and health boards are required to jointly prepare a local carers strategy.^{71,72,73}

Wales

- The 2016 Social Services and Well-being (Wales) Act introduced new rights and entitlements for carers and placed stronger duties on local authorities to identify, assess and support carers.⁷⁴ In 2017, the organisation responsible for regulating the social care workforce in Wales, Social Care Wales, acknowledged that more could be done to support unpaid carers and families.⁷⁵
- Three national priorities have been established: supporting carers to have reasonable breaks from their caring role; improving carer's recognition of their role and to ensure they can access the necessary support; and ensuring that carers receive appropriate information and advice where and when they need it.⁷⁶

Northern Ireland

- The most recent strategy for carers is the 2006 Caring for Carers.^{77,78} The most recent legislation was the 2002 Carers and Direct Payments Act (Northern Ireland).⁷⁷ This gave carers the right to an assessment and to be considered for services to meet their assessed needs.⁷⁹ The Government is currently taking forward a priority area in the Reform of Adult Care and Support project to recognise the contribution of carers and support them in their caring role.⁸⁰

Financial support

Financial support can be provided at national or local levels. The main type of financial support available to carers at national level is Carer's Allowance (CA).¹⁰⁸ This is a non-contributory, non-means-tested benefit paid to people who care full-time for someone in receipt of a qualifying disability benefit. To be entitled to CA, a person must be providing at least 35 hours of care a week for someone, not be in full-time education, and, if in paid work, have earnings (after certain deductions) of no more than £120 a week.^{109,110} It is currently worth £64.60 a week (2018-19 rate), increasing to £73.10 a week in summer 2018 in Scotland.²⁹ At local levels, personal budgets and direct payments are available for eligible people. These can be paid to carers directly or to care recipients to pay for the cost of arranging all or part of their own support, which can include family carers.^{111,112} Data from 2014–15 show a broad spread in the level of take-up of personal budgets and direct payments across local authorities.¹¹³

There have been few studies examining the effectiveness of providing financial support direct to carers.¹¹⁴ In interviews, CA claimants reported difficulties in accessing CA, such as finding relevant information and understanding how it interacted with other benefits.¹¹⁵ One small-scale study that examined a direct payment scheme in one local authority in England found that parent carers of disabled children reported that the scheme helped to alleviate financial pressures, relieve stress and facilitate effective support.¹¹⁶

Employment Support

There are few evaluations of the effectiveness of employment support for carers (Box 2).¹¹⁷ The House of Commons Work and Pensions Committee recommends that carers be given the right to request flexible working upon starting employment, and providing for paid statutory carer's leave.¹¹⁸ Services for care recipients, such as home care, are effective in supporting carers' employment.^{119,120}

Respite Care

Evidence on the effectiveness of respite care is mixed. It has been shown to increase wellbeing, increase satisfaction with carer's caring role, and reduce stress.^{117,121-123} One review found no evidence of any benefit for carers of people with dementia.¹²⁴ Another found no evidence for the impact of respite care on carers' physical health.¹²⁵ Evidence suggests that carers' confidence about the nature and quality of the alternative care being provided, the amount and nature of the activities provided and the personalisation of the care is important to the success of these programmes.¹¹⁷

Endnotes

- House of Commons Library (2017) [Adult social care \(England\)](#) CBP07903
- Department of Health and Social Care (2016) [How can we improve support for carers?](#)
- ONS (2016) [Changes in the value and division of unpaid care work in the UK: 2000 to 2015](#).
- Wanless D (2006) [Wanless social care review](#). King's Fund

Box 2: Example employment support programme for carers

The Government-funded Carers in Employment project, which ran from 2015 to 2017 in nine local authorities in England, aimed to examine 'what works' in supporting carers to remain in, or return to, employment by testing a range of support interventions. Support included advice and guidance, information, and free trials and installation of assistive technology equipment. An evaluation found that carers who received more comprehensive and intensive support were more likely to report benefits such as increased morale, reduced isolation, and better awareness of available help (such as local voluntary services).¹²⁶

Education and training

Carers report high levels of satisfaction and a better understanding of specific conditions such as dementia and schizophrenia from education and training programmes.¹¹⁷ There is mixed evidence about whether these interventions lead to changes in carers' behaviour. One review found active education and training that was appropriately targeted (rather than generic) was more likely to be effective.¹²⁵

Emotional and social support

Emotional and social support for carers can include support groups, befriending schemes and counselling services. Carers suggest that support groups provide them with emotional support.^{117,127} Carers also find online forums useful, but many struggle to purchase a computer and/or pay for internet access.¹²⁸ Many carers believe respite care is a better form of support as it allows them time to recharge and continue relationships with family and friends.¹²⁹ Meetings with social workers to discuss care responsibilities, or counselling have been shown to reduce stress and mental ill-health,^{130,131} particularly when combined with other types of support such as training to understand specific medical conditions.¹³²⁻¹³⁴ One review found that telephone counselling can reduce depressive symptoms for carers of people with dementia.¹³⁵

Barriers to accessing support

Evidence suggests that carers face many challenges in accessing support from health and social care services. These can include difficulty navigating the system and not receiving responses from social care providers.¹²⁷ Access to such services varies between different types of carers.¹³⁶ For example, ethnic minority carers are much less likely to receive practical or financial support and may struggle to access culturally appropriate services.^{28,137-139} Pilot studies by the University of Leeds found that multi-agency partnerships (liaising with each other and referring carers between services) were needed to improve the process of identifying carers, providing them with support, monitoring systems, and improving communication between services.¹⁴⁰

- Colombo F, Llena-Nozal A, Mercier J & Tjadens F (2011) [Help Wanted? Providing and Paying for Long-term Care](#). OECD Policy Brief [Accessed 3 July 2018].
- Royal College of General Practitioners (2013) Commissioning for carers

- 7 Baxter K, Heavey E & Birks Y (2017) [Older self-funders and their information needs](#). NIHR School for Social Care Research and Social Policy Research Unit, University of York
- 8 ONS (2013) [2011 Census analysis: Unpaid care in England and Wales, 2011 and comparison with 2001](#).
- 9 Carers UK (2001) It could be you: a report on the chances of becoming a carer.
- 10 Kingston A, Wohland P, Wittenberg R, Robinson L, Brayne C, Matthews F & Jagger C (2017) Is late-life dependency increasing or not? A comparison of the Cognitive Function and Ageing Studies (CFAS). *The Lancet* 390(10103): 1676-1684. DOI: [https://doi.org/10.1016/S0140-6736\(17\)31575-1](https://doi.org/10.1016/S0140-6736(17)31575-1)
- 11 Guzman-Castillo M, Ahmadi-Abhari S, Bandosz P, Capewell S, Steptoe A, Singh-Manoux A, Kivimaki M, Shipley M, Brunner E & O'Flaherty M (2017) Forecasted trends in disability and life expectancy in England and Wales up to 2025: a modelling study. *The Lancet* 2(7): e307-e313 DOI: [https://doi.org/10.1016/S2468-2667\(17\)30091-9](https://doi.org/10.1016/S2468-2667(17)30091-9)
- 12 Pickard L (2008) [Informal care for older people provided by their adult children: projections of supply and demand to 2041 in England](#). PSSRU
- 13 Salisbury C, Johnson L, Purdy S, Valderas J, Montgomery A (2011). Epidemiology and impact of multimorbidity in primary care: a retrospective cohort study. *British Journal of General Practice* 61 (582), e12-e21
- 14 Pickard L (2015) A growing care gap? The supply of unpaid care for older people by their adult children in England to 2032. *Ageing and Society*, 35(1): 96-123.
- 15 ONS (2016) [Household satellite accounts: 2005 to 2014](#).
- 16 Buckner L & Yeandle S (2015) [Valuing carers 2015. The rising value of carers' support](#). Carers UK
- 17 National Audit Office (2017) [A Short Guide to Local Authorities](#)
- 18 Local Government Association (2014) [LGA Adult Social Care Efficiency Programme. The final report](#)
- 19 Torbica A, Calciolari S & Fattore G (2015) Does informal care impact utilization of healthcare services? Evidence from a longitudinal study of stroke patients. *Social science and medicine* 124: 29-38. <http://dx.doi.org/10.1016/j.socscimed.2014.11.005>
- 20 Geerts J, Van den Bosch K (2012) Transitions in formal and informal care utilisation amongst older Europeans: the impact of national contexts. *European Journal of Ageing* 9 (1), 27-37
- 21 Carduff E, Finucane A, Kendall M, Jarvis A, Harrison N, Greenacre J & Murray S (2014) [Understanding the barriers to identifying carers of people with supportive and palliative care needs in primary care](#). 4 (1)
- 22 Rutherford A & Bu F (2017) Issues with the measurement of informal care in social surveys: evidence from the English Longitudinal Study of Ageing. *Ageing and Society*
- 23 ONS (2011) QS301EW and QS301SCa Provision of unpaid care.
- 24 Norman P & Purdam K (2013) [Unpaid Caring Within and Outside the Carer's Home in England and Wales](#). *Population, Space and Place* 19(1): 15-31.
- 25 Hutton S & Hirst M (2001) *Caring relationships over time*. Social Policy Research Unit: University of York.
- 26 Young H, Grundy E & Jital M (2006) *Care providers, care receivers: a longitudinal perspective*. York, Joseph Rowntree Foundation.
- 27 Young H, Grundy E & Kalogirou S (2005) Who Cares? Geographic variation in unpaid caregiving in England and Wales: evidence from the 2001 Census. *Population Trends* 120: 23-34.
- 28 Hoff A (2015) *Current and future challenges of family care in the UK. Future of an Ageing Population: Evidence review*. Foresight, Government Office for Science
- 29 House of Commons Library (2017) [Carers](#). Number 7756
- 30 Department for Work and Pensions (2017) [Family Resources Survey 2016/17](#).
- 31 ONS (2018) [Population estimates for UK, England and Wales, Scotland and Northern Ireland: mid-2017](#).
- 32 UK Government (2017) [Ethnic groups by region](#).
- 33 ONS (2013) [Ethnic variations in general health and unpaid care provision, 2011](#).
- 34 Scottish Government (2014) [Analysis of equality results from the 2011 Census](#).
- 35 ONS (2017) LC3304EW [2011 Census - Provision of unpaid care by age - England and Wales](#)
- 36 National Records of Scotland (2011) *Scotland's Census 2011 - Table LC3103SCdz - Provision of unpaid care by age*
- 37 Northern Ireland (2011) *Census 2011. Table DC3304NI: Long-term health problem or disability by provision of unpaid care by age by sex*
- 38 ONS (2011) *Provision of unpaid care. QS301EW*
- 39 NHS (2017) *Personal social services survey of adult carers in England (SACE)*.
- 40 Pickard L, Wittenberg R, Comas-Herrera A, King D & Malley J (2012) Mapping the future of family care: receipt of informal care by older people with disabilities in England to 2032 *Social Policy and Society*, 11(4): 533-45
- 41 Grundy E (2000) Co-residence of mid-life children with their elderly parents in England and Wales: changes between 1981 and 1991 *Population Studies*, 54(2): 193-206
- 42 Haberkern F, Schmid T, Neuberger F & Grignon M (2012) The role of the elderly as providers and recipients of care. In OECD. *The Future of Families to 2030*. OECD Publishing, Paris, 180-257
- 43 International Longevity Centre (2015) [The rise of the silver separators: Divorce and demographics in later life](#).
- 44 Brown R & Brown S (2014) Informal caregiving: A reappraisal of effects on caregivers. *Social issues and policy review* 8(1): 74-102
- 45 Kanters T, van der Ploeg A, Brouwer W & Hakkaart L (2013) The impact of informal care for patients with Pompe disease: An application of the CarerQoL instrument, *Molecular genetics and metabolism* 110: 281-286
- 46 ONS (2013) [Providing unpaid care may have an adverse affect on young carers' general health](#)
- 47 The Children's Society (2013) *Hidden from view. The experience of young carers in England*
- 48 Aldridge H & Hughes C (2016) [Informal carers and poverty in the UK: an analysis of the Family Resources Survey](#). New Policy Institute
- 49 Cheesbrough S, Harding C, Webster H, Taylor L & Aldridge J (2017) [The lives of young carers in England. Omnibus survey report](#). Department for Education.
- 50 Carers Trust [Key facts about carers and the people they care for](#).
- 51 Carers Trust [About young carers](#).
- 52 NHS (2015) [Bullying: The facts](#).
- 53 King D & Pickard L (2013) When is a carer's employment at risk? Longitudinal analysis of unpaid care and employment in midlife in England. *Health and Social Care in the Community* 21(3): 303-14
- 54 Van Houtven C, Coe N & Skira M (2013) The effect of informal care on work and wages. *Journal of Health Economics* 32(1): 240-52
- 55 Heitmueller A (2007) The chicken or the egg? Endogeneity in labour market participation of informal carers in England. *Journal of Health Economics* 26(3): 536-559
- 56 Robards J, Vlachantoni A, Evandrou M & Falkingham J (2015) Informal caring in England and Wales – stability and transition between 2001 and 2011. *Advances in Life Course Research* 24: 21-33
- 57 Trukeschitz B, Schneider U, Mühlmann R & Ponocny I (2013) Informal elder-care and work-related strain. *Journals of Gerontology: Psychological sciences and social sciences*, 68B(2): 257-267
- 58 Vlachantoni A (2010) The demographic characteristics and economic activity patterns of carers over 50: Evidence from the English Longitudinal Study of Ageing. *Population Trends* 141(1):51-73
- 59 Gomez-Leon M, Evandrou M, Falkingham J & Vlachantoni A (2017) [The dynamics of social care and employment in mid-life](#). *Ageing and Society* <https://doi.org/10.1017/S0144686X17000964>
- 60 Van Houtven C, Coe N & Skira M (2013) The effect of informal care on work and wages. *Journal of Health Economics* 32(1): 240-52
- 61 Carers UK [10 facts about women and caring in the UK on International Women's Day](#).
- 62 Schmitz H & Westphal M (2017) Informal care and long-term labor market outcomes. *Journal of Health Economics* 56(1): 1-18 doi: 10.1016/j.jhealeco.2017.09.002
- 63 Pickard L, King D, Brimblecombe N & Knapp M (2018) Public expenditure costs of carers leaving employment in England 2015-16. *Health and social care in the community* 26(1): e132-e142. DOI: 10.1111/hsc.12486
- 64 Institute for employment studies (2017) [Women, work and caring: unspoken expectations and stifled careers](#).
- 65 Carr E, Murray E, Zaninotto P, Cadar D, Head J, Stansfeld S & Stafford M (2017) [New caregivers give up paid employment](#). Insights 2017, Understanding Society
- 66 Department of Health and Social Care (2016) [Care Act factsheets. Guidance](#)
- 67 Bennett L (2016) *Care Act for carers: one year on*. London: Carers Trust.
- 68 Department of health and Social Care (2018) [Cross-government plan launched to support unpaid carers](#).
- 69 PQ 112788 21 November 2017
- 70 House of Commons Library (2018) [Social care: the forthcoming Green Paper on older people \(England\)](#). CBP 8002
- 71 Scottish Parliament (2015) [Carers \(Scotland\) Bill](#). SP Bill 61-PM
- 72 SPICE (2015) [Carers \(Scotland\) Bill](#). Briefing 15/24
- 73 Scottish Government (2018) [Carers' charter. Your rights as an adult carer or young carer in Scotland](#).
- 74 Welsh Government (2014) [Social services and well-being \(Wales Act 2014\)](#).
- 75 Social Care Wales (2017) *Making a positive difference to social care in Wales: our strategic plan 2017-2022*. Cardiff: Social Care Wales.
- 76 Irranca-Davies H (2017) [Written statement – A carer friendly Wales](#). 24 November 2017
- 77 Northern Ireland Assembly Research and Information Service (2016) [Carers: Legislation, policy and practice](#). Paper 24/7, NIAR 43-17

- 78 Department of Health, Social Services and Public Safety (2006) [Caring for Carers](#)
- 79 Thompson J (2017) [Carers in Northern Ireland: Where are we with legislation and policy to support them?](#) Research Matter, Blog of the Northern Ireland Research and Information Service, 7 June
- 80 Department of Health (2017) [Reform of adult care and support](#).
- 81 McDaid D (2001) Estimating the costs of informal care for people with Alzheimer's disease: methodological and practical challenges. *International Journal of Geriatric Psychiatry*, 16, 400-405
- 82 Children's Policy Research Unit (2017) [Family Finances and Disability: the cost of raising children with disabilities](#). UCL
- 83 Lemmon E & Bell D (2018) The cost of informal care in the UK: A standard of living approach. Unpublished paper. Please cost the author: Elizabeth Lemmon, University of Stirling, for further information.
- 84 Carers UK (2014) [Caring & Family Finances Inquiry: UK report](#).
- 85 Carers UK (2015) Facts about carers
- 86 Farina N, Page T, Daley S, Brown A, Bowling A, Basset T, Livingston G, Knapp M, Murray J & Banerjee S (2017) [Factors associated with carer quality of life of people with dementia: A systematic review of non-interventional studies](#). *Alzheimer's & Dementia*, 13 (5): 572-581. DOI: 10.1016/j.jalz.2016.12.010
- 87 NICE (2015) [Older people with social care needs and multiple long-term conditions](#). NG 22
- 88 Department of Health, Carers Trust and the Queen's Nursing Institute (2014) [Supporting the health and wellbeing of adult carers](#)
- 89 Bremer P, Cabrera E, Leino-Klip H, Lethin C, Saks K, Sutcliffe C, Soto M, Zwakhalen S & Wübker A (2015) Informal dementia care: Consequences for caregivers' health and health care use in 8 European countries. *Health Policy* 119: 1459-1471
- 90 Hiel L, Beenackers M, Renders C, Robroek S, Burdorf A & Croezen S (2014) Providing personal informal care to older European adults: Should we care about the caregivers' health? *Preventative Medicine* 70: 64-68
- 91 Vlachantoni A, Robards J, Falkingham J & Evandrou M (2016) Trajectories of informal care and health. *SSM-Population Health* 2: 295-501
- 92 Maun E (2017) [Longitudinal associations between co-resident caregiving and problematic sleep among older adults](#). Understanding Society Scientific Conference, Wednesday 12 July
- 93 O'Reilly D, Connolly S, Rosato M, Patterson C (2008) Is caring associated with an increased risk of mortality? A longitudinal study. *Social Science & Medicine* 67(8): 1282-90
- 94 Rahrig Jenkins K, Kabeto M, Langa K (2009) Does caring for your spouse harm one's health? Evidence from a United States nationally-representative sample of older adults. *Ageing & Society* 29(2): 277-93.
- 95 Fredman L, Cauley J, Hochberg M, Ensrud K, Doros G (2010) Mortality associated with caregiving, general stress, and caregiving-related stress in elderly women: results of caregiver-study of osteoporotic fractures. *Journal of the American Geriatric Society* 58(5): 937-43.
- 96 Lacey R, McMunn A & Webb E (2018) Informal caregiving and metabolic markers in the UK Household Longitudinal Study. *Maturitas* 109: 97-103 <http://dx.doi.org/10.1016/j.maturitas.2018.01.002>
- 97 Kaschowitz J & Brandt M (2016) Health effects of informal caregiving across Europe: A longitudinal approach. *Social science and medicine* 173: 72-80
- 98 La Fontaine J, Jutla K, Read K, Brooker D & Evans S (2016) [The experiences, needs and outcomes for carers of people with dementia: A literature review](#). The RSAs
- 99 Gursimran T, Oram S, Verey A, Greenberg N & Fear N (2016) Informal caregiving and intimate relationships: the experiences of spouses of UK military personnel. *Journal of the Royal Army Medical Corps* 163(4): 266-272
- 100 Vasileiou K, Barnett J, Barreto M, Vines J, Atkinson M, Lawson S & Wilson M (2017) Experiences of loneliness associated with being an informal caregiver: A qualitative investigation. *Frontiers in Psychology*, 8, Article 585.
- 101 Beeson, R. A. (2003). Loneliness and depression in spousal caregivers of those with Alzheimer's disease versus non-caregiving spouses. *Arch. Psychiatr. Nurs.* 17, 135-143. doi: 10.1016/S0883-9417(03)00057-8
- 102 Chukwuorji J, Amazue L & Ekeh O (2016) Loneliness and psychological health of orthopaedic patients' caregivers: does gender make a difference?. *Psychol. Health Med.* 22, 501-506.
- 103 Carers UK (2015) Facts about carers.
- 104 Carers UK (2015) [Alone and caring](#).
- 105 Rand S, Malley J & Netten A (2012) [Measuring the social care outcomes of informal carers](#). Quality and outcomes of person-centred care policy research unit. PSSRU Discussion Paper 2833. University of Kent, London School of Economics and Political Science and University of Oxford
- 106 Health and Social Care Information Centre (2016) [Community care statistics, social services activity, England – 2015-16](#). [NHS Digital](#)
- 107 Courtin E, Jemai N & Mossialos E (2014) Mapping support policies for informal carers across the European Union. *Health Policy*, 118 (1). pp. 84-94. ISSN 0168-8510. DOI: 10.1016/j.healthpol.2014.07.013
- 108 Carers UK (2018) [Carer's Allowance](#).
- 109 House of Commons Library (2016) [Carer's Allowance](#). Number 00846
- 110 UK Government (2018) [Carer's allowance: Eligibility](#). Accessed 18 July 2018
- 111 House of Commons Public Accounts Committee (2016) [Personal budgets in social care](#). HC 74
- 112 House of Commons Library (2015) [Social care: Direct payments from a local authority \(England\)](#). Number 03735
- 113 National Audit Office (2016) [Personalised commissioning in adult social care](#). HC 883
- 114 Sutcliffe K, Rees R, Dickson K, Hargreaves, K, Schucan-Bird K, Kwan I, Kavanagh J, Woodman J, Gibson K, Thomas J (2012) [The adult social care outcomes framework: a systematic review of systematic reviews to support its use and development](#). London: EPPi-Centre, Social Science Research Unit, Institute of Education, University of London. ISBN: 978-1-907345-43-2
- 115 Fry G, Singleton B, Yeandle S & Buckner (2011) Developing a clearer understanding of the Carer's Allowance claimant group. Research report for Department for Work and Pensions. Report no 739
- 116 Blyth C & Gardener A (2007) 'We're not asking for anything special': Direct payment and the carers of disabled children. *Disability and Society* 22(3): 235-249
- 117 Victor E (2009) A systematic review of interventions for carers in the UK: Outcomes and explanatory evidence. The Princess Royal Trust for Carers, Young Carers International Research and Evaluation, The University of Nottingham
- 118 House of Commons Work and Pensions Committee (2018) [Employment support for carers](#). HC 581
- 119 Pickard L, King D, Brimblecombe N & Knapp M (2015) [The effectiveness of paid services in supporting unpaid carers' employment in England](#). *Journal of Social Policy*, Available on CJO 2015 doi:10.1017/S0047279415000069
- 120 Pickard L, Brimblecombe N, King D & Knapp M (2018) 'Replacement care' for working carers? A longitudinal study in England, 2013-15. *Social Policy & Administration*, 52(3): 690-709. Available at <https://onlinelibrary.wiley.com/doi/abs/10.1111/spol.12345>
- 121 Pickard L (2004) [The effectiveness and cost-effectiveness of support and services to informal carers of older people](#). Personal Social Services Research Unit,
- 122 Zarit S, Parris Stephen M, Townsend A & Greene R (1998) Stress reduction for family caregivers: Effects of adult day care use. *Journal of Gerontology* 53B(5): S267-S277
- 123 Fields N, Anderson K & Dabelko-Schoeny H (2014) The effectiveness of adult day services for older adults: A review of the literature from 2000 to 2011. *Journal of applied gerontology*. 33(2): 130-163
- 124 Maayan N, Soares-Weiser K & Lee H (2014) Respite care for people with dementia and their carers. *Cochrane Database of Systematic Reviews*. DOI: 10.1002/14651858.CD004396.pub3
- 125 Parker G, Arksey H & Harden M (2010) Meta-review of international evidence on interventions to support carers. Working paper no. DH 2394, Centre for Reviews and Dissemination, University of York
- 126 Wilson S, Marvell R, Cox A & Teeman (2018) Evaluation of the Carers in Employment (CIE) Project. Institute for Employment Studies
- 127 Rand S & Malley J (2014) [Carers' quality of life and experiences of adult social care support in England](#). *Health and social care in the community*. 22(4): 375-385
- 128 Computers 4 Carers (2018) [Fighting back against carers isolation](#).
- 129 Oral evidence: support for carers. Work and Pensions Select Committee, 2018
- 130 Pickard L (2004) [The effectiveness and cost-effectiveness of support and services to informal carers of older people](#). Personal Social Services Research Unit
- 131 Yesufu-Udechuku A, Harrison B, Mayo-Wilson E, Young N, Woodhams P, Shiers D, Kuipers E & Kendall T (2015) Interventions to improve the experience of caring for people with severe mental illness: systematic review and meta-analysis. *The British Journal of Psychiatry* 206: 268-274 doi: 10/1192/bjp.bp.114.147561
- 132 Dickinson C, Dow J, Gibson G, Hayes, L, Robalino S & Robinson L (2017) Psychosocial intervention for carers of people with dementia: What components are most effective and when? A systematic review of review. *International Psychogeriatrics*. 29(1): 31-43 <https://doi.org/10.1017/S1041610216001447>
- 133 Elvish R, Lever S-J, Johnstone J, Cawley R & Keady J (2012) Psychological interventions for carers of people with dementia: a systematic review of quantitative and qualitative evidence. *British Association for Counselling and Psychotherapy*
- 134 Laver K, Milte R, Dyer S & Crotty M (2017) A systematic review and meta-analysis comparing carer focused and dyadic multicomponent interventions for carers with dementia. *Journal of Aging and Health* 29(8): 1308-1349
- 135 Lins S, Hayder-Beichel D, RÜcker G, Motschall E, Antes G, Meyer G & Langer G (2014) Efficacy and experiences of telephone counselling for informal carers

-
- of people with dementia. Cochrane database of systematic reviews. Issue 9. Art. No.: CD009126. DOI: 10.1002/14651858.CD009126.pub2.
- 136 Pickard L, King D, Knapp M & Perkins M (2011) Overcoming barriers: Unpaid care and employment in England. Personal Social Services Research Unit, London School of Economics and Political Science
- 137 Carers UK (2015) [Facts about carers: Policy briefing](#).
- 138 Wanless D (2006) [Securing good care for older people: Taking a longer term view](#). The Kings Fund
- 139 Greenwood N, Holley J, Ellmers T, Mein G & Cloud G (2016) Qualitative focus group study investigating experiences of accessing and engaging with social care services: perspectives of carers from diverse ethnic groups caring for stroke survivors. *BMJ Open* 6(1): :e009498. doi: 10.1136/bmjopen-2015-009498
- 140 Yeandle S & Wigfield A. Eds. (2011) [New approaches to supporting carers' health and well-being: Evidence from the National Carers' Strategy Demonstrator Sites programme](#). Centre for International Research on Care, Labour and Equalities, University of Leeds