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7 June 2021
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Summary

The Department of Health and Social Care (DHSC) has described an informal/unpaid carer as “...someone who provides unpaid help to a friend or family member needing support, perhaps due to illness, older age, disability, a mental health condition or an addiction”, as long as they are not employed to do so.

How many carers are there?

The Family Resources Survey (2021) estimated that in 2019/20 around 7% of the UK population were providing unpaid care. Since 2009/10, around 60% of informal carers are women.

Adults aged 55-64 were most likely to care for others, with younger age groups generally less likely to provide care. In age groups under 75, women were more likely to provide informal care than men.

A 2013 report from the Children’s Society 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 groups.

Research commissioned by Carers UK published in November 2015 estimated that 1.4 million people were providing 50 or more hours a week caring for a partner, friend or family member in the UK. As such, they make a significant contribution to society and relieve pressure on the NHS.

The NHS acknowledged this contribution, saying it was “critical and underappreciated ... not only to loved ones, neighbours and friends, but to the very sustainability of the NHS in England”.

Rise in unpaid care during the pandemic

A Carers Week report published in June 2020, found an estimated 4.5 million additional people had taken on caring responsibilities. This meant a quarter of UK adults were providing unpaid care.

Carers UK published the results of an online survey of around 6,000 current and former carers in October 2020. The survey found 81% were providing more care since the start of the pandemic and 78% said the needs of the person they care for have increased. 28% said they were “struggling to make ends meet.”
Informal carers

Carers UK made several recommendations, including ensuring that carers can continue to remain in work, publishing guidance for unpaid carers, and that Parliament delivers a new deal for carers.

**Support for unpaid carers during the pandemic**

The DHSC published [Covid-19 guidance for unpaid carers](https://www.gov.uk/government/publications/covid-19-guidance-for-unpaid-carers) (updated May 2021), which said that all eligible unpaid carers should have been invited for a coronavirus vaccination.

The Government’s [action plan for adult social care](https://www.gov.uk/government/publications/coronavirus-social-care-action-plan) (updated December 2020) also said care providers should contact unpaid carers to ensure they were able to receive supplies to help them with their care responsibilities. The Government has also provided additional funding for the Carers UK helpline. NHS England confirmed that carers can call [NHS volunteer responders](https://www.england.nhs.uk/coronavirus/volunteers/) for support during the pandemic.

The Government also confirmed that unpaid carers could [continue to claim Carer’s Allowance when self-isolating](https://www.gov.uk/government/publications/covid-19-guidance-for-unpaid-carers). During the pandemic, emotional support can also count towards the 35 hours a week Carer’s Allowance care threshold. Carers may, in certain circumstances, be eligible for statutory sick pay.


**Benefits for carers**

Carers are entitled to a range of benefits, but the main cash benefits are Carer’s Allowance, and the carer premium, which is 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](https://www.gov.uk/government/publications/coronavirus-guidance-for-unpaid-carers) must not be in full-time education or have earnings of more than £128 per week after deductions. This can create problems for those in paid work to receive additional paid support.

In November 2020, there were 1.3 million Carer’s Allowance claimants in Great Britain. Women made up 68% of the total.

**Support for carers in education**

If the carer is in [school](https://www.gov.uk/government/publications/coronavirus-guidance-for-unpaid-carers), they might have access to counselling. In England, they might also be eligible for additional Pupil Premium funding, which goes...
Informal carers
directly to their schools if they are, or have been, entitled to free school meals.

In further education, students in England with caring responsibilities might be able to access discretionary bursary support for 16-19-year-olds. However, they can’t claim Carer’s Allowance.

A carer in higher education can access additional student support funding if the adult they care for qualifies.

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

Other local authority support
Carers are entitled to a statutory assessment of their support needs, undertaken by the local authority.

The assessment must consider factors such as what assistance the carer needs to continue providing care, for their independent needs, and, for young people, whether it is appropriate for them to provide care.

Since 1 April 2015, any adult carer who meets national eligibility criteria must be provided with services. Even when the criteria are not met, local authorities have discretionary powers to provide support. Young carers do not need to meet national eligibility criteria and local authorities must only consider their assessment in deciding whether to provide support.

NHS support for carers
The Carers Action Plan 2018-2020 included a commitment for NHS England and the Care Quality Commission to work together in developing standards for GP surgeries. These should be used to show how effective they are in identifying and supporting carers.

The NHS Long Term Plan of January 2019 repeated a commitment to improve how the NHS identifies unpaid carers, and to better address their health needs.

Government policy
In March 2016, the Government launched a call for evidence on what should be included in a planned Carers Strategy for England. However, no Carers Strategy followed. Rather, in June 2018 the Government published a Carers Action Plan 2018–20 which “set out a cross-government programme of work to improve support for carers over the next two years”.

The Government has said that it intends to publish a final evaluation of the Carers Action Plan in 2021, alongside which it will “consider next steps to build on the work initiated through the…Plan.”
When the Government decided not to proceed with the publication of a Carers Strategy it stated that carers would instead be included in a then expected Green Paper on the reform of adult social care. However, the expected Green Paper had not been published by the time of the 2019 general election and the current Government no longer specifically refers to plans for a Green Paper.

The current position on broader reform of adult social care is that the Government is “committed to improving the adult social care system and will bring forward proposals in 2021.” It is not clear what form the proposals will take when published, or if they will include informal carers. Carers UK has called for reforms that “make sure unpaid carers get the practical and financial support they need to care” to be “delivered without any further delays.”

More information on social care reform can be found in the Library briefing CB8001, Reform of adult social care funding: developments since July 2019 (England).

**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.

Publications relating to devolved policy approaches:

- 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)
- Scottish Parliament Information Centre (SPiCe), Scotland Act 2016: Carer’s Allowance and Scottish Government, Unpaid carers
1 Who provides informal care?

The *Family Resources Survey* estimated that in 2019/20 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. The figure represents around 7% of the UK population.

Numbers have fluctuated over the past decade as shown in the chart below. They peaked at 5.6 million in 2012/13 and 5.4 million in 2016/17. The 2017/18 estimate of 4.5 million carers was the lowest recorded since 2007/08 and remained constant in 2018/19 and 2019/20. In each year shown, around 60% of informal carers are women.

The reduction in carer numbers since the peak of 5.6 million in 2012/13 may be due to fewer people providing smaller amounts of care per week. There’s been a slight increase in numbers providing over 50 hours care per week and a decrease among the proportions providing fewer hours of care per week.

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Informal carers

Adults aged 55-64 were most likely to care for others, with younger age groups generally less likely to provide care. 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.

Carers UK and Age UK published a report in April 2015, *Caring into later life*. Using a range of data sources, the report concluded there were 1.2 million informal carers in the UK in 2019/20.

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1. Family Resources Survey 2019/20
2. Carers, *Caring into later life*, April 2015
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. ³

The report also found that although carers were more likely to be female than male, this changed as carers get older, with 59% of carers aged 85 and over being male. ⁴

The report concluded 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. ⁵

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. ⁶

A 2013 report from the Children’s Society ⁷ suggested that young carers might be more prevalent among Black and Minority Ethic (BAME) groups. They found that young carers were 1.5 times more likely to be from BAME groups and twice as likely not to speak English as a first language.

Further information on young carers can be found in section 4.

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³ Carers UK, *Caring into later life*, April 2015., p6
⁴ Ibid., p8
⁵ Ibid., p24
⁶ Ibid.
⁷ Children’s Society, *Hidden from view*, 2013
**Impact of the Covid-19 pandemic**

Since the start of the pandemic, Carers UK estimate that the number of unpaid carers increased by around 4.5 million people. 8 Carers UK published the results of a survey in October 2020 which showed the impact of the pandemic on unpaid carers. 9 The survey found that since the start of the pandemic:

- 81% of carers are providing more care
- 38% of carers said the reason they were providing more care was due to reduced availability of local care and support services
- 78% of carers said the needs of the person they care for had increased, and 51% said this had impacted on their health and wellbeing 10

When asked what steps had been taken to support people who had become unpaid carers during the pandemic, Work and Pensions Minister Justin Tomlinson said:

...we have focussed on ensuring carers do not inadvertently stop receiving Carer’s Allowance because of changes to patterns of care. This includes allowing emotional support to count towards the 35 hours of care being provided by the carer as well as relaxing the rules around breaks in care. These changes aim to support carers whose role, in many cases, became harder due to the need to self-isolate or shield the person they care for. These provisions will be in place until the end of August 2021...

...As well as Carer’s Allowance, carers have access to the full range of social security benefits. For example, carers on Universal Credit can receive around an additional £1,950 a year through the Carer Element. And due to the temporary Covid-19 uplift, around 300,000 carer households receiving Universal Credit benefitted from an additional £1,040 during the 20/21 financial year...

...And very importantly the Department worked closely with the Department of Health and Social Care and NHS England to help identify unpaid carers who were eligible for a Covid vaccine as part of Priority Group 6. As a result, more than half a million carers receiving benefit received a letter inviting them to book an appointment for a vaccine. 11

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8 HC Deb Volume 690, National Carers Strategy, 12 March 2021, c1207; Carers UK, Facts & figures [accessed 25 May 2021]
9 Carers UK carried out an online survey between 11th September and 28th September 2020. A total of 5,904 carers and former carers responded to the survey
10 Carers UK, Caring behind closed doors: six months on, October 2020
11 PQ UIN 6471 [on Carers: Coronavirus], 24 May 2021
2 Carers’ employment, incomes, and earnings

Statistics on employment, incomes, and poverty

Employment

The DWP’s Family Resources Survey reports that over half of adult informal carers were in employment in 2019/20 (including carers aged 65 and over). 36% of carers were working full-time and 17% were working part-time.

24% of carers were retired while 21% were economically inactive (not in work and not looking for work) for other reasons. 

Chart 4

<table>
<thead>
<tr>
<th>Carers by employment status</th>
<th>Adult carers, 2019/20</th>
</tr>
</thead>
<tbody>
<tr>
<td>Full-time employed</td>
<td>Part-time employed</td>
</tr>
<tr>
<td>Carers</td>
<td>36%</td>
</tr>
<tr>
<td>All adults</td>
<td>48%</td>
</tr>
<tr>
<td>Male Carers</td>
<td>47%</td>
</tr>
<tr>
<td>All men</td>
<td>59%</td>
</tr>
<tr>
<td>Female carers</td>
<td>29%</td>
</tr>
<tr>
<td>All women</td>
<td>37%</td>
</tr>
</tbody>
</table>

Source: DWP, Family Resources Survey 2019/20, Table 5.4.
This highlights the challenges faced by those who combine work and caring, and how being an informal carer can affect incomes and increase the risk of poverty.

**Incomes and poverty**

For over half of carers, their main source of income was earnings from employment (57% of carers in 2019/20). State or private pensions were the main source of income for just over a quarter of carers (27%), while around one in eight carers (12%) drew most of their income from other benefits or tax credits.  

Half (50%) of adult carers had weekly disposable income (after taxes and benefits) below £300 per week.  

The Joseph Rowntree Foundation [2020/21 Poverty Report](https://www.jrf.org.uk/assets/documents/2020-21-poverty-report.pdf) estimated that in the UK in 2019/20, more than a quarter (over a million) of carers were living in relative poverty (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).  

Women carers experience higher poverty rates than men: in 2018/19, 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.  

**Impact of the coronavirus pandemic on carers’ incomes**

The Joseph Rowntree Foundation found that the coronavirus pandemic meant rising costs, reduced incomes, and more challenges in the labour market for carers. Disabled people and their carers may have purchased PPE and more cleaning equipment and had to turn to expensive convenience food or rely on taxis to avoid public transport.  

The pandemic has also resulted in an increase in caring responsibilities for 25.5% of people who were already providing care. According to Carers UK, this meant 9% of carers had to give up paid employment and 11% had to reduce their hours. We know that time spent caring also impacts poverty rates: in 2018/19 those who care for 20 hours or more a week were more likely to be in poverty.
Informal carers

Combining paid work with Carer’s Allowance

Carers may experience difficulties trying to combine paid work with caring duties while also satisfying conditions for Carer’s Allowance (covered in more detail in section 3). Carers can find that increases in the National Minimum Wage can push them above the Carer’s Allowance earnings limit.

Carers’ employment rights

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. Employers are only able to refuse a flexible working request on limited grounds identified by statute.

The Taylor Review (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.

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 is only available after 26 weeks of continuous employment.

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. In the Queen’s Speech in December 2019, it said it would “bring forward measures to encourage flexible working.”

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

17 Commons Library Research Briefing, 7 June 2021
made up of various different stakeholders and considers a wide range of issues surrounding flexible work. 25

In 2018, the Task Force was asked to consider a Government proposal to create a duty for employer to advertise jobs that can be done flexible from day one. 26 It is also currently looking at how to support new forms of hybrid working and ad hoc (non-contractual) flexible working.

The Task Force is expected to publish guidance on new forms of flexible working in advance of England entering Step 4 of the coronavirus roadmap. 27 In Step 4, the Government is set to lift the guidance that advises people to work from home where possible. The Task Force previously published guidance for employers on flexible hiring and promoted the Happy to Talk Flexible Working campaign.

In the December 2019 Queen’s Speech, the Government said that, subject to consultation, the Employment Bill would make flexible working the default for all jobs unless employers could show that there was a reason why it could not be flexible. The Bill was not introduced in the 2019-21 parliamentary session and was not included in the May 2021 Queen’s Speech.

Time off for dependants

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 (but not an employee, tenant, lodger or boarder). 28

Discrimination by association

Carers of disabled and elderly people may be protected at work from “discrimination by association”. Discrimination by association occurs where a person is treated less favourably 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

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25 Government and employers unite to kick-start flexible working, CIPD, 14 January 2019
26 New measures to support workers, businesses, and entrepreneurs, Gov.uk, 1 October 2018
27 Government taskforce urges permanent job flexibility for all workers, Guardian [online], 2 May 2021
28 Employment Rights Act 1996 as amended, section 57A
because Ms Battle is associated with a disabled person. It’s against the law to refuse to offer her the job for that reason. 29

**Dedicated employment rights for carers**

The Work and Pensions Committee’s 2018 report 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. 30

In the **Carers Action Plan 2018-2020** (June 2018) the Government announced 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). 31

The Government announced in the December 2019 Queen’s Speech that it would “introduce the entitlement to leave for unpaid carers” as part of the Employment Bill. 32 The Bill was not introduced in the 2019-21 parliamentary session and was not included in the May 2021 Queen’s Speech. 33

In March 2020, the Government launched a **consultation on carer’s leave**. The consultation proposed to create an entitlement to one week of unpaid leave for carers. It sought views on a range of issues, including:

- how carers use existing employment rights
- who should be eligible to take the leave
- what the leave can be taken for
- the process for taking the leave
- the costs and benefits to employers and employees. 34

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30 Work and Pensions Committee, Employment support for carers, HCS81, 9 May 2018, para. 47
31 Department for Health and Social Care, Carers Action Plan 2018-2020, June 2018, para. 2.3.
32 HM Government, Queen’s Speech December 2019: background briefing notes, December 2019
33 HM Government, Queen’s Speech 2021: background briefing notes, 11 May 2021
34 BEIS, Consultation on Carers’ Leave, March 2020
The consultation closed in August 2020. The Government has yet to publish a response but has committed to do so “in due course”. 35

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 workers a right to five days unpaid carers leave each year. The implementation deadline for the Directive is 2 August 2022. The UK is not required to implement the Directive as it is no longer bound by EU law. 36

**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 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. 37

A 2018 survey of carers found that many were struggling to make ends meet, or were in, or had been in, debt because of their caring role. 38

**Employment rights during the coronavirus pandemic**

At various stages during the coronavirus pandemic the Government has advised people who are clinically extremely vulnerable (CEV) to ‘shield’. Public Health England (PHE) has detailed guidance on shielding explaining what activities people who are CEV should and should not be undertaking.

At various points the shielding guidance advised those who were CEV not to go to work, even if they could not work from home. In England, the advice was in force nationally from 22 March to 31 July 2020, from 5 November to 2 December 2020 and from 5 January to 31 March 2021. At other times the

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35 PQ146755 [on Carers: Leave], 1 February 2021
36 See End of the Brexit transition: Workers’ rights, Commons Library Briefing Paper CBP-9099, 22 December 2020
37 Carers UK, Caring & Family Finances Inquiry: Carers struggling with alarming levels of hardship, February 2014
38 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.
Informal carers

guidance was in force for specific areas under local lockdown. The guidance has not been in force anywhere in England since 1 April 2021.

The guidance did not create a legal right to time off work. However, employment law protects employees who refuse to go to work because they reasonably believe there is a serious and imminent danger. Those who were shielding and unable to go to work could also be furloughed under the Coronavirus Job Retention Scheme (CJRS) or claim Statutory Sick Pay (SSP).

The PHE guidance was clear that those living with someone who was shielding could still go to work if they were unable to work from home. However, employment lawyers suggested that people living with someone who was CEV, including carers, might have certain protections under employment law if they refused to go to work. This is because, as explained above, employment law protects employees who refuse to go to work because they reasonably believe that there is a serious and imminent danger to themselves or to others. 39

No new legislation was passed to give carers increased rights to time off during the pandemic. The Advisory, Conciliation and Arbitration Service (Acas) guidance on leave during Covid-19 said that carers would need to rely on the usual rights, such as time off for dependants (discussed above). In March 2020, Business in the Community published guidance on supporting carers during Covid-19. This noted that many workers would have increased caring responsibilities during the pandemic or would have become carers for the first time. It recommended that employers update their carers policies and consider extending rights to time off or flexible working.

When it was first published, the HMRC guidance on eligibility for the CJRS said that employees could be furloughed if they had caring responsibilities resulting from coronavirus. On 5 January 2021, the guidance was updated and now specifically says that employees can be furloughed if they are caring for someone who is vulnerable to Covid-19. However, the decision to furlough is for the employer. 40

For a more detailed overview of these issues, see the Library Briefing, Coronavirus: Returning to work (CBP-8916).

Employment Support for Carers

In the work, health and disability Green Paper (2016) the Government reported that “an estimated 2 million people have given up paid work to care”. It also said that 315,000 of these did not return to work and remained unemployed after their caring role ended. 41

39 Cloisters, Returning to work in the time of coronavirus (Tenth Edition), 5 March 2021, para. 2.27
40 FAQs: Coronavirus Job Retention Scheme, Commons Library Briefing Paper CBP-8880, 8 March 2021
41 DWP/Department for Health (DH), Work, Health and disability green paper: improving lives, 2 November 2016
The Green Paper cited two 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.

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.

This strategy was not published, instead the Government published a Carers action plan in 2018. One of the themes of the action plan was to support carers in employment.

**Carers action plan**

The plan set out various actions to support working carers. These were broken down into three themes:

- **Improve working practices**: Actions for this theme include a benchmarking scheme, the consideration of dedicated employment rights for carers, and working with Business in the Community to share best practice of carer policies and practices.
- **Flexible working**: A flexible working taskforce was announced to tackle issues around flexible working. A new Carers’ Hub was launched to promote best practice.
- **Returning to work**: Actions here include e-learning resources focussed on the skills of carers, returner programmes in the public sector and funding to increase opportunities for returners in the private sector. 42

**Carers leave consultation**

As previously noted, the Government made a commitment to encourage flexible working, and said it would consult on making it the “default position”. It also consulted on proposals to introduce Carer’s Leave, a new employment right to one week’s additional leave for unpaid carers (see p19 for more information). 43

**Institute for Employment Studies project: Carers in Employment**

A series of Carers in Employment pilots were launched in April 2015, to help support them to stay in work or return to paid work alongside their caring responsibilities. 44

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42 DHSC, Carers action plan 2018 to 2020, 5 June 2018, pp16-20
43 PQ 169961, 23 March 2021
44 GEO/DHSC/DWP, Supporting carers to stay in paid employment, 13 February 2015
In January 2018 the Institute for Employment Studies published an evaluation of the Carers in Employment project. This project provided a range of support to carers and evaluated its impact. The support 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 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 said:

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.

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

Those employers who interacted with the project 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.

The review recognised that carer friendly employment includes informal arrangements, such as employers allowing carers extra leave to deal with emergencies, as well as formalised policies, such as a carers register enabling carers to access emergency leave. The review 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:

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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. 48

The review addressed barriers to employment re-engagement. The longer a carer has been disengaged from the labour market, the harder it is to re-engage. Carers have 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. 49

49 Ibid, p15
3 Benefits

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

- **Carer’s Allowance**, currently worth £67.60 a week (2021/22 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 £37.70 a week for 2021/22.
- The **carer element in Universal Credit** (UC), which mirrors the carer premium and is worth £163.73 a month in 2021/22. UC is replacing means-tested benefits for people of working-age.

**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, 50 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 2020 there were 1.3 million Carer’s Allowance claimants in Great Britain. 51 Women comprised 68% of the total.

Only 72% of Carer’s Allowance claimants at November 2020 (937,200) were receiving a payment. The remaining 363,100 claimants met the conditions set out above but were not receiving Carer’s Allowance due to the ‘overlapping benefits’ rule (see below), or other income.

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

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50 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.

51 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.
Between 2003 and 2020 the number of Carer’s Allowance claimants more than doubled, from 609,300 in August 2003 just over 1.3 million by November 2020. The caseload growth was mainly driven by working-age recipients, up from 450,500 in August 2003 to 988,900 by November 2020.

### Carer’s Allowance claimants, Great Britain
#### November 2020

<table>
<thead>
<tr>
<th></th>
<th>Total (a)</th>
<th>of whom: Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total: all ages</td>
<td>1,300,310</td>
<td>406,453</td>
<td>893,854</td>
</tr>
<tr>
<td>of whom: payment status</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Claimant receiving payment</td>
<td>937,213</td>
<td>255,455</td>
<td>681,761</td>
</tr>
<tr>
<td>Entitlement only (b)</td>
<td>363,095</td>
<td>151,002</td>
<td>212,094</td>
</tr>
<tr>
<td>% receiving payment</td>
<td>72%</td>
<td>63%</td>
<td>76%</td>
</tr>
<tr>
<td>Working age</td>
<td>988,876</td>
<td>272,959</td>
<td>715,921</td>
</tr>
<tr>
<td>of whom: payment status</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Claimant receiving payment</td>
<td>925,583</td>
<td>252,322</td>
<td>673,263</td>
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<tr>
<td>Entitlement only (b)</td>
<td>63,289</td>
<td>20,632</td>
<td>42,656</td>
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<tr>
<td>% receiving payment</td>
<td>94%</td>
<td>92%</td>
<td>94%</td>
</tr>
<tr>
<td>Over State Pension age</td>
<td>311,432</td>
<td>133,495</td>
<td>177,936</td>
</tr>
<tr>
<td>of whom: payment status</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Claimant receiving payment</td>
<td>11,631</td>
<td>3,131</td>
<td>8,497</td>
</tr>
<tr>
<td>Entitlement only (b)</td>
<td>299,804</td>
<td>130,366</td>
<td>169,435</td>
</tr>
<tr>
<td>% receiving payment</td>
<td>4%</td>
<td>2%</td>
<td>5%</td>
</tr>
</tbody>
</table>

Notes:

(a) Statistical disclosure control was applied to this table at source 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
Total real expenditure on Carer’s Allowance in Great Britain in 2020/21 is estimated to have been £3.0 billion. At the time of the Budget in March 2021, it was forecast to rise to £3.2 billion in 2021/22, and then to £4.02 billion by 2025/26 (all figures in real terms, at 2021/22 prices).  

There is no firm estimate of the proportion of carers eligible for Carer’s Allowance who take up the benefit. Past research undertaken for the DWP suggested the take-up rate for Carer’s Allowance might be around 65% or above, 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.”

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. It is not a payment for the care they provide or a ‘carer’s wage.’

The weekly rate of Carer’s Allowance (£67.60 for 2021/22) is however lower than most other income replacement benefits; Jobseeker’s Allowance for people aged 25 or over, for example, is currently £74.70 a week. The reasons for paying Carer’s Allowance at a lower rate than other income replacement

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52 DWP, Benefit expenditure and caseload tables: Spring Budget 2021
54 PQ 37081 [on Carer’s Allowance], 23 May 2016.
55 See for example HC Deb 27 March 2007 c1502
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. 56

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 – the section below on Carers’ Allowance and the State Pension 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. 57

**Carer’s Allowance and the State Pension**

Carers reaching State Pension age, and people who become carers after State Pension age, are often aggrieved to discover that Carer’s Allowance cannot be paid in addition to the State Retirement Pension. This is due to the ‘overlapping benefits’ rule. 58 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 contributory Employment and Support Allowance, contribution-based Jobseeker’s Allowance, Maternity 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”. 59 In response to a parliamentary question 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 employment.

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56 See section 3.2 of Commons Library briefing CBP-846, *Carer’s Allowance*
57 See Commons Library briefing CBP-6294, *The Benefit Cap*
58 For further information see CBP-6349, *Carer’s Allowance and the Retirement Pension*
59 National Insurance Advisory Committee, Report on overlapping benefit regulations, HC 36 1948/49
work and the earnings it would yield. The State Pension provides a replacement income in retirement.

…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.  

More information on claiming Carer’s Allowance and the State Pension can be found in the Library briefing CB00846, *Carer’s Allowance*.

In 2021/22, around 290,000 people over State Pension age in Great Britain are expected to satisfy the conditions for Carer’s Allowance, but only around 7,000 will receive the benefit.  

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 2020, 152,200 people on Pension Credit in Great Britain (8.8%) had an underlying entitlement to Carer’s Allowance and so qualified for the Pension Credit carer premium.  

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.” Successive governments have resisted calls to abolish the overlapping benefits rule. In January 2021, the Minister for Pensions, Guy Opperman, said that there were “no plans to reassess this policy.”  

### 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 – a ‘cliff edge’ situation.

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60 PQ 243551 15 April 2019
61 DWP, *Benefit expenditure and caseload tables: Spring Budget 2021*, accessed May 2021
62 DWP *Stat-xplore benefit combinations dataset*, accessed May 2021
63 Independent Age, *You don’t stop the worrying:* The difficulties of caring in later life, June 2015
64 PQ 132969 [on Carer’s Allowance], 15 January 2021.
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 more than 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 and losing their WTC.

From April 2020, the NLW for people aged 25 and over increased to £8.72 an hour – reaching the Government’s target of 60% of median employee earnings. From 1 April 2021, the main NLW rate – which now applies to people aged 23 and over – increased to £8.91 an hour. 65

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. 66

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 67, the Work and Pensions Committee recommended that, in addition to improvements to

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65 See Commons Library briefing CBP-7735, National Minimum Wage Statistics
66 PQ 45321 [on Carers’ Benefits: Living Wage]
67 HC 581 2017-19, 17 May 2018
guidance for carers on the earnings rules and better support for carers who want to work, the DWP should:

- 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. 68 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.” 69

**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 a few cases involved proven fraud. The Department had 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 Investigation into overpayments of Carer’s Allowance. 70 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 allowable expenses can also lead to overpayments. The NAO report said that the Department was reviewing its letters and online guidance, to clarify carers’ obligations.

68 [HC 1463 2017-19](http://www.publications.parliament.uk/pa/cm201719/cmselect/cmhuma/1463/1463.pdf), 31 July 2018
69 Ibid. para 23
70 [HC 2103 2017-19](http://www.publications.parliament.uk/pa/cm201719/cmselect/cmhuma/2103/2103.pdf), 26 April 2019
The Work and Pensions Committee also launched an inquiry and its report on Overpayments of Carer’s Allowance was published in August 2019. 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”.  

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.

The Committee was disappointed the Department had not accepted its recommendation to consider writing off overpayments, particularly where there had been substantial administrative failings by the Department or where its advice to claimants was unclear.

In response to a parliamentary question, the Minister for Disabled People, Health and Work, Justin Tomlinson, said that as of 13 April 2021, 42,400 people were repaying Carer’s Allowance overpayments. The total original

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71  HC 1772 2017-19  
72  Carers saving Treasury £billions every year “set up for a fall” by design of Carer’s Allowance, Work and Pensions Committee press release, 2 August 2019  
73  HC 102 2019, 5 November 2019, paras 14-16  
74  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
value of those debts was just over £138 million, and the total amount outstanding was £89 million. The Minister added:

The Department has a duty to recover overpaid benefits as quickly and efficiently as possible, but it is not intended that the recovery of an overpayment should cause any customer undue financial hardship.

Overpayment recovery of Carer’s Allowance, as with all benefits is subject to various legislative limitations and safeguards. 75

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. 76

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. 77 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 the Government consider lifting the 21 hour rule and reducing education and training fees for Carer’s Allowance recipients. 78 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. 79 No detailed plans were set out before the 2010 General Election; subsequent administrations have not indicated any desire to revisit the 21 hour rule.

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. 80 The Office for

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75 PQ 179232 [on Carer’s Allowance: Overpayments], 19 April 2021.
76 For details see section 3.4 of Commons Library briefing CBP-846, Carer’s Allowance.
77 See for example PQ 219974 [on Carer’s Allowance], 14 January 2015; PQ 12005 [on Carers’ Benefits], 20 October 2015.
80 HM Treasury, Budget 2020, chapter 2.1, 12 March 2020.
Budget Responsibility (OBR) believes it could take a further two years (to September 2026) before full caseload rollout is achieved. 81

Carer’s Allowance will remain outside Universal Credit, and the maximum amount of UC payable is reduced pound for pound by any Carer’s Allowance a person/family receives. If a person satisfies the care conditions for Carer’s Allowance, a ‘carer element’ is included in the calculation of their UC maximum amount. This mirrors the carer premium/addition payable with means-tested benefits, and is worth £163.73 a month (2021/22 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 2021, 337,800 households on Universal Credit in Great Britain had entitlement to the carer element (just under 7% of all households on Universal Credit). 82

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.

**Carer’s Allowance in Scotland**

The Scotland Act 2016 devolved responsibility for disability and carers’ benefits to the Scottish Parliament. 83

The Scottish Government introduced a Carer’s Allowance Supplement backdated to April 2018. It is paid twice yearly (in June and in December) and is broadly equivalent to the difference between the Jobseeker’s Allowance rate for people aged 25 or over and 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.

In October 2020, 83,825 carers in Scotland were identified as eligible for a Carer’s Allowance Supplement payment in December 2020, although it was

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81 OBR, *Economic and Fiscal Outlook*, March 2021, p193
82 DWP Stat-xplore, Households on Universal Credit dataset
83 For further details see Commons Library briefing CBP-9048, *Social security powers in the UK*, 9 November 2020.
expected that the numbers could increase by around 4,000 as further backdated payments were made.\textsuperscript{84}

An additional one-off Carer’s Allowance Supplement payment of £230.10 – on top of the usual payment in June 2020 – was made by the Scottish Government to provide further support for carers during the coronavirus outbreak.\textsuperscript{85}

The Carer’s Allowance Supplement rates payable in June and in December 2021 will be £231.40.

The Scottish Government had planned to take new claims for ‘Scottish Carer’s Assistance’ (replacing both Carer’s Allowance and the Carer’s Allowance Supplements) from early 2022, with existing Carer’s Allowance claimants in Scotland transferring to the new benefit between then and 2025.\textsuperscript{86} Following the coronavirus pandemic, the precise timetable for the introduction of Scottish Carer’s Assistance and other devolved benefits is unclear.\textsuperscript{87} The Scottish Government said it would consult to “to help identify priorities” for Carer’s Assistance.\textsuperscript{88}

In March 2021 the Scottish Government published a discussion paper on “proposed aims for Scottish Carer’s Assistance.”\textsuperscript{89} These are that Scottish Carer’s Assistance:

- is designed to maximise take-up and ensure carers have a positive experience of the social security system;
- provides stability and supports carers to pursue goals outside of caring, where they wish to; and
- recognises the role of unpaid carers, that different carers have different needs, and that different caring situations have different impacts.

The Scottish Government said the discussion paper was “the beginning of a process of engagement to develop the final aims for Scottish Carer’s Assistance”, which will include “discussion events with stakeholders and research with carers, including members of our Experience Panels.”\textsuperscript{90}

\textsuperscript{84} Scottish Government, Carer’s Allowance Supplement, October eligibility date 2020 and Carer’s Allowance, Disability Living Allowance, Attendance Allowance and Severe Disablement Allowance at August 2020: statistics, 23 February 2021
\textsuperscript{85} Scottish Government, Carer’s Allowance Supplement Guide: Coronavirus Carer’s Allowance Supplement, updated 1 April 2021
\textsuperscript{86} Scottish Government, Devolved social security benefits: stakeholder engagement toolkit, updated 21 February 2020
\textsuperscript{87} Scottish Government, Coronavirus (COVID-19) - update on devolved benefits: Cabinet Secretary speech, 1 April 2020
\textsuperscript{88} Scottish Government, Social security policy: Benefits for carers; Scottish Government, Coronavirus (COVID-19): Update on devolved benefits: Cabinet Secretary Speech, 1 April 2020
\textsuperscript{89} Scottish Carer’s Assistance: discussion paper, 19 March 2021. See also the letter from the Scottish Government Cabinet Secretary for Social Security and Older People to the Convenor of the Scottish Parliament Social Security Committee, 17 March 2021
\textsuperscript{90} Ibid.
Coronavirus and carers’ benefits

In response to the coronavirus pandemic, the Department for Work and Pensions introduced a series of temporary changes to the Carer’s Allowance rules. 91 These include allowing continued entitlement to Carer’s Allowance during breaks in care if the carer, or the disabled person they care for, has Covid-19 or is self-isolating because of symptoms. The DWP has also confirmed that providing ‘emotional support’ – including support provided remotely via the telephone or social media – can count towards the 35 hours a week care required for Carer’s Allowance. These ‘easements’ have been extended until the end of August 2021. 92

Some carers will also have benefited from the £20 a week ‘uplift’ to Universal Credit and to Working Tax Credit introduced from April 2020, which is now due to be withdrawn from October 2021. 93 The uplift did not extend to any of the ‘legacy’ benefits Universal Credit is replacing, or to other benefits including Carer’s Allowance.

In an open letter to the Secretary of State for Work and Pensions in July 2020, Carers UK and 91 other organisations said the financial hardship experienced by many carers and their families had been compounded by the coronavirus crisis, with carers on average providing 10 additional hours of care each week and 81% reporting spending more during the outbreak as a result of rising costs and extra demands placed on them. The letter called on the Government to recognise the financial impact Covid-19 had had on people caring by:

- Introducing an additional Carer’s Allowance supplement to match the £20 a week uplift to Universal Credit, with accompanying increases in the carer premium/addition payable with means-tested benefits, and equivalent payments for people with only an underlying entitlement to Carer’s Allowance; and
- Increasing the Carer’s Allowance earnings limit from £128 a week to at least £139.52 for 2020/21, and linking it to increases in the National Living Wage in future years.

Responding to a question in February 2021 about what discussions the DWP had had with the Treasury about the potential merits of a £20 a week supplement for carers entitled to Carer’s Allowance, the Minister, Justin Tomlinson, pointed to the fact that Carer’s Allowance had been increased line with inflation in each year since 2010. 94

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91 See Carers UK, A-Z of changes to benefits, assessments and support – COVID-19, updated 8 April 2021
92 See Commons Library briefing CBP-8973, Coronavirus: Withdrawing crisis social security measures, 30 April 2021
93 See Budget 2021: Social security measures, Commons Library Insight, 9 March 2021
94 PQ 155395 [on Carer’s Allowance], 24 February 2021
Young carers

The NHS describes a young carer as someone under the age of 18, who helps to look after a family member or relative with a disability, illness, mental health condition, or drug or alcohol problem. 95

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, except for Scotland which had a slight decrease (around 400 fewer in 2011). 96

Chart 6

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

Most 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.

95 NHS, Being a young carer: your rights, 22 March 2021
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.

The lives of young carers

The 2015 Conservative Government commissioned research into the lives of young carers in England. The resulting report was published in February 2016.  

Key findings included:

- 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 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 most 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

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97 DfE, The lives of young carers in England, February 2016
their condition to health and social care professionals due to a fear of the potential repercussions for their family.

**Impact of the Covid-19 pandemic**

In July 2020, the Carers Trust published a survey on the impact the coronavirus (Covid-19) pandemic had on young carers (aged 12-17). The survey found:

- Over half of young carers (58%) said their time spent caring had risen since the start of the pandemic. 11% of young carers felt this time had increased by over 30 hours per week.
- 8% of young carers said they had spent over 90 hours a week caring during the pandemic.
- 30% of young carers said they were now caring for more people.
- 40% of young carers said their mental health had been negatively impacted since the start of the pandemic. 98

More information on young carers in education can be found in section 4.5.

**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”. 99 Prior to 1 April 2015, however (when the relevant sections of the Children and Families Act 2014 came into force), there was no legal provision in force specifically for young carers. 100

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 101 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 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

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Survey consisting of 961 responses from young carers (aged 12-17) and young adult carers (aged 18-25) from across the UK.

99 Children Act 1989 as amended, section 17

100 The Carers and Disabled Children Act 2000 defined a carer as someone over 16.

101 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.
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.  

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 to ensure that a young person does not undertake inappropriate caring responsibilities.  

The Carers Trust has published several briefings on the rights of young carers in England.

Department for Education (DfE) research (January 2017) found that fewer than one in five (19%) parents of young carers helping within the household reported that their child had received an assessment of their 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.

In an earlier study for the DfE (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.

Benefits for young carers

The main benefit for carers – Carer’s Allowance – can be claimed from the age of 16, although those in full-time education are excluded from claiming. At November 2020, 3,783 young people under 18 were receiving Carer’s Allowance in Great Britain.

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102 HC Deb 8 October 2013 cc11WS-12WS
103 The Care and Support (Assessment) Regulations 2014 S.I. 2827/2014
104 DfE, The lives of young carers in England omnibus, January 2017, p8
105 DfE, The lives of young carers in England, February 2016, p10
106 DWP, CA: Cases with entitlement [Stat-Explore]
At present, families with young carers may get additional help through the **Severe Disability Premium (SDP)**, worth £67.30 a week (2021/22 rate). SDP is not a benefit as such, but 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-dependants’ residing with the person, but for these purposes anyone under 18, or aged 18-19 and qualifying for Child Benefit, does not count.

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, and there are concerns this could have a disproportionate impact on families with young carers.

Under the new welfare powers devolved by the Scotland Act 2016, the Scottish Government introduced a new ‘**Young Carer Grant**’ in October 2019. This is a single annual payment – now worth £308.15 – 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.

The Scottish Government said the Young Carer Grant would “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.” Between October 2019 and 31 January 2021, over 2,900 Young Parent Grant payments were authorised, totalling £861,634.

**Participation and attainment in education**

The Department for Education (DfE) doesn’t routinely publish data about the education of young carers, but there is some survey and other evidence.

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

- 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.

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107 See section 6.2 of Commons Library briefing SN06548, Draft Universal Credit Regulations 2013
108 Disability Benefits Consortium submission to the House of Lords Secondary Legislation Scrutiny Committee, 2013
109 Scottish Government Position Paper: Support For Carers, 28 February 2019
110 Young Carer Grant pays out more than £860k since launch, Scottish Government press release, 16 March 2021; Scottish Government, Young Carer Grant: high level statistics to 31 January 2021, 16 March 2021
• 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. ¹¹¹

DfE-commissioned research, published in January 2017, collected survey evidence from both young people and their parents. This was carried out 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 were that:

Most parents across both the face to face and comparison surveys reported 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 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. […]

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 these occurrences […] ¹¹²

Impact of the coronavirus pandemic

In July 2020, Carers Trust published the results of a survey of around 1,000 young carers across the UK, looking at the impact of the coronavirus pandemic on different aspects of young carers’ lives. On education, this found:

Notes (both charts): Surveys carried out on 420 parents of young carers, and 304 parents of non-carers between July 2015 and February 2016.
Informal carers

- 24% of young carers, and 23% of young adult carers, said that studying was a coping mechanism.
- 56% of young carers and 39% of young adult carers said their education was suffering.
- 44% of young carers and 30% of young adult carers would like more support with their education.
- 41% of young carers reported not having enough time to spend on schoolwork. ¹¹³

Support in schools

Pupil Premium (England)
The Government has cited research suggesting that around 60 per cent of young carers aged 14-16 were eligible for free school meals (FSM). ¹¹⁴ 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 2021-22 financial year is £1,345 per primary-aged pupil and £955 per secondary-aged pupil. ¹¹⁵

Young Carers in Schools Programme
The young carers in schools programme, run jointly by Carers Trust and The Children’s Society, works with schools across England and Wales 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.

Other parts of the UK
Information about support for young carers in schools in Scotland and Northern Ireland can be found online:

- NI Direct website article, ‘Young carers – support at school’, undated.

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

¹¹³ Carers Trust, ‘My future, my feelings, my family’, July 2020, p11.
¹¹⁴ PQ 243309 [on Young People: Carers], 23 April 2019
Informal carers

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. 116

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

- 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”. 117 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 2021-22 the maximum amount will be £3,190.

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. 118

The Office for Students has also published guidance on carers.

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), Student carers/ Living costs grant, undated.

117 See: PQ 20664 [on Carers: young people], 17 December 2015
Informal carers

- Student Finance Wales, [Adult Dependants’ Grants (2021-22)]
- Student Finance Northern Ireland’s [collection on undergraduate support].
5 Carers’ health and wellbeing

Analysis of the 2011 Census, widely cited by the Government and carers’ organisations, found 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.\(^{119}\)

Similarly, the most recent Carers UK survey, State of Caring 2019, found that caring responsibilities continued to impact on individual carer’s health. It found that carers who care for more than 50 hours a week reported poorer health with 25% reporting bad or very bad physical health and 29% reporting bad or very bad mental health.\(^{120}\) The survey also found that carers:

- who have been caring for over 15 years were more likely to report poorer health with 28% describing their physical health as bad or very bad and 27% describing their mental health as bad or very bad;
- looking after disabled children under the age of 18 reported significantly poorer mental health – 36% described their mental health as bad or very bad. 26% of these carers described their physical health as bad or very bad;
- are seven times more likely to say they are always or often lonely compared with the general population. Carers in the UK reported levels of happiness over a third (37%) lower than the general population. Overall, 8 in 10 (81%) of all carers reported having ever felt lonely or isolated as a result of their caring role.\(^{121}\)

The previous year’s survey (2018) found that across the UK, 72% of carers said they had experienced mental ill health as a result of their caring responsibilities and 61% said they’d experienced physical ill health.\(^{122}\)

As a result, in 2019 Carers UK called for:

...a new duty on the NHS to put in place policies to identify carers and to promote their wellbeing.\(^{123}\)

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\(^{119}\) DH et al. Supporting the health and wellbeing of adult carers. (2014)

\(^{120}\) Carers UK, State of Caring 2019, July 2019, p21

\(^{121}\) Carers UK, State of Caring 2019, July 2019, p21-2

\(^{122}\) Carers UK, State of Caring 2018, July 2018, p6

\(^{123}\) Carers UK, State of Caring 2019, July 2019, p26
The charity added that it was “regrettable that carers are currently omitted from the Green Paper on Prevention” published in 2019. It has called on the Government to ensure that carers’ breaks provision be “at the heart of the health and social care system in the short and longer term” and be “part of a core strategy to prevent loneliness and social isolation”.

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.

The Government (2017 emphasised the importance of integrated care as a way to better meet carers’ health and wellbeing needs:

> 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.

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. 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.

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.
Access to health services

Problems faced by carers in accessing health services

Carers’ organisations have raised concerns about difficulties faced by carers accessing health and social services for themselves, and for the people they care for. NHS England has 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. 132

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. 133

The charity/support group says 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 to identify carers as well as promote additional support in hospitals for carers, such as discounted or free parking. 134

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. 135

In May 2014 NHS England also published its Commitment to Carers, setting out the recognition and support they need. 136 It included 37 commitments spread across eight key 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

133 Carers UK, Pressure Points: carers and the NHS, September 2016
134 Carers UK, Carer Passports, March 2016
135 NHS England and partner organisations, NHS Five Year Forward View, October 2014, p13
136 NHS England’s Commitment to Carers, April 2014
Informal 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. A non-mandatory framework of quality markers was published in June 2019.

Further information on the Carers Action Plan is available in section 7.

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. This included a commitment to “encourage the national adoption of carer’s passports” and quality marks for carer-friendly GP practices to help carers identify GP services that can accommodate their needs.

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.

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 these issues are avoided by a patient giving consent for their private information to be shared. However, staff may need to decide 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.

137 DHSC, Carers Action Plan 2018-2020: Supporting carers today, June 2018
139 NHS England, NHS Long Term Plan, January 2019, para 2.33
Informal carers

- 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.\(^{140}\)

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.\(^{141}\)

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)”.\(^{142}\)

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\(^{140}\) 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

\(^{141}\) 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).

\(^{142}\) NICE, Supporting adult carers, January 2020, para 1.1.12
Local authority support for carers

Local authority carer’s assessments

Under section 10 of the Care Act 2014, where a carer in England appears to have a need for support, either now or in the future, the local authority must conduct a carer’s assessment. This applies to any adult providing care for another adult (see section below for information on adult/parent carers of disabled children).

Among other things, the carer’s assessment must look at the impact of the carer’s support needs on their ability to provide care. It must also assess what the carer wishes to achieve in day-to-day life, and the extent to which the provision of support could contribute to the achievement of these outcomes. 143

Where a carer’s support needs meet prescribed national eligibility criteria, set out in the Care and Support (Eligibility Criteria) Regulations 2015, the local authority has a duty to meet those needs. Under the regulations, a carer meets the national eligibility criteria if:

1. Their needs arise as a consequence of providing necessary care for an adult.
2. As a result of their needs, the carer’s physical or mental health is at risk of deteriorating, or they are unable to achieve any of a number of outcomes specified in the regulations (for example, they are unable to carry out caring responsibilities they have for a child, or they are unable to engage in work, training, education or volunteering).
3. As a consequence, there is, or there is likely to be, a significant impact on their wellbeing. 144

A carer’s needs are only eligible where they meet all three of these conditions.

Authorities have a power, but not a duty, to meet needs where they do not meet the national eligibility criteria.

Further information on the eligibility criteria is available in paragraphs 6.116 to 6.134 of the care and support statutory guidance, published by the Department of Health and Social Care. 145

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143 Care Act 2014, section 10.
144 The Care and Support (Eligibility Criteria) Regulations 2015, SI2015/313, regulation 3.
Where a local authority is required or decides to meet a carer’s needs, it must prepare a care and support plan setting out how those needs are going to be met. If the authority wishes to charge a carer for meeting their needs (whether eligible or not) it must carry out a financial assessment of what they can afford to pay.  

Further detail is available in Library briefing CBP01911, Social care: paying for care home places and domiciliary care (England).

Someone providing care as an employee under any form of contract or as a volunteer for a voluntary organisation is not entitled to a carer’s assessment.  

Further information is available in a factsheet published by Carers UK: Assessments - Your guide to getting help and support in England.

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?

**Respite care**

One way that a local authority may meet a carer’s support needs is through the provision of respite care. As set out above, a local authority is under a duty to meet a carer’s support needs where, among other things, they are unable to achieve any of a number of specified outcomes. This includes being unable to:

- develop and maintain family or other personal relationships
- engage in work, training, education or volunteering
- make use of necessary facilities or services in the local community including recreational facilities or services
- engage in recreational activities

Respite care allows a carer to take a break from caring, while the person they care for is looked after by someone else. There are several respite care options, including, for example, a short stay in a care home or having a volunteer sit with the person for a few hours.

Further information on respite care is available via the following links:

- Age UK, Respite care: having a break from caring
- Carers UK, Taking a break

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146 Care Act 2014, sections, 17 & 24-25.
147 Care Act 2014, section 10(9).
149 NHS, Carers’ breaks and respite care, last accessed 24 May 2021.
Parent carers of disabled children

Under section 17 of the Children Act 1989, local authorities have a general duty “to safeguard and promote the welfare of children within their area who are in need…by providing a range and level of services appropriate to those children’s needs.” 150 Disabled children are included within the definition of children in need.

The Act specifies the range of services that can be made available for a child in need. These include (but are not limited to):

• Occupational, social, cultural, or recreational activities.
• Home help (which may include laundry facilities).
• Assistance to enable the child and their family to have a holiday.
• Assistance in kind or in cash. 151

Any of the services listed in the Act (except day care or care or supervised activities) may also be provided to any member of the child in need’s family, “if it is provided with a view to safeguarding or promoting the child’s welfare” 152

Local authorities may charge what they consider reasonable for providing services to a child in need and their family (but not for advice, guidance or counselling). Local authorities are not, however, under a duty to charge for services and they may not charge more than a person can “reasonably be expected to pay” 153

Further information is available in Library briefing CBP07730, Local authority support for children in need (England).

Parent carer’s needs assessments

If a local authority considers that a parent carer of a disabled child may have support needs, they must carry out a “parent carer’s needs assessment” under section 17ZD of the Children Act 1989. Such an assessment must also be carried out if the parent carer requests one. The duty to carry out an assessment only applies where the local authority is satisfied that the child and their family are classed as in need under section 17 of the 1989 Act (see above). 154

Following an assessment, the local authority must decide whether the parent has needs for support and, if so, whether these needs could be met by services under section 17 of the Children Act 1989.

150 Children Act 1989, section 17.
151 Children Act 1989, section 17 and schedule 2.
152 Children Act 1989, section 17(3).
153 Children Act 1989, section 29.
154 Children Act 1989, section 17ZD.
Informal carers

Carers of disabled children who do not have parental responsibility for the child do not have a right to an assessment under the Children Act 1989. However, they can request an assessment under section 1 of the Carers (Recognition and Services) Act 1995. However, such carers have to show that they are providing, or intend to provide, “a substantial amount of care on a regular basis.”

Further information is available via the following charity factsheets:

- Contact, Carers assessments – help for parent carers
- Carers UK, Assessments: Your guide to getting help and support in England

**Short breaks**

Under Schedule 2 of the Children Act 1989, local authorities are required to provide services designed, among other things, to “assist individuals who provide care for [disabled] children to continue to do so, or to do so more effectively, by giving them breaks from caring”. Under The Breaks for Carers of Disabled Children Regulations 2011, local authorities must produce a short breaks services statement setting out these services and the eligibility criteria for accessing them.

Further information is available in guidance published by the Department for Education: Short break care: how local authorities should provide it.

**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. The fund was intended to provide £5 million over 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.

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156 Children Act 1989, Schedule 2, paragraph 6.
158 Department for Education, Short break care: how local authorities should provide it, 24 March 2011.
In July 2020, Carers UK reported that the fund had been suspended. It added that the Government intended “to use the budget to support carers via other means in due course.”  

161 Carers UK, Carers Innovation Fund suspended, 10 July 2020.
Past and future Government policy

A National Carers Strategy and the Carers Action Plan

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. 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. In it, the DHSC said it had received “an overwhelming response; 6,802 people and organisations took the time to give us their views, experiences and suggestions”. In addition, five focus group events were held around the country during 2016.

Six topics were subject to consultation:

- **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”;

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162 Department of Health, *How can we improve support for carers?*, 18 March 2016
163 Ibid.
164 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
Informal 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”;
- **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”. 165

**Dropping the proposed Carers Strategy**

Although the consultation closed in July 2016, no Carers Strategy was forthcoming and in June 2018 the Government confirmed that it would not publish a Carers Strategy. Instead, the Government said that carers would be included in a proposed Green Paper on social care (see below), 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”. 166

**Carers Action Plan 2018–2020**

In June 2018 the Government published a Carers Action Plan 2018–20 which “set out a cross-government programme of work to improve support for carers over the next two years”.

The introduction said:

> 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

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planned or already underway across government to support carers, their families and those they care for. 167

A summary was provided by the then-Minister for Care, Caroline Dinenage:

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.

[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. 168

The Government published a 1-year progress review in July 2019. This said that in addition to the projects already committed to, in 2019/20 the Government would:

• Commission survey data on experiences of carers in England through with the DSHC and NHS Digital;

168 HCWS732 5 June 2018
Informal carers

- 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. 169

The Government has said it plans to publish a final evaluation of the Carers Action Plan in 2021, alongside which it will “consider next steps to build on the work initiated through the...Plan.” 170

**Commons debate on a national carers strategy (March 2021)**

An adjournment debate on a national carers strategy was held in the Commons chamber on 12 March 2021. Opening the debate, Barbara Keeley noted that the Government had “so far declined to publish a national carers strategy, instead bringing in a carers action plan”, which she argued was a “flimsy document” which “offers few substantial commitments to improve support to carers and lacks the funding needed to transform services.”

Highlighting that the carers action plan expired at the end of 2020, Barbara Keeley hoped the Minister for Mental Health, Suicide Prevention and Patient Safety, Nadine Dorries, “will be able to confirm today that officials are working on a new strategy to give carers the support they need.” 171

In response, Nadine Dorries, said that “good progress has been made towards fulfilling the commitments set out in the [carers action plan].” The Minister did not, however, refer to any plans for a national carers strategy and instead highlighted plans to bring forward proposals for reform of adult social care by the end of 2021 (see below). She added:

> We recognise unpaid carers as a key part of our health and social care system and as part of ensuring the best outcomes for those they care for. That includes a wide range of people with different conditions and circumstances. We look forward to continuing to work with carer organisations and stakeholders across the Toggle showing location of public sector to help unpaid carers to gain access to the support that they are entitled to but often do not claim, and to build on the pandemic response.

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170 PQ 127617 [Carers], 17 December 2020.
171 HC Deb 12 March 2021 [National Carers Strategy], cc1207-8.
Ensuring support for carers does not rely on one Department or on Government alone. We will continue to work with the public sector and carer organisations and across Government to understand the needs of unpaid carers and how best to support them to care as they would wish to care, balancing their caring role with their own health and wellbeing.  

Reform of adult social care

As noted above, a planned, standalone, national carers strategy was dropped in preference to including the carers’ issues in a Green Paper on social care reform.

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.

However, the expected Green Paper on adult social care reform had not been published by the time of the 2019 general election and the current Government no longer specifically refers to plans for a Green Paper.

Rather, the current position, as most recently set out in background briefing notes to the 2021 Queen’s Speech, is that the Government is “committed to improving the adult social care system and will bring forward proposals in 2021.” It is not clear what form the proposals will take when published, or if they will include informal carers.

Further information is available in the Library Briefing: Reform of adult social care funding: developments since July 2019 (England).

Carers’ benefits

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

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172 HC Deb 12 March 2021 [National Carers Strategy], cc1212-4.
173 PQ 196242 5 December 2018
174 Prime Minister’s Office, Queen’s Speech 2021: background briefing notes, 11 May 2021.
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. ¹⁷⁵

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. ¹⁷⁶ 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. ¹⁷⁷

Further information on ongoing debates about reforming carers’ benefits can be found in section 7 of Commons Library briefing CBP-0846, Carer’s Allowance. ¹⁷⁸

¹⁷⁵ See for example Carers UK and Age UK, Walking the tightrope: The challenges of combining work and care in later life, 15 July 2016
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