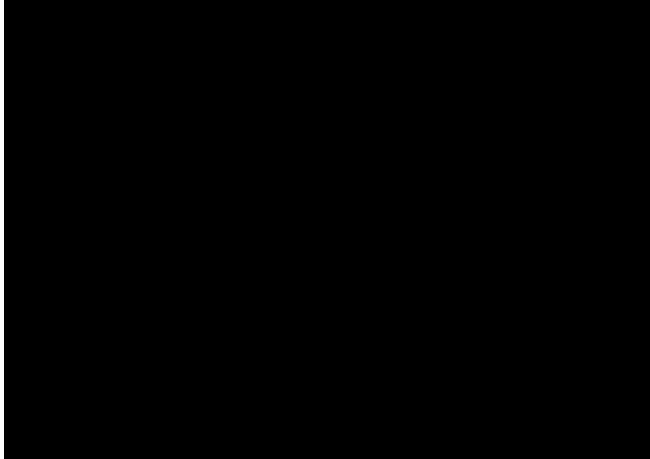




Unpaid care

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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

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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

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