



BRIEFING PAPER

Number 07756, 7 July 2020

Informal Carers

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Contents:

1. Who gives informal/unpaid care?
2. Carers' employment, incomes and earnings
3. Benefits
4. Older carers
5. Parent carers of disabled children
6. Young carers
7. Carers' health and wellbeing
8. Local authority assessments and health and social care support for carers
9. Past and future Government policy



Contents

Summary	4
1. Who provides informal care?	8
2. Carers' employment, incomes and earnings	10
2.1 Statistics on employment, incomes and poverty	10
Employment	10
Incomes and poverty	10
Combining paid work with Carer's Allowance	11
2.2 Employment rights of carers	11
Flexible working	11
Time off for dependants	12
Discrimination by association	12
Dedicated employment rights for carers	13
Additional cost of living	13
2.3 Employment Support for Carers	14
Work, Health and disability green paper	14
Fuller Working Lives	14
Institute for Employment Studies project: Carers in Employment	15
Informal Carers and Employment – Systematic review	15
3. Benefits	17
3.1 Carer's Allowance	17
3.2 Working and claiming Carer's Allowance	19
3.3 Carer's Allowance overpayments	21
3.4 Studying and claiming Carer's Allowance	22
3.5 Carers and Universal Credit	22
3.6 Carer's Allowance in Scotland	23
4. Older carers	24
4.1 Government support for older carers	24
4.2 Carer's Allowance and the State Pension	24
5. Parent carers of disabled children	26
6. Young carers	27
6.1 How many young carers are there?	27
6.2 The lives of young carers	27
6.3 Support for young carers in England	28
6.4 Benefits for young carers	29
6.5 Participation and attainment in education	30
6.6 Further and higher education	32
7. Carers' health and wellbeing	34
7.1 Access to health services	35
Problems faced by carers in accessing health services	35
NHS England's commitment to carers	35
7.2 Sharing patient information with carers and involvement in care	36
8. Local authority assessments and health and social care support for carers	38
8.1 Local authority assessments and support for adults	38
8.2 Changes in force from 1 April 2015 under the Care Act 2014	38
8.3 Respite breaks	39
8.4 Carers Innovation Fund	40

9. Past and future Government policy	41
9.1 The proposed Carers Strategy and the forthcoming social care Green Paper	41
Government's March 2016 consultation and response	41
Dropping of the proposed Carers Strategy	42
Carers Action Plan 2018–2020	42
The forthcoming social care Green Paper	43
9.2 Carers' benefits	44

Summary

The Department of Health and Social Care (DHSC) defines informal/unpaid carers as:

...people who look after family members, friends, neighbours or others because of long-term physical or mental ill health or disability, or care needs related to old age. This does not include any activities as part of paid employment.¹

The Family Resources Survey notes that informal carers can provide care for many, or only a few hours a week, and their caring takes many forms, being:

Individuals who provide any regular service or help to someone. That person can be within or outside of their household, and might be sick, disabled or elderly; this description excludes those who give this service or help as part of a formal job.²

How many carers?

The [Family Resources Survey](#) estimated that in 2018/19 around 7% of the UK population were providing unpaid care.

Contribution made by carers

Research commissioned by Carers UK and published in November 2015 estimated that 1.4 million people were providing 50 or more carer hours a week for a partner, friend or family member in the UK. As such they make a significant contribution to society and the NHS.³ The NHS has acknowledged this contribution, saying that it was “critical and underappreciated ... not only to loved ones, neighbours and friends, but to the very sustainability of the NHS in England”.⁴

Support for unpaid carers during the Coronavirus outbreak

Carers UK published a [Research report on unpaid carers during the Coronavirus outbreak](#) in April 2020. Its online survey of around 5,000 carers and former carers found that 70% were providing more care during the outbreak; 81% were spending more money, and 55% felt overwhelmed by the outbreak. Carers UK made several recommendations, including an increase to the Carer’s Allowance, publishing guidance for unpaid carers, and increasing the amount of personal protective equipment available.⁵

To mark Carers Week 2020, Carers Weeks charities commissioned a report, [The rise in the number of unpaid carers during the coronavirus \(COVID-19\) outbreak](#), which estimated that around 4.5 million additional people had taken on caring responsibilities and a total of a quarter UK adults were now providing unpaid care to an older, disabled or ill relative or friend. The experience of Northern Ireland, Wales and Scotland carers are described in the [report](#) (pp24-31).

The DHSC published [Covid-19 guidance for unpaid carers](#) in April 2020 and defined unpaid carers as “essential workers” and a priority group for testing on 4 May.⁶ The Government’s [Action plan for adult social care](#) (April 2020) also said local providers should contact unpaid carers to provide them with means to identify themselves to receive supplies and that the Government had provided additional funding for the Carers UK

¹ Department of Health and Social Care (DHSC), [How can we improve support for carers?](#) March 2016

² Department for Work and Pensions (DWP), [Family Resources Survey, UK, 2018/19, Background methodology](#), March 2020, pp9, 44

³ Buckner, L. and Yeadle.S. for Carers UK, [Valuing Carers 2015 – the rising value of carers’ support](#), 12 November 2016

⁴ NHS England press release, [‘We must recognise the vital contribution of carers’](#), 10 June 2015.

⁵ Carers UK, [Caring behind closed doors: Forgotten families in the coronavirus outbreak](#), April 2020, p6

⁶ PQ 34066 [\[Carers: Coronavirus\]](#), 12 May 2020

helpline.⁷ NHS England has confirmed that carers may call upon [NHS volunteer responders](#) for support during the outbreak.⁸

The Government has also said that “unpaid carers can continue to claim Carer’s Allowance if they need to self-isolate. During the outbreak emotional support can also count towards the 35 hours a week Carer’s Allowance care threshold”.⁹ They may, in certain circumstances, be eligible for statutory sick pay.¹⁰

The **Scottish Government** has issued [advice for unpaid carers](#), including information on testing, and will make a [one-off payment to unpaid carers](#) in June. Guidance has also been issued for [unpaid and young carers](#) in **Northern Ireland**. The **Welsh Government** issued a [statement](#) confirming that it expects local authorities to maintain the rights of unpaid carers provided under the 2014 Care Act. [Guidance](#) was issued on 5 June and [funding for the mental health of unpaid carers](#) has also been announced.

As noted by the [Welsh Parliament/Senedd Research Service](#), stakeholders did raise concerns that [The Coronavirus Act 2020](#), through providing for a relaxation of local authority duties around the provision of care and support needs, may place additional pressures on unpaid carers. The Commons Library briefing [Coronavirus: Local authorities’ adult social care duties \(the Care Act easements\)](#) provides more information.

Carers’ incomes, health and wellbeing

Employment and income

The Department for Work and Pensions (DWP) [Family Resources Survey](#) reports that half of informal carers were in employment in 2018/19 (including carers aged 65 and over).¹¹ 33% of carers were working full-time and 17% were working part-time.

25% of carers were retired while 22% were economically inactive (in other words, not in work and not looking for work) for other reasons.¹²

For just over half of carers, their main source of income was earnings from employment (54% of carers in 2018/19). State or private pensions were the main source of income for just over a quarter of carers (27%), while around 17% drew most of their income from other benefits or tax credits.

54% of adult carers had net weekly income (after taxes and benefits) below £300 per week.¹³

Benefits

Carers could be entitled to a range of benefits, but the main cash benefits for those caring for disabled people is Carer’s Allowance, and the carer premium payable with means-tested benefits such as Income Support, Pension Credit and Housing Benefit. Universal Credit, which is replacing means-tested benefits for people of working age, also includes a carer element. Recipients of [Carer’s Allowance](#) must not be in full-time education, and must not have earnings of more than £128 per week after deductions. Consequently, individuals can experience problems combining receipt of Carer’s Allowance with paid work.

⁷ DHSC, [COVID-19: Our action plan for adult social care](#), April 2020, para 3.8-3.9

⁸ Royal Voluntary Service/NHS Volunteer responders, [Need help from a volunteer responder?](#)

⁹ PQ 41020 [\[Social services\]](#), 12 May 2020; PQ 42186 [\[Social Security Benefits\]](#), 12 May 2020

¹⁰ PQ 31601 [\[Carers: Coronavirus\]](#), 26 March 2020

¹¹ DWP, [Family Resources Survey 2018/19](#), 26 March 2020, Table 5.4

¹² DWP, [Family Resources Survey 2018/19](#), 26 March 2020, Table 5.4

¹³ DWP, [Family Resources Survey 2018/19](#), 26 March 2020, Table 5.6

In November 2019 there were 1,296,700 Carer's Allowance claimants in Great Britain. Women comprised 69% of the total.

Other support for carers

In schools: carers in schools may be able to access counselling services. They may also attract additional Pupil Premium funding for their schools if they are, or have previously been, entitled to free school meals. Data suggests a large proportion of young carers fall into this category.

In further education: students in England with caring responsibilities may be able to access [discretionary 16-19 bursary support](#). However, being in full-time education means they cannot claim Carer's Allowance.

In higher education: mainstream student support funding includes additions for students with qualifying adult dependents.

Social services: carers are entitled to a statutory assessment of their support needs, undertaken by the local authority. The assessment must consider a range of factors such as what assistance the carer requires to continue providing care, and their own independent needs, and, in the case of young people, whether it is appropriate for the child to provide care in light of their own needs.

Since 1 April 2015, any adult carer who meets national eligibility criteria must be provided with services to meet their needs. Even when these eligibility criteria aren't met, local authorities have discretionary powers to provide support. For young carers, there are no national eligibility criteria and local authorities need only consider their assessment in deciding whether to provide support.

Health: NHS England's 2014 [Commitment to Carers](#) recognises and highlights the importance of carers to the NHS, and sets out a series of commitments that NHS England will do to support carers.¹⁴ The [Carers Action Plan 2018-2020: Supporting carers today](#), published in June 2018, included a commitment that the NHS England and the Care Quality Commission would work together to develop quality standards for general practitioner surgeries to demonstrate how effective they are in identifying and supporting carers.¹⁵ The [NHS Long Term Plan](#), published in January 2019, repeated the commitment to improve how the NHS identifies unpaid carers, and strengthen support for them to address their individual health needs.¹⁶ On 11 June 2019, NHS England announced a voluntary scheme for GP practices, aimed at young carers. This will encourage practices to identify and support children and young people providing informal care for family members.¹⁷

Additional briefings

The Commons Library has also published:

- [House of Commons Library briefing, Carer's Allowance](#)
- [House of Commons Library briefing, Carer's Allowance and the Retirement Pension](#).

Material has also been published relating to Devolved policies:

- Northern Ireland Assembly Research and Information Service, [Carers in Northern Ireland: Some Key statistics](#) (2018) and [Supporting Carers in Northern Ireland: Where are we with legislation and policy?](#) (2018)

¹⁴ NHS England, [Commitment to Carers](#), April 2014

¹⁵ DHSC, [Carers Action Plan 2018-2020: Supporting carers today](#). June 2018

¹⁶ NHS England, [NHS Long Term Plan](#), January 2019

¹⁷ NHS England press release, ['NHS sets out 'care for young carers' offer in GP surgeries'](#), 11 June 2019

- Scottish Parliament Information Centre (SPICe), [Scotland Act 2016: Carer's Allowance](#) and Scottish Government, [Unpaid carers](#)
- Welsh Senedd/Parliament's Health, Social Care and Sport Committee, [Caring for our future: An inquiry into the impact of the Social Services and Well-Being \(Wales\) Act 2014 in relation to carers](#) (2019)

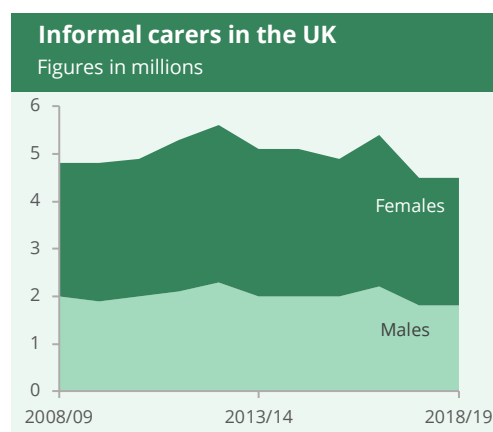
1. Who provides informal care?

The [Family Resources Survey](#) estimated that in 2018/19 around 4.5 million people in the UK were providing informal care. The survey defines informal caring as care that is not a paid job, and can occur for many, or only a few, hours a week.¹⁸ The figure represents around 7% of the UK population.

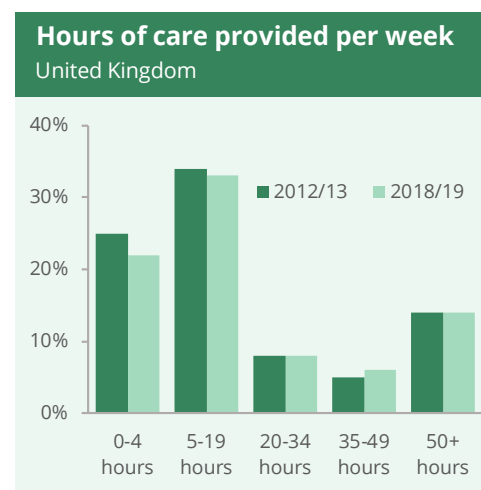
Figures have fluctuated over the past decade as shown in the chart opposite. Numbers peaked at 5.6 million in 2012/13 and 5.4 million in 2016/17. The 2017/18 estimate of 4.5 million was the lowest recorded since 2007/08 and remained constant in 2018/19. In each year shown, around 60% of informal carers are women.

The reduction in carer numbers in 2018/19, compared with the peak of 5.6 million in 2012/13, may be due to fewer people providing smaller amounts of care per week. There has been a slight increase in numbers providing over 35 hours care per week and a decrease among the proportions providing fewer hours care per week.

Adults aged 55-64 were most likely to care for others. In most age groups, women were more likely to provide informal care than men. However, among adults aged over 75 years men were more likely to provide informal care.



Source: [Family Resources Survey 2018/19](#)



Source: [Family Resources Survey 2018/19](#)

¹⁸ Department for Work and Pensions (DWP), [Family resources survey, UK, 2018/19, Background note and methodology](#), March 2020, p9

Carers UK and Age UK published a report in April 2015, [Caring into later life](#).¹⁹ Using a range of data sources, the report concluded there were 1.2 million people in England aged 65 and over providing unpaid care to a disabled, seriously ill or older relative or friend. This represented:

[A]n increase of 35% in just ten years, compared to an 11% rise in the number of all carers, and a 4% rise in the number of carers aged 25-64 in the same time period.

The fastest growing group is carers aged 85 and over, whose numbers have more than doubled, growing by a huge 128% in ten years to over 87,000.

These numbers will continue to grow, with estimates suggesting the number of older carers in England is set to increase to over 1.8 million by 2030. More than 200,000 of these carers will be aged 85 and over.²⁰

The report also found that although, overall, carers were more likely to be female than male, this changed as the carers get older, with 59% of carers aged 85 and over being male.²¹

The report concludes that older carers are a very diverse group and consequently had different needs:

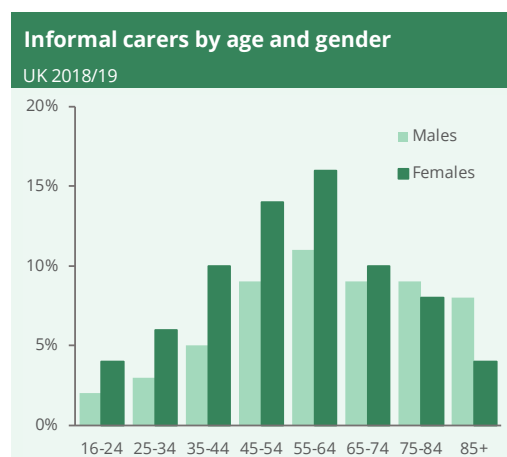
This report looks at some of these differences, highlighting the varying health and support needs of male and female carers at different stages in later life. Solutions must be found to better identify and support these different groups.²²

Those over 85 were especially in need of support, it argued:

[T]hose carers aged 85 and over identified as a priority in the NHS Five Year Forward View who are more likely than other carers to be caring around the clock, to be suffering anxiety and depression and to be in poor physical health themselves.²³

A 2013 report from the Children's Society²⁴ suggested that young carers might be more prevalent among Black and Minority Ethnic (BAME) groups. They found that young carers were 1.5 times more likely to be from BAME communities and twice as likely not to speak English as a first language.

Further information on young carers can be found in Section 6.



Source: Family Resources Survey 2018/19

¹⁹ Carers UK, [Caring into later life](#), April 2015

²⁰ Carers UK, [Caring into later life](#), April 2015., p6

²¹ Ibid., p8

²² Ibid., p24

²³ Ibid.

²⁴ Children's Society, [Hidden from view](#), 2013

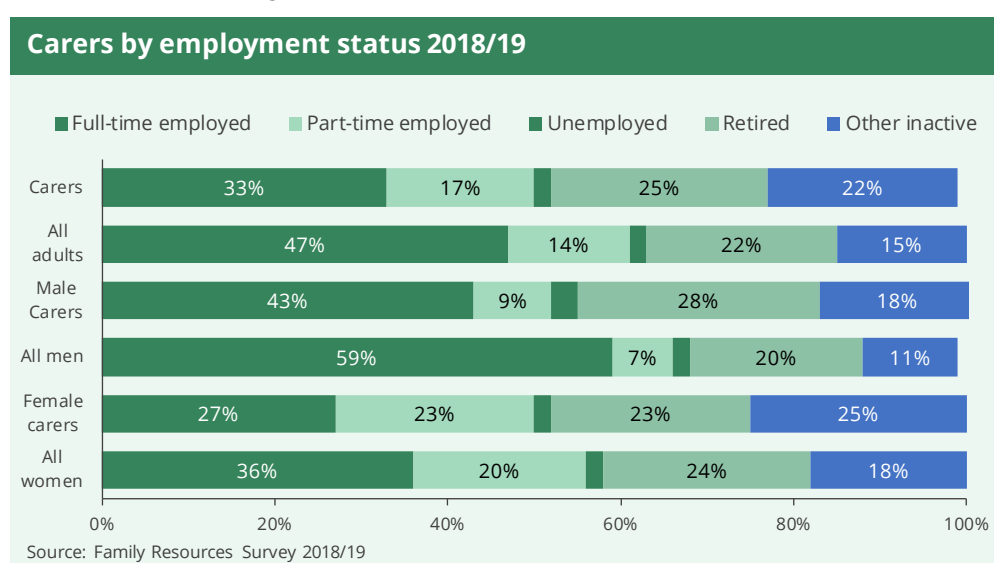
2. Carers' employment, incomes and earnings

2.1 Statistics on employment, incomes and poverty

Employment

The DWP's *Family Resources Survey* reports that half of informal carers were in employment in 2018/19 (including carers aged 65 and over).²⁵ 33% of carers were working full-time and 17% were working part-time.

25% of carers were retired while 22% were economically inactive (in other words, not in work and not looking for work) for other reasons.²⁶



A 2012 study by researchers at the London School of Economics highlighted the challenges faced by those who combine work and caring:

... Research clearly demonstrates that caring has a negative impact on people's ability to remain in work. Overall it is estimated that approximately 315,000 carers aged 16–64 in England have left employment to provide unpaid care and are currently out of employment. Of these, 120,000 are men and 195,000 are women.²⁷

Incomes and poverty

For just over half of carers, their main source of income was earnings from employment (54% of carers in 2018/19). State or private pensions were the main source of income for just over a quarter of carers (27%), while around one in six carers (17%) drew most of their income from other benefits or tax credits.

54% of adult carers had weekly disposable income (after taxes and benefits) below £300 per week.²⁸

The Joseph Rowntree Foundation 2019/20 poverty report estimated that in the UK in 2017/18 nearly a quarter (more than a million) carers were living in poverty, defined as

²⁵ DWP, [Family Resources Survey 2018/19](#), 26 March 2020

²⁶ Ibid., Table 5.5

²⁷ Linda Pickard, Derek King, Martin Knapp and Margaret Perkins, (2012) [Overcoming barriers: Unpaid care and employment in England](#), Personal Social Services Research Unit (PSSRU) at London School of Economics and Political Science

²⁸ DWP, [Family Resources Survey 2018/19](#), 26 March 2020, Table 5.6

being in *relative low income after housing costs* (this is the number of carers living in households with income below 60% of median household income, where income is measured after deducting housing costs).

On this basis, the poverty rate was around 25% of working age carers, compared to around 20% of non-carers. This poverty gap has persisted in the last ten years. Weekly household income is £100 a week less for carers.

Women carers experiences higher poverty rates than men; 28% of female working age carers, and 26% of male working age carers were in poverty. This gender gap is larger for carers under 35: nearly 40% of young female carers are in poverty, compared to just over 25% of young male carers.

Time spent caring also impacts poverty rates: those who care for 20 hours or more a week were more likely to be in poverty.²⁹ The inability to work is the key driver for poverty among carers, 36% of working-age carers were not in work, compared to 23% of non-carers. This gap has grown over the last 6 years. Those who care 35+ hours a week are three times less likely to be working as those caring fewer than 20 hours a week.

Combining paid work with Carer's Allowance

Carers may experience difficulties trying to combine paid work with their caring duties while also satisfying the conditions for the main social security benefit for carers, Carer's Allowance (covered in detail in section 3 below). In particular, carers can find that increases in the National Minimum/Living Wage can push them above the Carer's Allowance earnings limit.

2.2 Employment rights of carers

Flexible working

Carers for adults have had the right to request flexible working from their employers since the introduction of the *Work and Families Act 2006*. The 2010 Government extended this right beyond carers to cover all employees as part of the *Children and Families Act 2014*.³⁰ Employers are only able to refuse a flexible working request on limited grounds identified by statute.³¹

The Taylor Review, published in July 2017, briefly considered issues surrounding flexible working and made the following recommendation:

As part of the statutory evaluation of the Right to Request Flexible Working in 2019, Government should consider how further to promote genuine flexibility in the workplace. For example it should consider whether temporary changes to contracts might be allowed, to accommodate flexibility needed for a particular caring requirement. Government should work closely with organisations like Timewise and Working Families to encourage flexible working and initiatives like "happy to talk flexible working" to a wider range of employers.³²

In May 2018, the Work and Pensions Committee published a report on carers and employment. Amongst other things, the report recommended that the Government make flexible working a 'day one' right, rather than one that only available after 26 weeks of continuous employment.³³

²⁹ Joseph Rowntree Foundation, [UK poverty 2019/20](#). 7 February 2020.

³⁰ [Children and Families Act 2014](#), part 9

³¹ For more information see House of Commons Library Standard Note SN01086, [Flexible working](#)

³² [Good Work: The Taylor Review of Modern Working Practices](#), 2017, p95

³³ Work and Pensions Committee, [Employment support for carers](#), HC581, 9 May 2018, para. 36

The Government has committed to review the impact of the existing ‘right to request’ legislation in 2020, to ensure that it continues to have the desired effect.³⁴ In the Queen’s Speech in December 2019, it said it would “bring forward measures to encourage flexible working.”³⁵

In March 2018, the Department for Business, Energy and Industrial Strategy (BEIS) set up the Flexible Working Task Force, which it co-chairs with the Chartered Institute of Personnel and Development (CIPD). The Task Force is made up of various different stakeholders and considers a wide range of issues surrounding flexible work.³⁶ The Task Force is currently considering a Government proposal, announced in October 2018, to create a new duty for employers to consider which jobs can be done flexibly and make clear in advertising which jobs can be done flexible from Day 1.³⁷ The Task Force has also published guidance for employers on flexible hiring and is promoting the *Happy to Talk Flexible Working* campaign.

Describing this approach, the Government’s response to the Work and Pension Committee’s report states:

43. This is a little different from the Select Committee’s recommendation in an important respect as it places the responsibility on the organisation to offer flexible working, rather than on the employee to ask.

44. Government considers that the key challenge is designing work so that it can be flexible. That question needs to be tackled organisationally to achieve real change. Businesses need to explore how flexible working can work across the board – rather than just in relation to specific roles. That is a broader and more challenging question which is why we are seeking to work with business and other organisations through the taskforce.³⁸

Time off for dependants

In addition, employees have the right to reasonable time off if a dependant is ill, injured or their care arrangements are disrupted. A dependant, as well as being a spouse, civil partner, parent or child, can also be a person living in the same house as the employee (although not an employee, tenant, lodger or boarder).³⁹

Discrimination by association

Carers of disabled and elderly people may also be protected at work from “discrimination by association”. Discrimination by association occurs where a person is treated less favourably not because of a protected characteristic that they possess but because of their association with another person who has a protected characteristic.

The *Equality Act 2010* protects those caring for disabled or elderly people from discrimination or harassment. Guidance from the Government Equalities Office provides the following example:

Ms Battle applies for a job which involves a lot of travelling. She has the best skills and experience but the company knows that Ms Battle cares for her son who is disabled. The company makes an assumption that she cannot manage because she has a disabled son and so it doesn’t offer her the job. This is direct discrimination because

³⁴ [PQ 269051, 2 July 2019](#)

³⁵ HM Government, [Queen’s Speech](#), December 2019

³⁶ [Government and employers unite to kick-start flexible working](#), CIPD, 14 January 2019

³⁷ [New measures to support workers, businesses, and entrepreneurs](#), Gov.uk, 1 October 2018

³⁸ Work and Pensions Committee, [Employment Support for Carers: Government Response to the Committee’s Thirteenth Report](#), HC 1463, 31 July 2018, paras. 43-44

³⁹ [Employment Rights Act 1996](#) as amended, section 57A

Ms Battle is associated with a disabled person. It's against the law to refuse to offer her the job for that reason.⁴⁰

Dedicated employment rights for carers

The Work and Pensions Committee's 2018 report also recommended that the Government consider creating certain dedicated employment rights for carers:

Statutory unpaid leave would be a welcome solution for some carers but simply unaffordable to many others. An existing model of parental leave, paid at a statutory rate, already assists parents while providing compensation to employers, including special assistance for small businesses. In supporting the Parental Bereavement (Leave and Pay) Bill, the Government has demonstrated a willingness to extend this assistance into further circumstances. There is a strong case for five days' statutory paid carer's leave based on the existing statutory leave system. We recommend the Government introduce this policy when resources allow and provide a full impact assessment for such a policy in response to this report.⁴¹

In the *Carers Action Plan 2018-2020*, published in June 2018, the Government announced that it had set up an official level working group involving various Departments to consider the creation of dedicated employment rights for carers to exist alongside existing employment rights (e.g. flexible working).⁴²

The Government announced in the Queen's Speech that it would "bring forward introduce the entitlement to leave for unpaid carers."⁴³ It is currently consulting on creating an entitlement to one week of additional leave for unpaid carers, looking at issues such as:

- how carers use existing employment rights
- who should be eligible to take the leave
- what the leave can be taken for
- how the leave would be available to take and the process for taking the leave
- the costs and benefits to employers and employees.⁴⁴

In July 2019 the EU formally adopted the Directive on the Work Life Balance of Parents and Carers ([Directive \(EU\) 2019/1158](#)). Among other things, the Directive will give all workers a right to five days unpaid carers leave each year. However, the implementation deadline for the Directive is 2 August 2022. Unless the implementation period under the [UK-EU Withdrawal Agreement](#) is extended, EU law will not be binding on the UK at this time.

For further information, see Section 6 of the Library Briefing, [Insecure Work: the Taylor Review and the Good Work Plan \(CBP-8817\)](#).

Additional cost of living

Carers UK carried out a 12 month investigation into the financial situation of carers and their families, the results of which were published in February 2014 as a report, [Caring & Family Finances Inquiry](#). The inquiry found there were significant additional costs associated with caring for loved ones who are older, disabled or seriously ill:

Experiences of carers who gave evidence to the Inquiry, included the need to keep the vulnerable and ill warm, meant families footing bills for running heating for 12 and more hours a day, with no let-up in warmer months when those with serious illness

⁴⁰ Government Equalities Office/ Citizens Advice Bureau, [Equality Act 2010: What do I need to know as a carer?](#), 2010

⁴¹ Work and Pensions Committee, [Employment support for carers](#), HC581, 9 May 2018, para. 47

⁴² Department for Health and Social Care, [Carers Action Plan 2018-2020](#), June 2018, para. 2.3.

⁴³ HM Government, [Queen's Speech](#), December 2019

⁴⁴ BEIS, [Consultation on Carers' Leave](#), March 2020

must be kept cool; costs of travel to medical appointments and the need to rely heavily on taxis; the need to wash three or more loads of washing a day when caring for someone with continence problems, or who is tube fed; the increasingly prohibitive price of buying in care to simply get out of the door for work or respite, compounding the isolation caring can bring; the cost to future financial security and resilience of quitting work or cutting hours to care.⁴⁵

One recent survey of carers found that many were struggling to make ends meet, or were in, or had been in, debt as a result of caring.⁴⁶

2.3 Employment Support for Carers

Work, Health and disability green paper

In the Work, health and disability Green Paper the Government reported that “an estimated 2 million people have given up paid work to care”. It also reports that 315,000 of these did not return to work and remained unemployed after their caring role ended.⁴⁷

The Green Paper cited two of the reasons why carers can find it difficult to balance caring with employment:

- A risk-averse attitude among employers to recruiting those with caring responsibilities.
- A lack of flexible working arrangements in many organisations.

It goes on to outline the support that the government will provide to carers:

A key objective of our future work will be to support carers of all ages to enter, remain in and re-enter work. The government’s Fuller Working Lives programme focuses on the challenges for older workers to remaining in or returning to work due to caring responsibilities, ill health or disability. As part of the programme a series of Carers in Employment pilots was launched in April 2015, to help support carers to stay in work or return to paid work alongside their caring responsibilities. Early next year the government will publish a new, cross-government and employer-led national strategy, which will set out the future direction of this Fuller Working Lives agenda.⁴⁸

Fuller Working Lives

In February 2017 the DWP published [Fuller Working Lives](#). This publication announced that a new cross-Government Carers Strategy, led by the Department of Health, would support carers to remain in and re-enter employment. It also announced that a final evaluation report of the ‘Carers in Employment’ pilots would be published in 2017:

Led by the Department of Health, we are aiming to support carers through a new cross-Government Carers Strategy. We intend it to include measures to provide further support to carers to remain in, and re-enter, the workforce; balancing their working life with their essential caring role. There will be an important role for employers, building on the work described throughout this document to ensure that the working environment both supports and values carers.

In addition, the Department of Health and the Government Equalities Office (GEO) have provided funding for nine ‘Carers in Employment’ pilot projects to explore, through close working with Local Authorities, how working carers can be supported to stay in paid work alongside fulfilling their caring responsibilities. Interim findings

⁴⁵ Carers UK, [Caring & Family Finances Inquiry: Carers struggling with alarming levels of hardship](#), February 2014

⁴⁶ Carers UK, [State of Caring 2018](#), July 2018. Note that this survey is not completely representative of all carers - respondents were more likely to be female and caring for a high number of hours every week.

⁴⁷ DWP/Department for Health (DH), [Work, Health and disability green paper: improving lives](#), 2 November 2016

⁴⁸ DWP/DH, [Work, Health and disability green paper: improving lives](#), 2 November 2016

are expected in Spring 2017 with the final evaluation report to follow later in the year.
49

Further information on the Carers Strategy is provided in section 9 of this briefing.

Institute for Employment Studies project: Carers in Employment

In January 2018 the Institute for Employment Studies published an evaluation of the [Carers in Employment project](#).⁵⁰

This project provided a range of support to carers and evaluated the impact of this support. The support provided ranged from light touch contact, such as advice and guidance materials, to more intensive support, such as regular ongoing contact with a support worker.

A key finding of the project was that carers receiving the more intensive support were more likely to report benefits, and that having a personalised caseworker for carers may help them to continue in work. It states that:

The evaluation suggests that named caseworkers assigned to deliver bespoke information, advice and guidance to working carers may be effective in facilitating job retention and helping working carers to continue in work. Advocacy and support worker services provided by the project were reported to have helped working carers cope better at crucial 'tipping points' or domestic crises that otherwise were likely to have had a more detrimental effect on maintaining the balance of care and work.⁵¹

Another finding from the project was that the use of assistive technology helped carers to stay in employment.

Those employers who interacted with the project also reported an increased awareness of the challenges faced by working carers. This led to some employers introducing "carer-friendly" HR policies and practices, such as the promotion of flexible working arrangements.

Informal Carers and Employment – Systematic review

In September 2019 the DWP published a summary report of a systematic review of the strategies for employment retention of people who care.⁵²

The review recognised that carer friendly employment includes informal arrangements, such as employers allowing carers extra leave days to deal with emergencies, as well as formalised policies, such as a carers register enabling carers to access emergency leave. The review also said a carers passport (a document drawn up between an employee and manager outlining the needs of employees with caring responsibilities) could be significant in retaining employment.

Another finding of the review was that local authority statutory care assessments, designed to assess the needs of people who need care and enable carers to access services, do not discuss work, so potentially hinder carers' search for employment:

It was a common finding for carers to report that assessors did not discuss work, despite the centrality of working and caring to carer assessment guidelines.⁵³

The review also addressed barriers to employment reengagement. The longer carer has been disengaged from the labour market, the harder it is to reengage. Carers have

⁴⁹ DWP, [Fuller Working Lives](#), February 2017, p37

⁵⁰ Institute for Employment Studies, [Evaluation of the Carers in Employment Project](#), January 2018

⁵¹ Institute for Employment Studies, [Evaluation of the Carers in Employment Project](#), January 2018, pii

⁵² DWP, [Informal Carers and Employment: Summary Report of a Systematic Review](#), September 2019

⁵³ DWP, [Informal Carers and Employment: Summary Report of a Systematic Review](#), September 2019, p12.

difficulty finding flexible employment and obtaining formal care during their potential working hours.

Problems with flexibility of formal care have been previously identified, meaning carers can have trouble arranging alternative care arrangements during their potential working hours.⁵⁴

⁵⁴ Ibid. p 15

3. Benefits

A carer could potentially be entitled to a range of benefits, but cash benefits specifically for people caring or a disabled person consist of:

- **Carer's Allowance**, currently worth £67.25 a week (2020/21 rate);
- The **carer premium/addition** payable with means-tested benefits such as Income Support, Pension Credit, and Housing Benefit. It is payable to those who satisfy the conditions for Carer's Allowance and is £37.50 a week for 2020/21.
- The **carer element** in Universal Credit (UC), which mirrors the carer premium and is worth £162.92 a month in 2020/21. UC is replacing means-tested benefits for people of working age.

3.1 Carer's Allowance

[Carer's Allowance](#) – formerly Invalid Care Allowance – is a non-contributory, non-means-tested benefit paid to people who care full-time for someone who is severely disabled. To be entitled to Carer's Allowance, a person must be providing at least 35 hours of care a week for someone in receipt of a qualifying disability benefit,⁵⁵ not be in full-time education, and, if in paid work, have earnings after certain deductions of no more than £128 a week.

In November 2019 there were 1,296,700 Carer's Allowance claimants in Great Britain.⁵⁶ Women comprised 69% of the total.

Only just over two-thirds of Carer's Allowance claimants (884,500, 68%) actually receive a payment. The remaining claimants (412,200, 32%) fulfil the entitlement criteria for Carer's Allowance by virtue of their caring responsibilities but receive no payment due to the 'overlapping benefits rule' (see below) or to other income.

Among pensioners claiming Carer's Allowance, the vast majority (96%) receive no Carer's Allowance payment, mainly due to the way that State Pensioners are affected by the overlapping benefits rule (see below).

Between 2003 and 2019 the number of Carer's Allowance claimants more than doubled, from 600,000 to just under 1.3 million by the end of 2019. The caseload growth was mainly driven by working-age recipients, up from 380,900 in August 2003 to 872,300 by November 2019.

⁵⁵ The qualifying benefits are Disability Living Allowance (middle or higher rate care component), the Personal Independence Payment daily living component, Attendance Allowance, Constant Attendance Allowance at or above the normal maximum rate with an Industrial Injuries Disablement Benefit or basic (full day) rate with a War Disablement Pension, and Armed Forces Independence Payment.

⁵⁶ The figures in this section include Carer's Allowance in Scotland. The Scottish Government took over executive competence for Carer's Allowance in Scotland in September 2018, but the DWP continues to deliver the benefit in Scotland under an [agency agreement](#). See the later section in this briefing on Carer's Allowance in Scotland.

Carer's Allowance claimants, Great Britain, November 2019

	Total (a)	of whom:	
		Male	Female
Total	1,296,702	408,445	888,257
<i>of whom: payment status:</i>			
Claimant receiving payment	884,472	240,330	644,144
No payment: entitlement only ^(b)	412,226	168,120	244,106
<i>receiving payment as % of total claimants</i>	<i>68%</i>	<i>59%</i>	<i>73%</i>
Working age: total			
Working age: total	956,342	262,966	693,374
<i>of whom: payment status:</i>			
Claimant receiving payment	872,320	237,189	635,136
No payment: entitlement only ^(b)	84,017	25,775	58,244
<i>receiving payment as % of working age total</i>	<i>91%</i>	<i>90%</i>	<i>92%</i>
Over State Pension age: total			
Over State Pension age: total	340,361	145,481	194,883
<i>of whom: payment status:</i>			
Claimant receiving payment	12,149	3,138	9,011
No payment: entitlement only ^(b)	328,213	142,340	185,868
<i>receiving payment as % of pension age total</i>	<i>4%</i>	<i>2%</i>	<i>5%</i>

Note

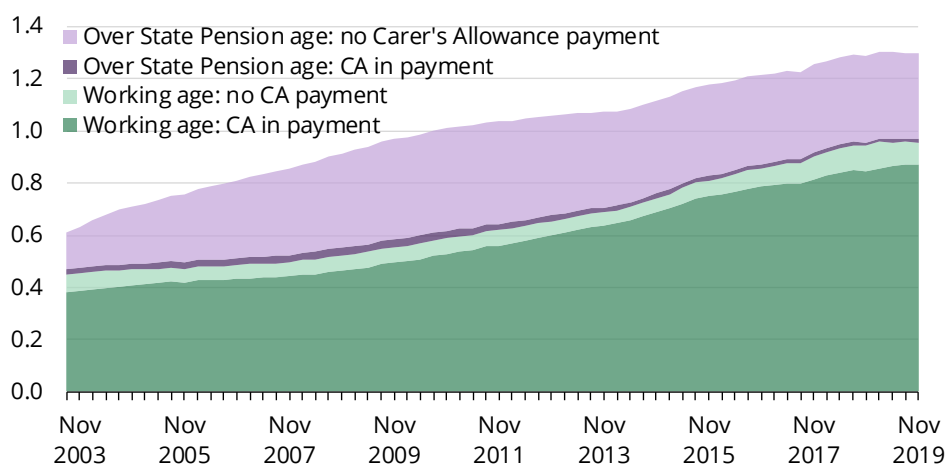
(a) Statistical disclosure control was applied at source to this table to avoid the release of confidential data. Components may not sum to totals due to the disclosure control applied.

(b) Claimants recorded as having underlying entitlement to Carer's Allowance but who receive no CA payment due to overlapping benefits or other income.

Source [DWP Stat-xplore](#)

Carer's Allowance caseload, by payment status and age group, Great Britain, 2003 to 2019

millions of claimants



Source [DWP Stat-xplore](#)

Total real expenditure on Carer's Allowance in Great Britain in 2019/20 is estimated to have been £2.92 billion. At the time of the Budget in March 2020 it was forecast to rise to £3.0 billion in 2020/21, and then to £3.64 billion by 2024/25.⁵⁷

There is no firm estimate of the proportion of carers eligible for Carer's Allowance who actually take up the benefit. Past research undertaken for the DWP suggested that the take-up rate for Carer's Allowance might be around 65% or above,⁵⁸ but the DWP argues that given the complex entitlement conditions for Carer's Allowance there is "no basis on which we could accurately make ... an assessment on take-up rates."⁵⁹

There is often confusion about the role of Carer's Allowance, and about the rules on who can and cannot get it. Formally, Carer's Allowance is an 'income replacement' benefit – it is intended to provide a *measure* of income maintenance where someone cannot work full-time because of their caring responsibilities.⁶⁰ It is not a payment for the care they provide or a 'carer's wage.' The weekly rate of Carer's Allowance (£67.25 for 2020/21) is however lower than most other income replacement benefits; Jobseeker's Allowance for people aged 25 or over, for example, is currently £74.35 a week. The reasons for paying Carer's Allowance at a lower rate than other income replacement benefits are obscure, but appear to be related to its origins in the mid-1970s as a new benefit not dependent on National Insurance contributions.⁶¹

Carer's Allowance is only one of several income-replacement benefits; others include contribution-based Jobseeker's Allowance, contributory Employment and Support Allowance, and the Retirement Pension. The long-standing 'overlapping benefits' rule means that a person cannot get more than one income replacement benefit in full at the same time. The main group affected by this rule are carers over State Pension Age – section 4 of this briefing looks at this in more detail.

Since 7 November 2016, households receiving Carer's Allowance (or the carer element of Universal Credit – see below) have been exempt from the Benefit Cap, which limits the total amount in benefits a family can receive.⁶²

3.2 Working and claiming Carer's Allowance

Carer's Allowance supports those unable to work full-time, but the rules allow people in receipt of Carer's Allowance to undertake some paid work. There is no limit on the number of hours of paid work a person can do, but Carer's Allowance is not payable if earnings (after certain deductions) exceed a certain amount in any week.

The earnings limit has been increased substantially in recent years, but carers' organisations still argue that the rules make it difficult for carers to combine paid work with their caring responsibilities. A person loses entitlement to Carer's Allowance completely as soon as their earnings exceed the threshold – the 'cliff edge' problem.

More recently, attention has focused on the problem whereby increases in the National Minimum Wage (now the National Living Wage (NLW)) mean that carers working 16 hours a week (in order to qualify for Working Tax Credit) can find themselves earning above the Carer's Allowance earnings limit – and are forced to choose between giving up their Carer's Allowance, or reducing their working hours to stay within the earnings limit

⁵⁷ DWP, [Benefit expenditure and caseload tables: Spring Budget 2020](#)

⁵⁸ Richard Berthoud, [The take-up of Carer's Allowance: A feasibility study](#), DWP Working Paper No 84, 2010

⁵⁹ [Written question 37081 \[Carer's Allowance\]](#) answered on 23 May 2016

⁶⁰ See for example HC Deb 27 March 2007 c1502

⁶¹ See section 3.2 of Commons Library briefing CBP-846, [Carer's Allowance](#)

⁶² See Commons Library briefing CBP-6294, [The Benefit Cap](#)

and losing their WTC. From April 2020, the NLW for people aged 25 or over increased to £8.72 an hour – reaching the Government’s target of 60% of median employee earnings.⁶³

In response to a parliamentary question on what assessment had been made of the impact of the NLW on the Carer’s Allowance earnings limit, and if the Government would bring forward proposals to increase the earnings limit, the then DWP Minister Penny Mordaunt said on 12 September 2016:

The primary purpose of Carer’s Allowance is to provide a measure of financial support and recognition for people who give up the opportunity of full-time employment in order to provide regular and substantial care for a severely disabled person. It is not, and was never intended to be, a carer’s wage or a payment for the services of caring, nor is it intended to replace lost or forgone earnings in their entirety.

The earnings limit for Carer’s Allowance is a net figure which is the figure left once income tax, National Insurance contributions and half of any contributions to an occupational or personal pension are deducted from earnings. There are also a number of other deductions which can be made that mean that people can earn significantly more than £110 per week and still be eligible for Carer’s Allowance.

Whilst the Government does not link the earnings limit to any other particular factor (including the National Living Wage), we do keep it under regular review and increase it when it is warranted and affordable, and this will continue to be our approach. Most recently in April 2015 the earnings limit was increased by 8% to £110, far outstripping the general increase in earnings.⁶⁴

Since then, the earnings limit has increased further and now stands at £128 a week.

In its May 2018 report on [Employment support for carers](#)⁶⁵, the Work and Pensions Committee recommended that, in addition to improvements to guidance for carers on the earnings rules and better support for carers who want to work, the DWP:

- address the “cliff edge” problem by introducing a “taper” at the same rate as used for Universal Credit, so that Carer’s Allowance is withdrawn gradually as earnings increase; and
- formally link the National Living Wage to the Carer’s Allowance earnings limit so that the threshold is equivalent to no less than 16 hours at the NLW.

The Department rejected both recommendations.⁶⁶ It argued that the earnings limit serves a different purpose from that of a taper – the former is a test of whether the person is in “gainful employment”, whereas tapers are designed to make sure that work pays. It also pointed out that for a taper to be “cost neutral”, benefit would have to start to be withdrawn at a level lower than the earnings limit – introducing a disincentive to work for carers with the lowest incomes, and adding complication.

On linking the earnings limit to the National Living Wage, the Department noted that as the earnings limit is net of certain expenses, many carers can work for 16 hours a week while retaining access to Carer’s Allowance and benefits such as Working Tax Credit. It believes that the earnings limit “is generally working well for many claimants and allows them to keep a foothold in the labour market while undertaking their full-time caring responsibilities.”⁶⁷

⁶³ See Commons Library briefing CBP-7735, [National Minimum Wage Statistics](#)

⁶⁴ [PO 45121](#) [on Carers’ Benefits: Living Wage]

⁶⁵ [HC 581 2017-19](#), 17 May 2018

⁶⁶ [HC 1463 2017-19](#), 31 July 2018

⁶⁷ *Ibid.* para 23

3.3 Carer's Allowance overpayments

In 2018 it emerged that the DWP had detected higher rates of overpayment of Carer's Allowance than in the past, following an exercise to match claims to earnings data. Most of the overpayments identified were caused by carers' earnings exceeding the earnings limit, though few cases involved proven fraud. The Department had however been slow to take compliance action, due to staff shortages. It was seeking to recover around £150 million overpaid Carer's Allowance from just under 80,000 carers.

The National Audit Office (NAO) launched an investigation and on 24 April 2019 it published a report, [Investigation into overpayments of Carer's Allowance](#).⁶⁸ The NAO found that most overpayments arose because carers failed to notify the DWP with the correct information about their earnings. It noted that some had been involuntarily caught out by the "cliff edge" earnings limit, and that uncertainty about what are allowable expenses can also lead to overpayments. The NAO report stated that the Department was reviewing its letters and online guidance, to clarify carers' obligations.

The Work and Pensions Committee also launched an inquiry and its report on [Overpayments of Carer's Allowance](#) was published on 2 August 2019.⁶⁹ The Committee concluded that carers were being "disproportionately heavily penalised for years of DWP administrative errors or their own honest mistakes, in a confusing and outdated system where the IT cannot even adapt a basic information letter within a year".⁷⁰

The Committee noted that carers facing substantial overpayment debts can suffer considerable stress and anxiety as they face substantial financial debts, compounded by the Department's approach to recovering overpayments. It recommended that DWP reassess its approach and:

- review individual cases where it was seeking to recover overpayments, where its own administrative failures had allowed overpayments to accrue.
- consider on a case by case basis whether overpayments were worth pursuing given its culpability, the cost of recouping the overpayments and the impact on the lives of carers and those who they care for.
- start with cases of overpayments worth over £2,500, most of which its internal audit team found it could have detected earlier, and decide whether to write off amounts claimants failed to report changes in their circumstances: errors that were "easily understandable given the complexity of the rules around CA and unclear advice issued by the Department."

In its response, the DWP said that it did not accept that Carer's Allowance is a "particularly complex benefit". It added that legislation and case law had always made it clear that claimants had a responsibility to report changes in their circumstances, including changes to earnings. The Department also noted that overpayments could only be waived in very limited circumstances, usually where recovery would cause substantial medical and/or financial hardship.⁷¹

The Committee was particularly disappointed that the Department had not accepted its recommendation to look into writing off overpayments, particularly where there had been

⁶⁸ [HC 2103 2017-19](#), 26 April 2019

⁶⁹ [HC 1772 2017-19](#)

⁷⁰ [Carers saving Treasury fbillions every year "set up for a fall" by design of Carer's Allowance](#), Work and Pensions Committee press release, 2 August 2019

⁷¹ [HC 102 2019](#), 5 November 2019, paras 14-16

substantial administrative failings by the Department or where its advice to claimants was unclear.⁷²

3.4 Studying and claiming Carer's Allowance

A person cannot receive Carer's Allowance if they are in full-time education. A person may be treated as being in full-time education if the school, college or university describes the course as such, or if the course involves at least 21 hours a week supervised study.⁷³

The reasoning behind this is that people in full-time education, including those with caring responsibilities, are already supported through the educational maintenance system, via its range of loans and grants.⁷⁴ The rule has however been criticised as a barrier to carers wishing to expand their skills with a view to entering or returning to the labour market. In 2008 the House of Commons Work and Pensions Committee said that carers faced a "stark choice between engaging in education and training without any financial support or living on benefits", and recommended that the Government consider lifting the 21 hour rule and reducing education and training fees for Carer's Allowance recipients.⁷⁵ In its response, the Labour Government said that rather than make piecemeal changes to Carer's Allowance, it intended to look specifically at the support offered to carers through the benefits system as part of its wider plans to develop a single benefit for people of working age.⁷⁶ No detailed plans were set out before the 2010 General Election; and subsequent administrations have not indicated any desire to revisit the 21 hour rule.

3.5 Carers and Universal Credit

Universal Credit (UC) is replacing means-tested social security benefits and tax credits for working-age families. UC is being introduced gradually and under the latest rollout schedule the benefit will not have replaced the existing 'legacy' benefits completely until September 2024.⁷⁷

Carer's Allowance will remain outside Universal Credit and the maximum amount of UC payable will be reduced pound for pound by any Carer's Allowance a person/family receives. Where a person satisfies the care conditions for Carer's Allowance, a 'carer element' will be included in the calculation of their UC maximum amount. This mirrors the carer premium/addition currently payable with means-tested benefits, and is worth £162.92 a month (2020/21 rate). A person does not have to be in receipt of Carer's Allowance or have made a claim for it to receive the carer element – the calculation of the UC award will include the carer element for as long as the person satisfies the care conditions. An award of UC can include the carer element even if Carer's Allowance would not be payable because the person's earnings exceed the Carer's Allowance earnings limit.

As of February 2020, 206,100 households on Universal Credit in Great Britain had entitlement to the carer element (8% of all households on Universal Credit).⁷⁸

⁷² [Committee publish Government response to Overpayments of Carer's allowance report](#), Work and Pensions Committee press release, 5 November 2019; [letter from Frank Field to the Secretary of State for Work and Pensions](#), 30 October 2019

⁷³ For details see section 3.4 of Commons Library briefing CBP-846, [Carer's Allowance](#)

⁷⁴ See for example [PQ 219974 \[on Carer's Allowance\]](#), 14 January 2015; [PQ 12005 \[on Carers' Benefits\]](#), 20 October 2015

⁷⁵ Work and Pensions Committee, [Valuing and supporting carers](#), HC 285 2007-08, 21 July 2008, para 163.

⁷⁶ HC 105 2008-09, 19 December 2008, para 39

⁷⁷ HM Treasury, [Budget 2020](#), chapter 2.1, 12 March 2020

⁷⁸ [DWP Stat-xplore](#), Households on Universal Credit dataset

The introduction of Universal Credit is being accompanied by a new ‘conditionality’ regime setting out what people will be required to do in return for receiving it. People who satisfy the conditions for the carer element will be in the ‘no work-related requirements’ group. This means that they will not be expected to look for work or undertake any work-related activities to receive UC.

3.6 Carer’s Allowance in Scotland

The Scotland Act 2016 devolves responsibility for disability and carers’ benefits to the Scottish Parliament.

The Scottish Government has introduced a [Carer’s Allowance Supplement](#), backdated to April 2018. It is paid twice yearly and is broadly equivalent to the difference between the Jobseeker’s Allowance 25+ rate and the rate of Carer’s Allowance, multiplied by 26 weeks. The increase is not clawed back elsewhere, and does not affect other benefits which remain reserved, including Income Support, tax credits and Universal Credit. Carer’s Allowance Supplement payments were made to 78,125 carers in Scotland who were eligible in October 2019.⁷⁹

An additional one-off Carer’s Allowance Supplement payment of £230.10 – on top of the usual June payment – is being made by the Scottish Government to provide further support for carers during the coronavirus outbreak.⁸⁰

The Scottish Government had planned to take new claims for “carer’s assistance” (replacing Carer’s Allowance and the Carer’s Allowance Supplements) from early 2022, with existing Carer’s Allowance claimants in Scotland transferring to carer’s assistance between then and 2025.⁸¹ Following the coronavirus pandemic, the precise timetable for the introduction of Carer’s Assistance and other devolved benefits is unclear.⁸² The Scottish Government is to consult to “to help identify priorities” for Carer’s Assistance. The timescale for this is to be confirmed.⁸³

⁷⁹ Scottish Government, [Carer’s Allowance at August 2019 and Carer’s Allowance Supplement to October eligibility date 2019: statistics](#), 18 February 2020

⁸⁰ Scottish Government, [Carer’s Allowance Supplement Guide: Coronavirus Carer’s Allowance Supplement](#), updated 3 June 2020

⁸¹ Scottish Government, [Devolved social security benefits: stakeholder engagement toolkit](#), updated 21 February 2020

⁸² Scottish Government, [Coronavirus \(COVID-19\) - update on devolved benefits: Cabinet Secretary speech](#), 1 April 2020

⁸³ Scottish Government, [Social security policy: Benefits for carers](#); Scottish Government, [Coronavirus \(COVID-19\)- Update on devolved benefits: Cabinet Secretary Speech](#), 1 April 2020

4. Older carers

4.1 Government support for older carers

In a 2016 PQ Baroness Wheeler asked about the resources the then-government was providing to support carers over 80:

Carers over 80: Support

Asked by: Baroness Wheeler

To ask Her Majesty's Government what additional social care resources they will provide to support the numbers of carers aged over 80, in the light of estimates that half of those are providing over 35 hours caring per week.

Answered by: The Parliamentary Under-Secretary of State, Department of Health (Lord Prior of Brampton)

My Lords, we recognise the invaluable contribution carers make to society and that many provide long hours of wonderful care. We support wholeheartedly the implementation of the improved rights for carers established by the Care Act 2014, providing just over £186 million of funding to local authorities for these improved rights. We are committed to continuing to improve support for carers through the publication of a new national carers strategy by the end of 2016.⁸⁴

4.2 Carer's Allowance and the State Pension

Carers reaching State Pension age, and people who become carers after State Pension age, are often unhappy to discover that Carer's Allowance (see section 3 above) cannot be paid in addition to the State Retirement Pension. This is due to the "overlapping benefits rule".⁸⁵ The rule applies not only to people eligible for Carer's Allowance and the Retirement Pension, but to people who would satisfy the conditions for more than one non-means-tested "income replacement" benefit. Income replacement benefits also include Incapacity Benefit, contributory Employment and Support Allowance, contribution-based Jobseeker's Allowance, Bereavement Allowance, and Widowed Parent's Allowance.

If a person eligible for Carer's Allowance is also in receipt of another overlapping income replacement benefit, they will not be paid any Carer's Allowance if the other benefit is paid at an equivalent or higher rate. If the other benefit is less than the amount of Carer's Allowance, then the difference is made up.

The rationale is that Carer's Allowance is paid to provide income for a person unable to work because of their caring responsibilities. It cannot therefore be paid in addition to any of the other income replacement benefits. To do so would be against the long-standing feature of the social security system that "double provision should not be made for the same contingency".⁸⁶ In response to a PQ in April 2019, Work and Pensions Minister Justin Tomlinson said:

There is no upper age limit to claiming Carer's Allowance, but it cannot normally be paid with the State Pension. Carer's Allowance provides a measure of replacement income where the duties of caring for a severely disabled person limit the prospect of full-time work and the earnings it would yield. State Pension provides a replacement income in retirement.

It is a long-standing and basic principle of the social security system that only one benefit at a time can be paid for the same purpose. Even though the circumstances

⁸⁴ [HL Deb 13 June 2016 vol. 773 cc994-7](#)

⁸⁵ For further information see CBP-6349, [Carer's Allowance and the Retirement Pension](#)

⁸⁶ National Insurance Advisory Committee, Report on overlapping benefit regulations, HC 36 1948/49

which give rise to entitlement to Carer's Allowance and State Pension are different, they are both designed to provide a degree of replacement for lost or foregone income.

The overlapping benefits rules, which prevent both benefits being paid, were established to reflect the general principle that flat-rate benefits designed to help with income maintenance e.g. Carer's Allowance and State Pension, should not be added together and paid in full, even though a person may qualify for both. However, if a carer's State Pension is less than Carer's Allowance, State Pension is paid and topped up with Carer's Allowance to the basic weekly rate of Carer's Allowance which, from April 2019, increased to £66.15.⁸⁷

In 2020/21, around 310,000 people over State Pension age in Great Britain are expected to satisfy the care conditions for Carer's Allowance, but only around 8,000 will actually receive the benefit.⁸⁸

People over State Pension age may however still benefit from claiming Carer's Allowance even though they may not actually receive it because of the overlapping benefits rule. This is because an "underlying entitlement" to Carer's Allowance means that they are eligible for the carer premium/addition in means-tested benefits such as Pension Credit and Housing Benefit. In November 2019, 172,900 people on Pension Credit in Great Britain (9.5%) had an underlying entitlement to Carer's Allowance and so qualified for the Pension Credit carer premium.⁸⁹

Nevertheless, the overlapping benefits rule as it affects older carers continues to cause confusion, anger and distress. Older carers interviewed as part of a study undertaken by Independent Age in 2015 generally perceived the rule to be "grossly unfair."⁹⁰ Successive governments have however resisted calls to abolish the overlapping benefits rule.

⁸⁷ [PO 243551 15 April 2019](#)

⁸⁸ DWP, [Benefit expenditure and caseload tables: Spring Budget 2020](#), accessed June 2020

⁸⁹ [DWP Stat-xplore](#) benefit combinations dataset, accessed June 2020

⁹⁰ Independent Age, ["You don't stop the worrying": The difficulties of caring in later life](#), June 2015

5. Parent carers of disabled children

Under section 97 of the *Children and Families Act 2014*, as amended, any parent carer of a disabled child who may have support needs is now entitled to a local authority assessment. As with young carers, the local authority must only consider whether to provide any services the parent carer is assessed to need.

The [Breaks for Carers of Disabled Children Regulations](#) state that a local authority must, as far as is reasonably practical, provide a range of services to assist parent carers to provide care.^{91,92}

The local authority must also produce a short breaks services statement setting out these services and their eligibility criteria for accessing them. [Government guidance](#) states that services can be provided to families without an assessment, and that, based on legal precedent, eligibility criteria cannot be applied mechanistically without a consideration of a family's needs.⁹³

The National Network of Parent Carer Forums ([NNPCF](#)) was launched in 2011, and is funded by central government. They are a network of over 150 parent forums in England and each Parent Carer Forum has parent carer members with a wide range of experiences in Health, Education and Social Care as their children have a wide range of conditions. The parent forums work with local authorities and health authorities at all levels.

⁹¹ Links to Statutory Instruments and Acts in this note may be to legislation as made and may not reflect subsequent amendments.

⁹² SI 2011/707

⁹³ Department for Education (DfE), [Short break care. How local authorities should provide it](#), 24 March 2011

6. Young carers

6.1 How many young carers are there?

The Family Resources Survey does not provide detailed information on young carers. However, Census data provides some information.

The 2011 Census found that there were **491,000 young carers** aged 24 or younger in the UK, an increase of around 87,000 since 2001. Numbers increased in all constituent countries of the UK, with the exception of Scotland which had a slight decrease (around 400 fewer in 2011).⁹⁴

In 2011, Northern Ireland had the highest percentage of young carers among the 0-24 year olds population (3.6%), and Scotland had the lowest rate (2.4%).

The majority of young carers were providing 1 to 19 hours of care per week, but over 10% were providing weekly care of 50 or more hours.

The rate per 1,000 population providing over 50 hours care per week increased in all countries between 2001 and 2011.

Census data also provides figures on the number children aged under 16 providing unpaid care. The latest data shows that in 2011 there were around 134,000 children aged 0-15 providing unpaid care in the UK, an increase of around 20,000 since 2001.

The rate of 0-15 year olds providing unpaid care per 1,000 population increased between 2001 and 2011 in all countries except Scotland. In 2011, Northern Ireland had the highest rate of 0-15 year olds providing unpaid care (14.4 per 1,000).

Most children provided 0-19 hours of care per week, but across the UK around 12,400 were providing 50 hours or more care per week in 2011.

6.2 The lives of young carers

The 2015 Conservative Government commissioned a research project into the [lives of young carers in England](#). The resulting report was published in February 2016.⁹⁵

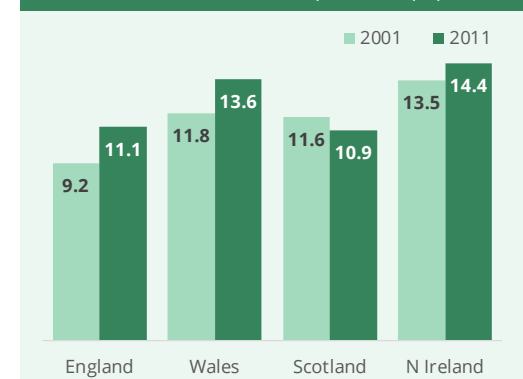
0-24 year olds providing unpaid care
Census 2001 and 2011



0-24 year olds providing 50 hours or more unpaid care
Census 2001 and 2011: Rate per 1,000 population



0-15 year olds providing unpaid care
Census 2001 and 2011: Rate per 1,000 population



⁹⁴ Office for National Statistics, [2011 Census: Population Estimates for the United Kingdom](#), March 2011

⁹⁵ DfE, [The lives of young carers in England](#), February 2016

Key findings included that:

- Parents reported that most of the young carers aged 5 to 17 were caring for someone inside the home. Of these, over half (55%) were caring for their mother and one in four (25%) were caring for a sibling. Lone parent families were over-represented in the sample.
- Cared-for parents/siblings all had a single or dual diagnoses of physical or mental health illnesses/disabilities, however these were often also accompanied by other physical and/or mental health issues that had not been formally diagnosed.
- Nearly eight out of ten (78%) young carers were reported by their parents to be undertaking practical tasks as part of their caring responsibilities, such as cooking, cleaning, doing paperwork or helping with household chores. As might be expected, caring responsibility increased with age. Over one in four (26%) were providing nursing care and parents considered over half (57%) also provided emotional support.
- Although the majority of parents (53%) reported that their child was providing up to an hour or so of care a day during the school or college week, around one in seven (14%) reported four or more hours caring each day rising to over one in four (26%) at the weekends.
- School holiday periods were particularly challenging for most of the young carers due to an increase in their caring responsibilities at home and reduced opportunities to engage in other activities both inside and outside the home as compared to term-time.
- Caring was seen to be a very rewarding role by the majority of the young carers – regardless of age or length of time caring - bringing with it a range of positive emotional and psychological benefits. However caring also had adverse effects: anxiety, stress, tiredness, strain within family relationships, restrictions in social activities and relationships and under-engagement in education.
- Formal or informal support helped reduce the extent of young carers' responsibilities. However not all parents were comfortable disclosing their condition to health and social care professionals due to a fear of the potential repercussions for their family.

6.3 Support for young carers in England

Under the [Children Act 1989](#) as amended, local authorities have a duty “to safeguard and promote the welfare of children within their area who are in need”.⁹⁶ Prior to 1 April 2015, however (when the relevant sections of the [Children and Families Act 2014](#) came into force), there had been no legal provisions in force specifically for young carers.⁹⁷

Section 96 of the *Children and Families Act 2014* amended the *Children Act 1989* to give young carers under the age of 18 in England the same right to a needs assessment as adult carers, including the appropriateness of the child providing care in light of their own needs. This was articulated in a written statement on the *Children and Families Bill*⁹⁸ by the then Secretary of State for Education, Michael Gove:

It is clear therefore that we need to do more to support young carers. With the Care Bill also under consideration by Parliament, this is an ideal opportunity to ensure that young carers get equal consideration and protection. That is not to say that they

⁹⁶ [Children Act 1989](#) as amended, section 17

⁹⁷ The [Carers and Disabled Children Act 2000](#) defined a carer as someone over 16.

⁹⁸ When Parliament is debating legislation, it is called a Bill. When Parliament has approved legislation, and it has received Royal Assent, the Bill becomes an Act.

should be treated the same as adult carers. We are committed to ensuring that young people are protected from excessive or inappropriate caring responsibilities. The best way to achieve that is to ensure that the person being cared for, whether that is an adult or a child, is assessed and has all their eligible needs met first. To do this effectively requires local services working together across the statutory and voluntary sectors to consider the whole family's needs.⁹⁹

Unlike carers assessments provided for adult carers, there are no national eligibility criteria for provision of services, and local authorities need only consider the assessment in deciding whether to provide support.

Regulations under the [Care Act 2014](#) set out how assessments of adults in England must be carried out to ensure the needs of the whole family are considered. This could include assessing what support an adult needs in order to ensure that a young person does not undertake inappropriate caring responsibilities.¹⁰⁰

The Carers Trust has published several [briefings on the rights of young carers in England](#).

Department for Education (DfE) research (January 2017) reported that fewer than one in five (19%) parents of young carers helping within the household reported that their child had received an assessment of the child's needs by the local authority, falling to 13% among those caring outside the household. Nearly two thirds (64%) were receiving no support, whether formal or informal. Of those receiving help, the most common source was a young carers' project, followed by their school or college.¹⁰¹

In an earlier [study](#) for the DfE (published February 2016) parents and young carers identified a number of factors that would promote access to support. These included:

- increasing the inclusivity and availability of young carers' services (e.g. greater support for younger carers and enabling access through central locations or transportation to and from services);
- ensuring that health and social care support services communicate the availability and nature of young carers' services quickly and effectively;
- standardising age-appropriate activity and information across young carers' services; and
- improving support for cared-for family members to help meet diverse needs.¹⁰²

6.4 Benefits for young carers

The main benefit for carers – [Carer's Allowance](#) – may be claimed from the age of 16, although those in full-time education are excluded from claiming the benefit. At November 2019, 3,250 young people under 18 were receiving Carer's Allowance in Great Britain.¹⁰³

At present, families with young carers may be able to get additional help through the [Severe Disability Premium \(SDP\)](#), worth £66.95 a week (2020-21 rate). SDP is not a benefit in its own right but is an additional amount payable with certain means-tested benefits including income-related Employment and Support Allowance. SDP is intended to give additional help to those severely disabled people who, because they live independently and do not have someone caring for them who receives Carer's Allowance, are most likely to rely on bought-in care. SDP is not payable if there are other "non-

⁹⁹ [HC Deb 8 October 2013 cc11WS-12WS](#)

¹⁰⁰ [The Care and Support \(Assessment\) Regulations 2014 S.I. 2827/2014](#)

¹⁰¹ DfE, [The lives of young carers in England omnibus](#), January 2017, p8

¹⁰² DfE, [The lives of young carers in England](#), February 2016, p10

¹⁰³ DWP, [CA: Cases with entitlement \[Stat-Explore\]](#)

dependants” residing with the person, but for these purposes anyone under 18, or aged 18-19 and qualifying for child benefit, does not count.

As noted above, Universal Credit (UC) is replacing existing means-tested benefits and tax credits for working age families. Under UC there will be no equivalent of the Severe Disability Premium,¹⁰⁴ and there are concerns this could have a disproportionate impact on families with young carers.¹⁰⁵

Under the new welfare powers devolved by the *Scotland Act 2016*, the Scottish Government introduced a new “[Young Carer Grant](#)” – worth £300 a year – in October 2019. This is payable to young people aged 16-18 who provide at least 16 hours of care a week to a person receiving a qualifying disability benefit, but do not qualify for Carer’s Allowance. It is part of a broader planned package of support which will also include free bus travel from 2020/2021, “subject to successful piloting.”¹⁰⁶ The Scottish Government states that the Young Carer Grant will “help around 1,700 young carers each year get respite and access life opportunities which are the norm for many other young people, as they make the transition into adulthood.”¹⁰⁷

6.5 Participation and attainment in education

The Children’s Society 2013 report (which analysed the findings of the DfE’s [Longitudinal Study of Young People in England](#)) found that:

- Around 1 in 20 young carers missed school because of caring responsibilities.
- Young carers had significantly lower educational attainment at GCSE level, the equivalent to nine grades lower overall than their peers e.g. the difference between nine B’s and nine C’s.
- Young carers were more likely than the national average to be not in education, employment or training (NEET) between the ages of 16 and 19.¹⁰⁸

DfE-commissioned research published in January 2017 carried out surveys with both young people and their parents. This was carried out in order to compare the experience of young people with caring responsibilities (aged 5 to 17) to those with no such responsibilities. On schooling, some of the findings of the surveys showed:

Most parents across both the face to face and comparison surveys reported that their children were happy at school and considered they were attending well and performing better than average. [...]

However, parents of young carers were significantly more likely than those in the comparison survey to report that their child was being bullied. The greatest difference was among 16 to 17 year olds of whom over one in five parents (16%) considered their child was being bullied, compared to only 4% of parents of children the same age in the comparison survey. [...]

Just over half (55%) of parents of young carers reported their child had been absent from school at least a few times in the last year compared to around one third of parents in the comparison survey. Further, 12% of parents of 12 to 15-year-old carers were aware that their child had fallen asleep at school at least a few times in the last 12 months compared to only 3% of parents of children the same age in the comparison group. [...]

¹⁰⁴ See section 6.2 of Commons Library briefing SN06548, [Draft Universal Credit Regulations 2013](#)

¹⁰⁵ [Disability Benefits Consortium submission to the House of Lords Secondary Legislation Scrutiny Committee, 2013](#)

¹⁰⁶ [Scottish Government Position Paper: Support For Carers](#), 28 February 2019

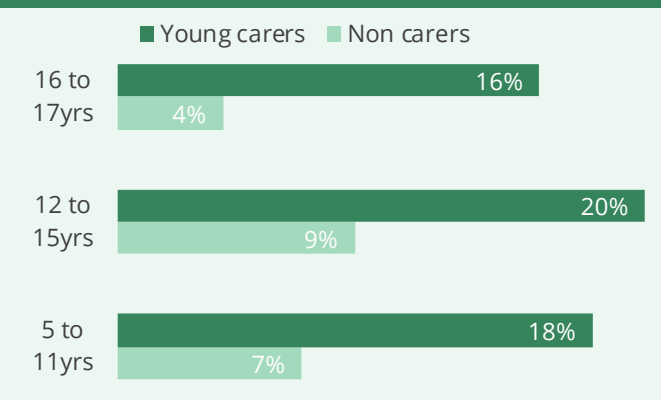
¹⁰⁷ Ibid.

¹⁰⁸ The Children’s Society, [Hidden from view. The experience of young carers in England](#), May 2013

When asked about being late for school, absenteeism and falling asleep, young people in both surveys were more likely than the parents to report all of these occurrences [...].¹⁰⁹

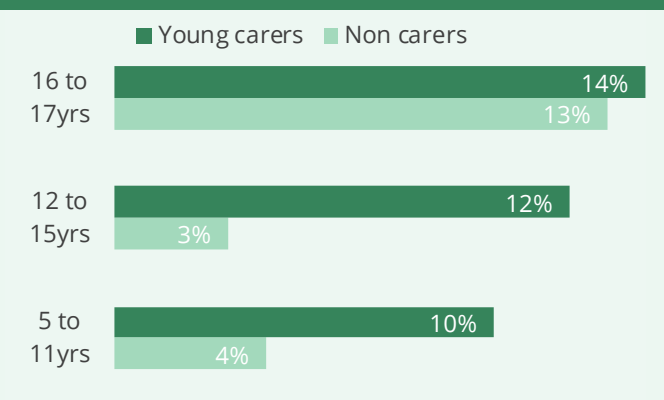
Carers in each age group were reportedly more likely to be bullied at school

% of children being bullied at school



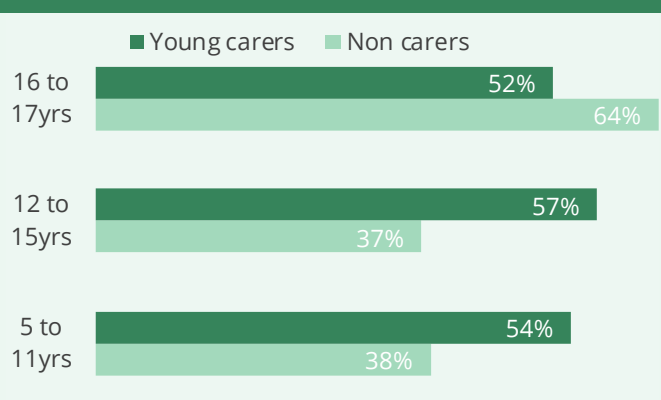
Carers in each age group were reportedly more likely to fall asleep at school

% of children falling asleep at least once in the last 12M



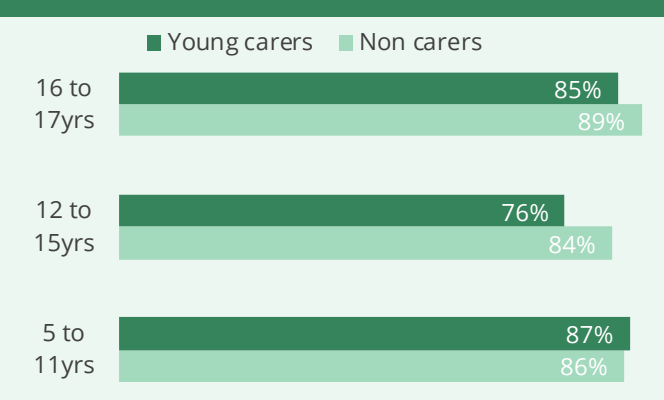
Younger carers were reportedly more likely to miss school at least once

% of children absent at least once in the last 12M



Carers reportedly enjoyed going to school at broadly similar rates to peers

% of children that enjoy going to school



Notes: Surveys carried out on 420 parents of young carers and 304 parents of non carers between July 2015 and Feb 2016. Responses are according to the perceptions of parents. Source: DfE, [The lives of young carers in England. Omnibus survey report Research report](#), January 2017, Table 14, Table 16, and Table 17.

Pupil Premium

The Government has cited research suggesting that around 60 per cent of young carers aged 14-16 were eligible for free school meals (FSM).¹¹⁰ Children in England who are eligible for FSM, or who have been eligible at any point in the last 6 years, ('Ever 6') attract the Pupil Premium. This is extra funding for schools to support the education of disadvantaged children. The annual value of the deprivation pupil premium in the 2020-21 financial year is £1,345 per primary-aged pupil and £955 per secondary-aged pupil.¹¹¹

Information about support for young carers in schools in Scotland and Northern Ireland can be found online:

- [MyGov.Scot website article, 'Young carers: support'](#), 12 November 2019.

¹⁰⁹ DfE, [The lives of young carers in England. Omnibus survey report Research report](#), January 2017, pp 9-10.

¹¹⁰ [PQ 243309, 23 April 2019](#)

¹¹¹ See: Gov.uk guidance, ['Pupil premium: conditions of grant 2020-2021'](#), 25 February 2020.

- [NI Direct website article, 'Young carers – support at school'](#), undated.

The [young carers in schools programme](#), run jointly by Carers Trust and The Children's Society, works with schools across England to share good practice, and provide training and support to local authorities and young carers services to increase the identification of young carers in their area- and to increase school engagement.

6.6 Further and higher education

In England, eligible young carers aged 16-19 in further education may be entitled to a discretionary 16-19 bursary. This is extra money intended to remove barriers to learning. Government guidance to schools and FE providers on administering the bursaries makes clear that they should encourage young carers to apply:

Young people with caring responsibilities, for example, caring for a parent or other relative, may be reluctant to say so because of fear of being stigmatised. Institutions should ensure confidentiality to reduce these concerns, publicise the availability of help from the bursary fund and encourage young carers to apply where they have a financial need.¹¹²

Information on financial and other support for further education in the rest of the UK can be found at:

- [Care Information Scotland, 'Help for carers who work or study'](#), January 2019.
- [NI Direct website article, 'Carers and learning'](#), undated.
- [Student Finance Wales website](#) (general information, not specific to carers)

The 2015 Government acknowledged that young carers “face challenges participating in higher education and they may require additional support to do so effectively”.¹¹³ English-domiciled higher education students who have caring responsibilities for children can apply for funding to help with childcare, in addition to mainstream student loans. Some students with adult dependants who meet eligibility criteria may qualify for an [Adult Dependants' Grant](#). This is non-repayable and in 2020-21 the maximum amount will be £3,094.

Many higher education institutions have adopted Carers Policies to support students who are carers as part of their equality agenda. Carers Policies aim to allow flexibility for student carers and attempt to make sure that students are not disadvantaged by their caring responsibilities, whilst ensuring that any accommodations made for students do not compromise academic standards. In 2015 the Carers Trust published a guidance document to help universities formulate their carers policies, [Supporting Students with Caring Responsibilities: Ideas and Practice for Universities to Help Student Carers Access and Succeed in Higher Education England version](#) – this document contains examples of universities' carers policies.¹¹⁴

Further information about support for HE students with caring responsibilities in other parts of the UK can be found online:

- [Student Awards Agency for Scotland \(SAAS\), Support for student carers, undated.](#)
- [Student Finance Wales, Dependants' Grants \(2020-21\)](#)

¹¹² DfE, [16 to 19 Bursary fund guide 2020-21](#): 2020-21, 30 April 2020.

¹¹³ See: [PQ 20664 \(on Carers: young people\), 17 December 2015](#)

¹¹⁴ The Carers Trust, [Supporting Students with Caring Responsibilities: Ideas and Practice for Universities to Help Student Carers Access and Succeed in Higher Education England version](#), 2015

- [Student Finance Northern Ireland collection on undergraduate support.](#)

7. Carers' health and wellbeing

Analysis of the 2011 Census, widely cited by the Government and carers' organisations, found that the general health of carers deteriorates incrementally with the increasing hours of care provided: 5.2% of carers reported their own health as 'not good' and this rose to almost 16% among those caring for more than 50 hours a week.¹¹⁵

Carers UK's [State of Caring 2018](#) survey similarly found that caring responsibilities impacted upon an individual's health, including that:

- Across the UK, 72% of carers said they had experienced mental ill health as a result of their caring responsibilities.
- 61% said they'd experienced physical ill health.
- 81% of people caring for disabled children reported mental ill health, as did 80% of 'sandwich carers' (i.e., those caring for a non-disabled child under 18, plus someone else) and carers struggling to make ends meet financially.
- Those most likely to experience physical ill health as a result of their caring responsibilities were carers providing end-of-life palliative care (72% of this group), those struggling to make ends meet financially, and those providing round-the-clock care – 69% and 66% of these groups, respectively.

The previous year's survey (2017) found that caring affected carers' ability to find time to exercise, maintain a balanced diet and get sufficient sleep. It also found that in over two thirds of those surveyed said their GP knew they were a carer, but did not do anything different as a result. As a result, Carers UK in 2019 called for:

...a new duty on the NHS to put in place policies to identify carers and to promote their wellbeing.¹¹⁶

The Government's mandate to NHS England for 2018-19 included an expectation that:

Carers should routinely be identified and given access to information and advice about the support available.¹¹⁷

Successive Governments have also acknowledged that carers, and young carers in particular, are more likely to develop mental health problems.¹¹⁸

As part of its *Commitment to carers* programme (launched in 2014), NHS England published [An integrated approach to identifying and assessing Carer health and wellbeing](#) in May 2016, setting out approaches to joint working between organisations. This also set out principles for improved support for carers, including:

- Improving the identification and assessment of carers in primary care
- Providing an integrated support package in order to help carers' with physical and mental health needs
- Giving carers choices about how support is delivered.¹¹⁹

The Government has emphasised the importance of integrated care as a way to better meet carers' health and wellbeing needs:

¹¹⁵ DH et al. [Supporting the health and wellbeing of adult carers](#) (2014)

¹¹⁶ Carers UK, [State of Caring 2019](#), July 2019, p26

¹¹⁷ DH, [The Government's mandate to NHS England for 2018-19](#), May 2019, para 2.4

¹¹⁸ PQ 19558 [[Carers: Mental Health](#)], 15 December 2015

¹¹⁹ NHS England, [An integrated approach to identifying and assessing Carer health and wellbeing](#), May 2016, para 3.3

The National Health Service contribution to the Better Care Fund, which helps to join up health and care, includes funding to support the implementation of the Care Act 2014, including £130 million earmarked for the provision of carers' breaks.¹²⁰

More information on the Better Care Fund can be found in the Commons Library briefing paper, [Health and social care integration](#).

In July 2016, NHS England established a Young Carers Health Champion Programme to support health literacy and promote health and wellbeing among this group.¹²¹

In June 2019, NHS England announced a voluntary scheme for GP practices, aimed at young carers. This will encourage practices to identify and support children and young people providing informal care for family members.¹²²

7.1 Access to health services

Problems faced by carers in accessing health services

Carers' organisations have raised concerns about the problems faced by carers accessing health and social services for themselves, and for the people they care for. NHS England has also cited research showing that health professionals only identify around one in ten carers, and 66% of carers feel that healthcare staff don't help to signpost them to relevant information or support.¹²³

In September 2016 Carers UK published [Pressure Points: carers and the NHS](#), which found widespread problems faced by carers in accessing primary and community support services for the people they care for.¹²⁴ Carers UK state that it is important that the huge contribution of carers is recognised across the NHS and taken into account, especially when developing services to support out of hospital care. It notes that "Carer Passports" are one way in which the NHS can make sure that carers are identified and signposted to available support. Carers UK has written a research summary on [Carer Passports](#), drawing on existing best practice that looks at how hospitals can introduce passports in order to identify carers as well as promote additional support in hospitals for carers, such as discounted or free parking.¹²⁵

NHS England's commitment to carers

The [NHS Five Year Forward View](#) (FYFV), published in 2014, committed the NHS to find new ways to support carers, to build on the new rights created by the Care Act and to help the most vulnerable carers – the approximately 225,000 young carers and the 110,000 carers who are themselves aged over 85. The FYFV also recognised the contribution carers make to the NHS:

The five and a half million carers in England make a critical and underappreciated contribution not only to loved ones, neighbours and friends, but to the very sustainability of the NHS itself.¹²⁶

In May 2014 NHS England also published its [Commitment to Carers](#), setting out the recognition and support they need.¹²⁷ It included [37 commitments](#) spread across eight key

¹²⁰ PQ 1550 [[Carers](#)], 4 July 2017

¹²¹ PQ 3741 [[on Carers: Children and Young People](#)], 18 July 2017

¹²² NHS England press release, '[NHS sets out 'care for young carers' offer in GP surgeries](#)', 11 June 2019

¹²³ NHS England, [Commitment to Carers](#), April 2014; NHS England, [Carer facts- Why investing in carers matters](#)

¹²⁴ Carers UK, [Pressure Points: carers and the NHS](#), September 2016

¹²⁵ [Carers UK, Carer Passports, March 2016](#)

¹²⁶ NHS England and partner organisations, [NHS Five Year Forward View](#), October 2014, p13

¹²⁷ [NHS England's Commitment to Carers](#), April 2014

priorities which included raising the profile of carers, education and training, and person-centred coordinated care and primary care, that were developed in partnership with carers, patients, partner organisations and care professionals.

As part of its commitment to carers, NHS England published [Commissioning for Carers: Principles and resources to support effective commissioning for adult and young carers](#), to help Clinical Commissioning Groups (CCGs) better identify and help carers to stay well. The 10 principles aim to help CCGs deliver the best outcomes for carers, with a self-assessment questionnaire for commissioners to identify where they can provide further support at a population level. The [Principles have been published](#) alongside other materials for commissioners and providers from the [Royal College of General Practitioners](#), to provide improved support for unpaid carers.

The [Carers Action Plan 2018-2020: Supporting carers today](#), published in June 2018 included a commitment that the NHS England and the Care Quality Commission would work together to develop quality standards for general practitioner surgeries to demonstrate how effective they are in identifying and supporting carers.¹²⁸ A non-mandatory [framework of quality markers](#) was published in June 2019.

The [NHS Long Term Plan](#), published in January 2019, repeated the commitment to improve how the NHS identifies unpaid carers, and strengthen support for them to address their individual health needs.¹²⁹ This included a commitment to “encourage the national adoption of carer’s passports”.¹³⁰

The National Institute for Health and Care Excellence (NICE) published [Guidelines for supporting unpaid adult carers](#) in January 2020. It sets out the responsibilities of local authorities and NHS organisations (such as GPs, pharmacists and hospitals) to identify, support and involve carers when assessing and planning services.

7.2 Sharing patient information with carers and involvement in care

Difficulties can arise when health and social care staff have to balance the need to inform families and carers with professional and legal requirements to protect patient confidentiality. In most cases such issues are avoided by a patient giving consent for their private information to be shared. However, staff may need to make a decision on what is in the patient's best interest before sharing information if the patient lacks capacity to consent. When considering whether to share confidential information with a carer or family member, the confidentiality guidance for health and care staff should be followed:

- Professionals should establish with the service user or patient what information they want to be shared, with whom, and in what circumstances.
- Confidential information should be shared with the carer when the service user or patient has given explicit, informed consent and when the carer consents to be told.
- Where the service user or patient does not have capacity to give valid consent, confidential information should be shared with the carer where it is in the person’s best interests.¹³¹

¹²⁸ DHSC, [Carers Action Plan 2018-2020: Supporting carers today](#). June 2018

¹²⁹ NHS England, [NHS Long Term Plan](#), January 2019

¹³⁰ NHS England, [NHS Long Term Plan](#), January 2019, para 2.33

¹³¹ HSCIC (now known as NHS Digital), [A guide to confidentiality in health and social care](#). (2013), p13. Information can also be found in [NHS England’s quick guide to sharing information](#)

Chapter 5 of the [Code of Practice](#) to the [Mental Capacity Act 2005](#) (MCA) provides detailed guidance for health and social care staff on taking “Best Interests” decisions, where someone lacks capacity. In particular, health and social care staff have a duty under section 4(7) of the MCA to take into account the views of anyone involved in caring for the person and anyone interested in their welfare (for example family carers and other close relatives) as part of a best interests decision.

NICE recommends that carers are involved in decisions about patient’s hospital discharge plans, if the patient and their carers agree.¹³²

NICE’s [Guidelines for supporting unpaid adult carers](#) in January 2020 also recommends that NHS providers should “share with carers the information they need to provide care effectively and safely while respecting confidentiality (explain to them the constraints of confidentiality)”.¹³³

¹³² NICE, [Transition between inpatient hospital settings and community or care home settings for adults with social care needs Quality standard](#) [QS136], December 2016, Quality Standard 5. Each hospital has its own discharge policy which should be available from the ward manager or the hospital’s Patient Advice and Liaison Service (PALS).

¹³³ NICE, [Supporting adult carers](#), January 2020, para 1.1.12

8. Local authority assessments and health and social care support for carers

8.1 Local authority assessments and support for adults

Any carer in England who may have needs for support, whether currently or in the future, is entitled to a carer's assessment by their local authority. Carers assessments were introduced by the [Carers \(Recognition and Services\) Act 1995](#) and have been since been strengthened by subsequent legislation, most recently the [Care Act 2014](#).

The assessment must look at any assistance that the carer requires to continue to provide care, and a carer remains entitled to an assessment even if the care recipient refuses an assessment for themselves. It must also look at the carer's needs independent of the needs of the care recipient, including care breaks, and a carer's outside interests.¹³⁴

There was previously no duty on local authorities to meet a carer's assessed needs, only for them to be taken into consideration. Since the *Care Act 2014* came into force, however, any carer who meets national eligibility criteria must have services provided to meet their needs. Local authorities also retain the power to provide support to those who have been assessed, even if they do not have a statutory duty to under the eligibility criteria.

Where a local authority provides services following a carer's assessment, the carer is entitled to request a direct payment to give them control over how these services are provided.

Legislation on carer's assessments states that someone providing care as an employee under any form of contract or as a volunteer for a voluntary organisation is not entitled to an assessment.

Further detail is set out in the DHSC's [Care and Support Statutory Guidance](#).

Brief information on local authority duties towards carers in the rest of the UK is available in an explainer published by the Nuffield Trust: [What are carers in each of the four UK countries entitled to?](#)

8.2 Changes in force from 1 April 2015 under the Care Act 2014

Section 10 of the Care Act gives the right to an assessment to any carer who may have needs for support now or in future. This changes the previous right to assessment, which was limited only to those who provided a "substantial amount of care on a regular basis"¹³⁵

Prior to the Act coming into force, carers also needed to request an assessment from the local authority in order to have their needs considered. The *Care Act 2014* instead puts the responsibility on the local authority to identify those in need of an assessment and carry this out, although the carer remains able to refuse an assessment.

In a significant change to previous carers' legislation, section 20 of the *Care Act 2014* introduces a legal duty to meet carers' needs should these fall within national eligibility

¹³⁴ *Carers (Recognition and Services) Act 1995*, Section 1

¹³⁵ [Carers \(Recognition and Services\) Act 1995](#) as amended

criteria. These are set out in regulation 3 of the [Care and Support \(Eligibility Criteria\) Regulations 2015](#).¹³⁶

8.3 Respite breaks

The stress and physical demands of care have been argued to have a detrimental effect on carer's health. Iain McKenzie MP raised this issue in a House of Commons debate on 20 June 2013, and highlighted the importance of respite breaks:

Carers' health can also suffer. People providing high levels of care are twice as likely to fall sick. The fact that 625,000 people suffered mental and physical ill health last year as a direct consequence of the stress and physical demands of caring illustrates the true impact on carers' 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 that their condition had worsened since becoming a carer.

Caring clearly takes a huge toll on carers' physical and mental health, and those not receiving respite are far more likely to suffer from mental health problems. The impact is often exacerbated by carers being unable to find time for medical check-ups or treatment for themselves, with two in five carers saying that they are forced to put off treatment because of their caring responsibilities. Research by Carers UK includes cases of carers discharging themselves from hospital because of an absence of alternative care.¹³⁷

Lord Rix, the then chairman of the learning disability charity MENCAP, attempted in 1996 to introduce a legal right to respite care, and highlighted the absence of this provision from the 1995 Act.¹³⁸ His *Disabled Persons and Carers (Short-term Breaks) Bill* did not make it on to the statute book.

The power for local authorities to offer respite breaks through assessments was introduced in the [Carers and Disabled Children Act 2000](#). This allowed the provision of vouchers for temporary care through community care services, so giving the carer a short term break from their caring responsibilities.

The right to care breaks have been strengthened with the introduction of the *Care Act 2014*, as set out above, as the eligibility criteria for carer's support include an inability to achieve the following:

- developing and maintaining family or other personal relationships;
- engaging in work, training, education or volunteering;
- making use of necessary facilities or services in the local community, including recreational facilities or services;
- engaging in recreational activities.¹³⁹

On top of the money made available to local authorities to meet their statutory duties with regards to care, since 2015 £130 million a year has been made available for carers' breaks via the Better Care Fund.¹⁴⁰

Carers UK has raised concerns that as this allocation in the Better Care Fund is not ring-fenced, the money could end up being used elsewhere in local authority budgets.¹⁴¹ The Carers Trust has similarly criticised previous joint funds earmarked for carers' breaks where

¹³⁶ SI 2015/313

¹³⁷ [HC Deb 20 June 2013 cc1097-8](#)

¹³⁸ [HL Deb 17 April 1996 c751-782](#)

¹³⁹ [Care and Support \(Eligibility Criteria\) Regulations 2015, SI 313/2015, para 3\(2\)\(b\)\(v-viii\)](#)

¹⁴⁰ [PQ229090](#), 11 March 2019.

¹⁴¹ Carers UK, "[Carers UK responds to the publication of Guidance on Care Funding](#)", 20 December 2013

the money was not ring-fenced, as this led to the money allegedly being spent elsewhere in the health service.¹⁴²

8.4 Carers Innovation Fund

On 12 June 2019, the Government provided [further details](#) on its new Carers Innovation Fund, originally announced in 2018's Carers Action Plan.¹⁴³ The fund will provide £5 million in funding over the next two years, for innovative projects that can demonstrate impacts in terms of:

- carers' health and wellbeing
- carers' ability to manage work alongside caring responsibilities
- carers' ability to take a break from their caring role
- reducing loneliness and social isolation

Details on how to apply for funding are available on the [Gov.uk website](#).

¹⁴² Carers Trust press release, "The Princess Royal Trust for Carers' response to the Government announcement of their vision for adult social care, including £400m in new funding for carers breaks", 16 November 2010

¹⁴³ DHSC news story, '[£5 million fund to develop support for unpaid carers](#)', 12 June 2019.

9. Past and future Government policy

9.1 The proposed Carers Strategy and the forthcoming social care Green Paper

Government's March 2016 consultation and response

In March 2016, the Government launched a call for evidence on what should be included in its planned Carers Strategy for England.¹⁴⁴ Setting out the reasoning behind the call for evidence, the Department of Health said:

Caring for others should not be to the detriment of the carer's own health and wellbeing and carers can receive support in a number of ways – including from social services, the NHS, or the benefit system.

We think that we need a new strategy for carers setting out how we can do more. One which reflects their lives now, the health and financial concerns they have, and gives them the support they need to live well whilst caring for a family member or friend.

The call for evidence closed on 31 July 2016.

The Government response was not published until June 2018 – perhaps because of uncertainty about how to proceed with the Carers Strategy (see below).

In the Government's response, the DHSC noted that it had received "an overwhelming response; 6,802 people and organisations took the time to give us their views, experiences and suggestions".¹⁴⁵ In addition, five focus group events were held around the country during 2016.

Six topics were consulted upon:

- Impact of caring – respondents "reported that caring had a significant effect on their physical and mental health, on their ability to pursue educational opportunities and to maintain full-time employment";
- Identifying carers – "half of carers who responded to this question said they had not received any help to identify themselves", while "most people agreed that there were things that health, care and educational organisations and workers could do to help identify people as unpaid carers";
- Valuing carers – while roughly half of carers felt valued and involved in the cared for person's care, "most respondents felt strongly that it was important that services valued and involved carers more in future"
- Information and advice – only half of carers said they had "received information about caring and the support available to them" and "most people commented about things that they would like to see happen in future, rather than things that had worked well for them in the past";
- Supporting adult carers – "individuals and organisations felt it was a priority to improve support", and, looking ahead, "responses said that accessible and affordable respite care or sitting services would significantly improve their lives";

¹⁴⁴ Department of Health, [How can we improve support for carers?](#), 18 March 2016

¹⁴⁵ Department of Health and Social Care, [How can we improve support for carers? Government response to the 2016 carers call for evidence](#), June 2018, p4

- Supporting young carers – “most respondents on this theme said they had not received any services or other formal support for young carers and had not had help to maintain their education or balance life outside caring”.¹⁴⁶

Dropping of the proposed Carers Strategy

Although the consultation closed in July 2016, no Carers Strategy was forthcoming and a parliamentary question tabled in July 2017 asked the Government whether it still intended to publish it. The response did not mention the Carers Strategy, saying only that “we have said that more widely we will consult on proposals to improve social care. Next steps will be set out in due course”.¹⁴⁷

In June 2018, the Government confirmed that it would not now publish a Carers Strategy. Instead, the Government said that carers would be included in the proposed Green Paper on social care, as this presented “an opportunity for a more fundamental approach to tackling the challenges carers face, by considering them alongside our strategy for social care”.

Although at that point the Green Paper was due to be published before the end of July 2018 (since postponed further, see below), it would only have been a consultation paper – even if it had been published then, it would have been expected that several months would pass following publication to allow responses to be submitted, and then for the Government to consider them and devise its own response. Therefore, to bridge this gap, the Government also published in June 2018 the Carers Action Plan 2018–20 which “set out a cross-government programme of work to improve support for carers over the next two years”.¹⁴⁸

Carers Action Plan 2018–2020

The cross-departmental Carers Action Plan for the period 2018 to 2020 was also published in June 2018.

The introduction to the Action Plan stated:

This action plan outlines the cross-government programme of work to support carers in England over the next two years and builds on the National Carers Strategy. It retains the strategic vision for recognising, valuing and supporting carers from 2008, which has been the vision of successive governments. It sets out this Government’s commitment to supporting carers through 64 actions across five priorities emerging from the carers’ Call for Evidence. The actions focus on delivery and tangible progress that can be made in the near future, and give visibility to the wide range of work that is planned or already underway across government to support carers, their families and those they care for.¹⁴⁹

A helpful summary was provided by the Minister for Care, Caroline Dinéage:

The cross-government Carers Action Plan is an essential step towards realising the Government’s commitment to value, recognise and support carers to provide care in a way that supports their own health and wellbeing, employment and other life chances.

The plan sets out a two-year programme of targeted work to support unpaid carers. It puts a focus on practical actions to support carers and gives visibility to the work already underway or planned within government.

¹⁴⁶ Department of Health and Social Care, [How can we improve support for carers? Government response to the 2016 carers call for evidence](#), June 2018, pp7–12

¹⁴⁷ [PO 3320 13 July 2017](#)

¹⁴⁸ Department of Health and Social Care, [How can we improve support for carers? Government response to the 2016 carers call for evidence](#), June 2018, pp5–6

¹⁴⁹ Department of Health and Social Care, [Carers Action Plan 2018 – 2020: Supporting carers today](#), June 2018, p7

[The consultation responses] have informed its development and content, helping us to focus actions around the following five themes:

- Services and systems that work for carers
- Employment and financial wellbeing
- Supporting young carers
- Recognising and supporting carers in the wider community and society
- Building evidence and research to improve outcomes for carers

In this way, we will seek to build accessible carer friendly communities and public services, promote innovative local projects and support carers to stay in work.

[...]

The Government wants to ensure that caring is a choice or responsibility that is always recognised and valued. The publication of this Carers Action Plan today is an important part of that commitment.¹⁵⁰

The Government published a [1-year progress review](#) in July 2019. In 2019/20, the Government said it would, in addition to the commitments previously made:

- Commission survey data on experiences of carers in England through with the DSHC and NHS Digital;
- Undertake a project to support parent carers to navigate the transition from child to adult services as their child approaches the age of 18;
- Undertake a project which focuses on young carers, particularly to support better identification among Black, Asian and minority ethnic families;
- Explore the potential for a national recognition scheme for young carers and hold a young carers Parliament day;
- Fund further dissemination of the Carers UK Carer Passport Scheme; and
- Provide further funding to promote the Carer Confident benchmarking scheme for employers.¹⁵¹

The forthcoming social care Green Paper

As noted above, a planned, standalone, Carers Strategy was dropped in preference to including the topic of carers in the forthcoming social care Green Paper.

Although it had published the two-year Carers Action Plan, the Government subsequently said in December 2018:

We recognise that there is still more to do and that is why the forthcoming Adult Social Care Green Paper will include a focus on how society supports carers as a vital part of a sustainable health and social care system so that they are properly valued, recognised and supported to provide care in a way that supports their own health and wellbeing.¹⁵²

The date of publication of the Green Paper is unknown – five stated publication dates have already been missed (the first of which was summer 2017). The current position is that it will be published “at the earliest opportunity”.¹⁵³

For more information on the Green Paper, see the Library briefing paper [Social care: forthcoming Green Paper \(England\)](#).

¹⁵⁰ [HCWS732 5 June 2018](#)

¹⁵¹ DHSC, [Carers Action Plan 2018-2020: Support carers today](#), July 2019, pp23-4

¹⁵² [PQ 196242 5 December 2018](#)

¹⁵³ [PQ 259016 6 June 2019](#)

9.2 Carers' benefits

Major changes to the benefits system are currently underway as a result of the Coalition Government's welfare reform programme, and further measures initiated by subsequent governments. Some changes have already been introduced while others are either being phased in. As it stands, the full impact of the overall welfare reform package will not be felt until the mid-2020s.

Carers will be affected by some of these changes – Universal Credit in particular – but perhaps less so than other claimant groups. Carer's Allowance will remain outside Universal Credit, and the rules around working or studying and claiming Carer's Allowance, its level and how it interacts with other benefits, are basically unchanged. Carers' organisations continue to press the case for these and other issues to be addressed.¹⁵⁴

Welfare provision for carers was last examined in detail in Parliament in 2008, when the Work and Pensions Committee published its report *Valuing and Supporting Carers*.¹⁵⁵ The report argued that the current system of benefits for carers was outdated and recommended the introduction of two distinctive "tiers" of support for carers, offering: (i) income replacement support for carers unable to work, or working only part-time; and (ii) compensation for the additional costs of caring for all carers in intensive caring roles.

In its response in December 2008 the Labour Government accepted the general principle put forward by the Committee that a future system of support for carers should distinguish between income replacement and the extra costs faced by carers. However, it gave no specific timetable, saying that any changes would be looked at as part of its wider welfare reform programme. No further announcements were made before the 2010 General Election.¹⁵⁶

Further information on ongoing debates about reforming carers' benefits can be found in section 7 of Commons Library briefing CBP-0846, [Carer's Allowance](#), 9 January 2020.

¹⁵⁴ See for example Carers UK and Age UK, [Walking the tightrope: The challenges of combining work and care in later life](#), 15 July 2016

¹⁵⁵ Work and Pensions Committee, [Valuing and supporting carers](#), HC 485 2007-08, 29 August 2008

¹⁵⁶ [Valuing and Supporting Carers: Government Response to the Committee's Fourth Report of Session 2007–08](#), HC 105 2008-09, 19 December 2008

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