

Carers' health and experiences of primary care

Data from the 2021 GP Patient Survey



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Introduction



72%

of carers have not had any breaks throughout the pandemic

The census in 2011 found there were 6.5 million carers in the UK¹ but this number is likely to have increased as the population ages and the recent impact of the COVID-19 pandemic.²

Carers UK estimated there were as many as 13.6 million carers at the height of the pandemic.³

Carers have been significantly impacted by the pandemic with many local organisations having to close or reduce their services and the needs of the person they care for have increased for many.⁴ Almost three-quarters (72%) of carers have not had any breaks throughout the pandemic and even more (74%) are exhausted as a result of caring.⁵

The impact of caring on someone's physical and mental health has been well documented. Carers UK's own research has shown that caring impacts on carers' health and wellbeing, with almost three-quarters (72%) of carers experiencing mental ill health such as stress or depression as a result of caring, and well over half (61%) saying their physical health had worsened as a result of caring.⁶ To what extent caring impacts on someone's health is likely compounded by many factors, such as being from a marginalised group or providing more than 50 hours of care each week.

The **GP Patient Survey** is an independent survey run on behalf of NHS England which asks questions about people's experiences of their GP practice and their general health. By looking specifically at the data for carers, we learnt more about their experiences of healthcare over the pandemic and how caring may be impacting people's health and wellbeing.

- 1 Office for National Statistics (2011) Census Data
- 2 Carers UK (2020) *Carers Week 2020 Research Report: The rise in the number of unpaid carers during the coronavirus (COVID-19) outbreak*
- 3 Ibid
- 4 Carers UK (2020) *Caring Behind Closed Doors*
- 5 Carers UK (2021) *Breaks or Breakdown*
- 6 Carers UK (2019) *Facts about Carers 2019*

In this paper, we explore which groups of carers have poorer health and wellbeing than others and take a look at how caring may be impacting specific marginalised groups.

With an increase in the number of people caring and pressures on health and social care services as a result of the pandemic and funding shortages, it is imperative to understand more about the impact of caring on the health of carers and their experiences of primary care.



18%

of survey respondents had some caring responsibilities

Breakdown of respondents

Overall, there were approximately 850,000 respondents to the 2021 GP Patient Survey and almost 150,000 of these were unpaid carers, which equates to almost 1 in 5 (18%) respondents having some caring responsibilities.

The breakdown of these carers is broadly representative of carers and the UK population and can be seen in the table in the appendix.

However, there are a few notes regarding the analysis. The ethnic breakdown of respondents is derived from the GP patient survey data, and it is not possible to disaggregate the groups any further than we have done so here. In addition, the GP Patient Survey does not ask a question that allows us to identify transgender carers. Therefore, we are only able to present data on carers who are lesbian, gay or bisexual. Carers UK is committed to research that involves transgender carers and distinguishes more fully based on ethnicity. We will be conducting more research with both lesbian, gay and bisexual carers and Black, Asian and Minority Ethnic carers throughout our Making Carers Count project. Finally, some of the percentages do not add up to 100 due to respondents selecting “prefer not to say” or declining to answer.

Physical health



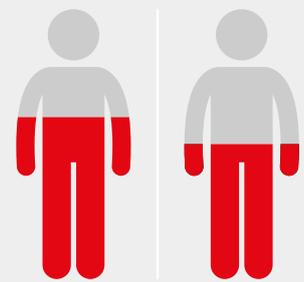
Long-term conditions and disability

The 2021 GP patient survey found that carers are more likely to be in poor health, with 6 in 10 (60%) of carers surveyed stating they had a long-term condition, disability or illness compared to half (50%) of those who weren't caring. Of these carers, almost two-thirds (64%) report that this condition reduces their ability to carry out day-to-day activities. The number of carers with long term conditions has stayed relatively stable since 2018, when 61% of carers reported a long-term condition.

The conditions that carers were most likely to have were arthritis or ongoing back or joint problems (21%) and high blood pressure (17%), both of which may be affected by the stress and physical demands of caring. Indeed, carers were far more likely to have either of these conditions than those who aren't caring, who reported these conditions at 16% and 15% respectively.

Long-term conditions are a significant contributor to poor quality of life and are one of many aspects of health that affect certain groups far more than others, known as health inequalities.⁷ The COVID-19 pandemic has brought into sharp relief the impact of health inequalities, with Black people more than four times as likely to die from COVID-19 than White people.⁸ Understanding how health inequalities affect carers, particularly carers from marginalised groups, will be key to ensuring an equal recovery from the effects of the pandemic.

As expected, certain groups of carers are more likely to have a long-term condition, disability, or illness. In particular, the more caring you do, the more likely you are to be in poor health. Over two-thirds (69%) of those providing more than 50 hours a week have a long-term condition, compared to 58% of those providing less than 35 hours.



60%

of carers reported having a long-term physical or mental health condition, compared to **50%** of those who weren't caring

⁷ The King's Fund (2020) *What are health inequalities?*

⁸ The Health Foundation (2020) *Emerging findings on the impact of COVID-19 on black and minority ethnic people*

In the 2011 census, 1.4 million people were providing 50 or more hours of unpaid care each week. This number is likely to have grown to include even more carers, all of whom have an increased risk of having a long-term condition, disability, or illness.

Older and retired carers were also most likely to have a long-term condition at 79% and 76% respectively. However, younger carers (under 25) and carers who are not in work are markedly more likely to state that these conditions affect their day-to-day activities, at 78% and 80% respectively, suggesting that even though these groups are less likely to have a long-term condition, the effects of these conditions have a far greater impact on their lives.

Contrary to other research, White carers were the most likely to have a long-term condition (62%) followed by carers from a Mixed ethnic background (55%) and Black carers (53%). However, carers aged 55-64 from ethnicities other than white were more likely to have a long term condition. Almost three-quarters (74%) of carers from Other ethnic backgrounds⁹ reported an impact on their day-to-day activities compared to 69% of carers from a Mixed ethnic background, 68% of Asian carers, 63% of White carers and 59% of Black carers.

7 in 10 (70%) lesbian, gay and bisexual carers reported a long-term health condition or disability compared to 60% of straight carers. Three-quarters (75%) of lesbian, gay and bisexual carers reporting a long-term condition stated that it affected their day-to-day life compared to 62% of straight carers.

Physical mobility

Carers were more likely to report having problems with their physical mobility, with 14% of carers identifying this as a problem over the last 12 months compared to 11% of those who aren't caring. This has stayed relatively stable since 2018, at 14% of carers in 2018 and 15% in 2019 and 2020.

The percentage of carers reporting problems with their physical mobility increases with age from 8% of under-25s to 20% of those over 65, and carers who weren't working were also more likely to report problems with physical mobility than both retired carers and carers in work. 23% of carers not in work had problems with their physical mobility, compared to 18% of retired carers and 9% of working carers.

Unlike other markers of health, problems with physical mobility were broadly similar regardless of ethnicity and ranged from 12% of Asian carers to 15% of Black carers. Finally, lesbian, gay and bisexual carers (17%) were more likely to have problems with their physical mobility than straight carers (13%).



69%

of carers providing more than 50 hours of care a week have a long-term health condition, illness or disability

Percentage of carers who said their long-term conditions affected their ability to carry out their usual day-to-day activities, by ethnicity:

Black	59%
White	63%
Asian	68%
Mixed	69%

⁹ The GP Patient Survey groups those who do not identify as being from a White, Black, Asian or Mixed ethnic group into the "Other" category for data analysis purposes

Mental health and wellbeing



The percentage of carers reporting a long-term mental health condition has been steadily increasing from **11%** in 2018 to **14%** in 2021

Mental health conditions

14% of carers reported having a long-term mental health condition, compared to 10% of those who aren't caring. This number changes dramatically depending on other factors, many of which reflect wider trends in mental health. The percentage of carers reporting a long-term mental health condition has been steadily increasing from 11% in 2018 to 13% in 2020. While some of this can be explained by the general increase in people reporting mental health problems, some can also be attributed to the pandemic as there is widespread evidence that mental health has worsened substantially due to the coronavirus pandemic.¹⁰

Over a quarter (26%) of carers under the age of 25 had a mental health condition, compared to just 5% of carers over 65. This reflects existing research that suggests caring at a young age can impact many aspects of someone's life, including their health, wellbeing and education.¹¹ With such high numbers of younger carers reporting a long-term mental health condition, adequate and timely support is vital. Carers who weren't working were also more likely to have a mental health condition than those who were in work or retired. Over a quarter (27%) of carers not in work declared they had a mental health condition compared to 12% of working carers and just 5% of retired carers.

¹⁰ The Health Foundation (2020) *Emerging Evidence on COVID-19's impact on mental health and health inequalities*

¹¹ Joseph, Sempik, Leu & Becker (2020) *Young Carers Research, Practice and Policy: An Overview and Critical Perspective on Possible Future Directions*

Over a third (36%) of lesbian, gay and bisexual carers had a mental health condition compared to 13% of heterosexual carers, making them almost three times as likely to be experiencing a long-term mental health condition. This aligns with existing research that suggests lesbian, gay and bisexual people are more likely to have poor mental health than their heterosexual counterparts.¹²

Carers from a Mixed ethnic background and White carers were the most likely to report a long-term mental health condition at 18% and 15% respectively. This does not reflect other research which suggests that Black, Asian and other Minority Ethnic communities have higher rates of mental illness.¹³ However, these communities are also the least likely to access mental health support through primary care,¹⁴ which may account for the low numbers seen in this survey.

Feelings of isolation

Feeling lonely or isolated is a common experience for carers, with 8 out of 10 (81%) carers reporting feeling lonely or socially isolated as a result of their caring role in Carers UK's State of Caring Survey, which includes carers who are providing significant amounts of care.¹⁵

When asked about the last twelve months, 18% of carers in this survey reported feeling isolated compared to 14% of those who weren't caring. The much lower number here may be due to the difference in language, with carers more likely to agree if they are asked if they are lonely, rather than isolated. It may also be due to the fact that Carers UK's State of Caring survey tends to capture the experiences of people who are providing significant amounts of care.



36%

of lesbian, gay and bisexual carers had a mental health condition compared to **13%** of heterosexual carers



35%

of lesbian, gay and bisexual carers feel lonely or isolated compared to **17%** of heterosexual carers

¹² Stonewall, *LGBT In Britain – Health*

¹³ Race Equality Foundation, *Racial Disparities in Mental Health: Literature and Evidence Review*

¹⁴ Race Equality Foundation, *Racial Disparities in Mental Health: Literature and Evidence Review*

¹⁵ Carers UK (2019) *Facts About Carers 2019*

As expected due to the pandemic, the percentage of carers reporting feeling isolated was strikingly higher than in previous years at just 8% in 2019 and 9% in 2020. This reflects other research that found around a million more people became chronically lonely (identifying as “often” or “always” feeling lonely) throughout the pandemic.¹⁶

The feeling of isolation was markedly higher for some groups of carers than others. Almost a third (32%) of young carers aged under 25 reported feeling isolated over the last twelve months, compared to 12% of carers aged over 65, making them almost three times as likely to feel isolated. Similarly, over a third (35%) of lesbian, gay and bisexual carers have felt isolated, compared to 17% of straight carers. In terms of ethnicity, carers with a Mixed ethnic background were much more likely to report feeling isolated compared to other ethnic groups. The impact of isolation on health is wide-reaching, including increased risks of death, cognitive decline, dementia, coronary heart disease and stroke.¹⁷

For these groups of carers who are more likely to feel isolated, the effect on their health cannot be underestimated.

Primary care and mental health

The survey also asked if the healthcare professional they saw recognised and/or understood any mental health needs that they might have. There was a mixed response from carers in how understanding they rated the healthcare professional. 85% of heterosexual carers said yes compared to 79% of lesbian, gay and bisexual carers. White carers were also more likely to say yes, with 86% agreeing compared to 76% of Asian carers, 78% of Black carers, 79% of carers from Mixed ethnic groups and 77% of carers from any other ethnic group. This is concerning as it indicates that marginalised carers, who are more likely to experience a mental health condition, do not feel as understood by primary care when discussing their mental health.



The percentage of carers feeling isolated doubled from 2020 to 2021



26%
of carers under 25 have a mental health condition compared to **15%** of those under 25 who aren't caring

¹⁶ Campaign to End Loneliness (2021) *Loneliness beyond COVID-19: Learning the lessons of the pandemic for a less lonely future*

¹⁷ Campaign to End Loneliness (no date) *The Facts on Loneliness*

Satisfaction with GP services



1 in 10

carers rated their experience with their local GP service as poor or very poor, compared to **1 in 16** of non-carers

The GP patient survey asks people how satisfied they were with their GP service overall, as well as how good the healthcare professional they most recently saw was at giving them enough time, listening to them and treating them with care and concern.

When reflecting on their most recent appointment, there was minimal difference between carers and non-carers. There were also similar responses amongst carers, regardless of how much care they provided and their current working status. However, younger carers consistently rated the healthcare professional lower than other age groups and only 79% of under-25s said the professional was good or very good at treating them with care and concern, compared to 91% of over-65s.

When asked about their overall satisfaction with their local GP service, almost 1 in 10 (9%) carers rated their experience as poor or very poor, compared to 6% of those who aren't caring. This number is steadily increasing from 7% of carers rating their GP practice as very or fairly poor in 2018 and 8% in both 2019 and 2020. This number was also higher for particular groups of carers with 12% of carers aged under-25 and 11% of lesbian, gay and bisexual carers rating their overall experience as fairly or very poor. White and Black carers were most satisfied with their overall experience and Asian carers were least satisfied with 13% rating it as fairly or very poor.

Impact of shielding



51%

of carers they had avoided making an appointment compared to **40%** of those who weren't caring

In order to understand the impact of COVID-19 on people's experiences of their local GP, the survey asked if they had been shielding and if they had avoided making a GP appointment for any reason. Almost 4 in 10 (38%) carers had been shielding, compared to 23% of people who weren't caring. Carers were also more likely to have avoided the GP, with over half (51%) saying they had avoided making an appointment compared to 40% of those who weren't caring.

Some groups of carers were more likely to report they had been shielding, broadly reflecting those who were most at risk from COVID-19. The groups most likely to have been shielding were carers who provided more than 50 hours of care a week (60%), older carers (52%), carers not in work (49%) and retired carers (47%). Asian carers were also more likely to shield, with almost half (46%) reporting that they had been shielding compared to between 37-39% of carers from all other ethnic groups.

Carers who had avoided making a GP appointment were not always those who had been shielding. 61% of carers under 25 hadn't made an appointment, compared to only 42% of the over-65s. Similarly, 60% of lesbian, gay and bisexual carers and 58% of carers not in work reported avoiding making a GP appointment. Asian carers and carers from Mixed ethnicities were also the most likely to have avoided making a GP appointment, with 61% of carers from both groups stating they had avoided the GP.

Percentage of carers who avoided making a GP appointment during the COVID-19 pandemic, by ethnicity:

White	50%
Black	52%
Asian	61%
Mixed	61%

Conclusion and recommendations

The NHS depends heavily on the role and input of those who care for people with long term conditions and disabilities in the community.



Before the pandemic, carers saved the economy around £132 billion each year¹⁸ and this rose to £193 billion during the pandemic, currently outstripping what is spent on the NHS in England.¹⁹

Despite this, the findings in this paper show that caring negatively impacts on carers' health and wellbeing, and that a variety of factors results in some carers being more impacted than others. Carers should not have their health negatively impacted as a result of caring, and should be supported by healthcare professionals to manage their own health and the health of the person they care for.

We believe there are steps the NHS and Government should take to support carers to do this.

¹⁸ Carers UK (2020) *Unseen and undervalued: The value of unpaid care provided to date during the COVID-19 pandemic*

¹⁹ Carers UK (2019) *Facts about Carers 2019*

Recommendations

The GP Patient Survey should continue to run and include caring as a question

The GP Patient Survey should be used to improve knowledge of health inequalities of marginalised groups. We would encourage the NHS and local authorities to particularly look at the data marginalized groups such as carers from ethnic minorities, lesbian, gay and bisexual, young and disabled carers. We would also encourage NHS England to ensure that the the data nationally can be broken down further by specific ethnic minority groups.

Carers need to be included as part of programmes to combat health inequalities

As caring has been identified by Public Health England as a social determinant of health, caring must be part of this agenda.

NHS Digital Health and Care Strategy to ensure carer data markers are clear and easy to use

If data markers are clearly evident in patient related data, it will be easier for the system to track carers' experiences and identify inequalities. This data-driven approach will inform efforts to tackle inequalities and improve carers' health and wellbeing.

Develop national and local public health strategies to support carers

Caring has been identified as a social determinant of health. This, coupled with increasing evidence that certain groups of carers are particularly affected, means that local health and wellbeing strategies need to have specific actions to support carers.

The government should introduce a duty on the NHS to have regard to carers and to promote their health and wellbeing

Carers are still not routinely identified or supported by health and social care professionals. Greater consistency is needed in connecting carers to the support available to look after their own mental and physical health and wellbeing. A duty on the NHS in England to have regard to carers and promote their health and wellbeing should be introduced to bring a more systematic approach to carers' health.

GP Practices should identify carers quickly and make services as accessible as possible

GP practices need to accelerate their identification of carers, particularly those new to caring. GP practices should be supported to identify carers earlier in their caring journey and to have conversations with them about the support available to help them look after their own health and wellbeing. The government should look actively at measures to increase the speed and rate of carer identification by GP practices. In addition, if the NHS England Quality Marker ambitions set out in the Long Term Plan are delivered, this can help to improve carers' experience of services and reduce inequalities.

The government should accelerate their plan for social care reform and ensure there is adequate funding for social care now

The government should recognise the amount of pressure the system has been under during the pandemic, and the funding shortages that were widely recognised for many years before the crisis. While we welcome the government's commitment to social care reform, for many carers 2023 will be too late and we urge the government to accelerate plans and funding. Greater investment in care will lead to a healthier and happier population better able to balance important aspects of their lives, including personal relationships, work and family.

Appendix

Table of respondents

Gender	
Female	58%
Male	42%
Age	
Under 25	6%
Aged 25 – 64	73%
Over 65	21%
Ethnicity	
White British	81%
Any Other White Ethnic Group	5%
Any Asian Ethnicity	8%
Any Black Ethnicity	3%
Any Mixed Ethnicity	2%
Any Other Ethnic Group	2%
Sexual orientation	
Heterosexual/straight	91%
Gay or lesbian	2%
Bisexual	2%
Other	1%
Employment	
Full or part-time work	56%
Full-time education	3%
Retired	20%
Not in work for any other reason	17%
Other	4%
Religion	
No Religion	32%
Buddhist	1%
Christian	54%
Hindu	2%
Jewish	1%
Muslim	5%
Sikh	1%
Other	2%

Methodology

The survey results were analysed using NHS England's GP Patient Survey analysis tool and carers were defined as those who had answered "Yes" to Q56 below regardless of the number of hours per week they had selected.

"Do you look after, or give any help or support to, family members, friends neighbours or others because of either: long-term physical or mental ill health / disability, or problems related to old age?"

Demographic breakdown was done based on answers to Q51, Q53, Q54, Q55 and Q60 which asked about gender, ethnicity, age, working status and sexual orientation, respectively.

Their answers to the following sections were analysed:

- Your last appointment
- Overall experience
- Your health.

About this project

Carers UK, in partnership with Carers Trust, has received funding from the Covid-19 Support Fund to support the “Making Hidden Carers Count” project. This part of the three-year project seeks to understand the experiences of four traditionally under-represented groups of carers both during and beyond the COVID-19 pandemic. These are LGBTQ+ carers, Black, Asian and Minority Ethnic carers, older carers without access to the internet and carers of faith.

This project is pulling together existing knowledge and engaging in new research to more fully understand the experiences of these carers and the unique challenges they may experience in their caring role as well as collating examples of best practice. This knowledge gained will be applied to Carers UK services and shared with other service delivery organisations and commissioners to improve access to and outcomes from support, information and advice for marginalised carers.



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