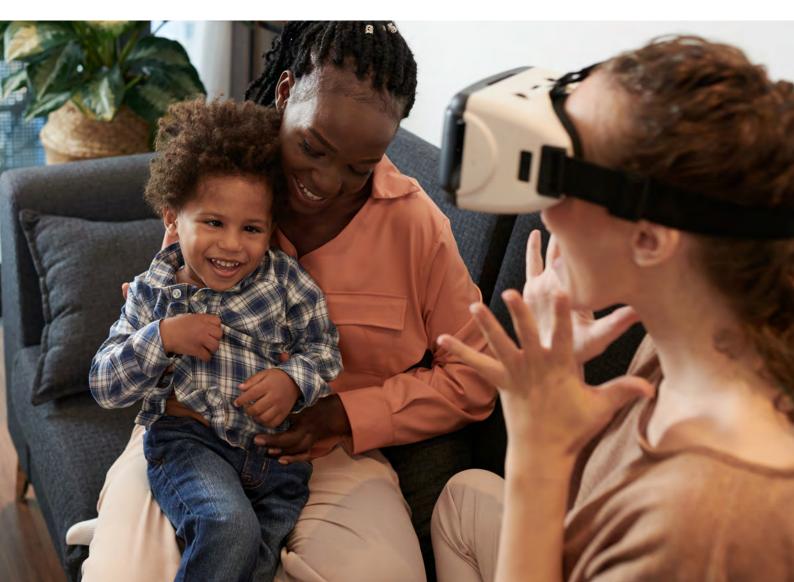


# The experiences of lesbian, gay and bisexual carers during and beyond the COVID-19 pandemic



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## Introduction



Carers UK estimates that there could be up to 13.6 million people in the UK currently providing unpaid care<sup>1</sup> and caring is likely to be part of all of our lives, with 3 in 5 people becoming carers at some point in their lives.<sup>2</sup>

This briefing aims to examine the experiences of carers who are gay, lesbian or bisexual. This is a group of carers that may face additional challenges in relation to their caring role, and barriers to accessing services, yet there is a limited body of research looking at their views and needs. Unfortunately, due to sample sizes being too small, we are unable to include analysis about trans carers<sup>3</sup> in this report. Trans carers are likely to be further disadvantaged and have their own unique challenges. Carers UK is committed to research that involves trans carers and specific and targeted research is required to fully understand their experiences and the types of support that are most beneficial.

In this briefing we will review this existing evidence base and share new analysis of Carers UK surveys, to compare the experiences of lesbian, gay and bisexual carers with heterosexual carers, as well as examining trends over time. In particular we will examine the impact of the COVID-19 pandemic. Research has shown that carers are more likely to live in poverty,<sup>4</sup> experience greater isolation<sup>5</sup> and loneliness<sup>6</sup> and suffer worsening health due to their caring role. The COVID-19 pandemic has worsened many of these challenges. 1 Carers UK (2020) Carers Week 2020 Research Report: The rise in the number of unpaid carers during the coronavirus (COVID-19) outbreak

> www.carersuk.org/images/CarersWeek2020/ CW\_2020\_Research\_Report\_WEB.pdf

2 Carers UK (2019) Facts about Carers

www.carersuk.org/newsand-campaigns/press-releases/facts-and-figures

3 We have used Stonewall's definition of 'trans' as "an umbrella term to describe people whose gender is not the same as, or does not sit comfortably with, the sex they were assigned at birth"

> www.stonewall. org.uk/help-advice/ faqs-and-glossary/list-lgbtq-terms

4 New Policy Institute (2016) Informal carers &poverty in the UK: An analysis of the Family Resources Survey

> www.npi.org.uk/ files/2114/6411/1359/ Carers\_and\_poverty\_in\_ the\_UK\_-\_full\_report.pdf

5 Carers UK (2017) The world shrinks: Carer loneliness

www.carersuk.org/images/News\_campaigns/ The\_world\_Shrinks\_Final. pdf

6 Carers UK (2012) Carers Week 2012 Research Report: Supporting Carers to be Health and Connected This report aims to add to this growing body of knowledge and experience, to stimulate the conversation around any unique challenges faced by lesbian, gay and bisexual carers and make recommendations on how best to support them.

This report will be followed by a good practice briefing which sets out what service providers who support carers (such as local authorities, health bodies and the voluntary and community sector) can do to better support lesbian, gay and bisexual carers and address the problems highlighted in this research.

#### Methodology

This briefing is based on several surveys undertaken by Carers UK. Data from before the pandemic is drawn from the 2019 State of Caring survey, the UK's most comprehensive piece of research into the lives and experiences of carers. Pandemic data is based on the Caring behind closed doors surveys, conducted in April and September 2020. Further data is from the 2021 State of Caring survey. Each of these surveys was completed by thousands of carers and offer comprehensive data on carers' experiences before and during the pandemic. Additional evidence is gained from Carers UK's analysis of the GP Patient survey.

The data we have been able to gather is based on survey responses from up to 170 gay, lesbian and bisexual carers. Although relatively small, we are able to draw some conclusions. Due to a change in data collection, we are unable to disaggregate lesbians and gay men in the two Caring behind closed doors surveys, or State of Caring 2021, and instead have analysed them together. In our State of Caring 2019 survey we included gay men and lesbians as two separate categories when asking carers to report on their sexuality, and have therefore analysed responses from gay men and lesbians separately when reporting on this survey.

Unfortunately, due to sample sizes being too small, we are unable to include analysis about trans carers in this report. Carers UK is committed to research that involves trans carers and we will be taking further action to ensure that they are able to participate in our research. This might include holding focus groups with trans carers and ensuring that our surveys are disseminated to organisations who are working directly with them. Due to small sample sizes, we are also unable to include analysis of carers who chose to self-describe their sexuality.

# Background and previous research



As already noted, historically there has been a lack of research into the specific experiences of lesbian, gay, bisexual and trans carers despite many people from these groups caring for friends, family and neighbours, and there being the potential for multiple disadvantages experienced as LGBTQ+ carers.

This has started to change more recently, with notable publications such as *Can You See Us? Experiences of LGBT Carers in England*, a joint report by Gaddum, an advocacy, carers support and therapy services provider in Greater Manchester, and LGBT Foundation.<sup>7</sup> This research, based on a survey of LGBT carers, identified mental wellbeing as the top priority for this group, followed by being financially stable, having good physical health, having someone trusted to talk to, and being in contact with others in LGBT communities.

Of those who had accessed services, a majority (73%) said that the service had met their needs. However, over half said that work commitments were a barrier to accessing services, and a further four in ten said that their mental wellbeing was a barrier. Lack of awareness of services and concerns that services would not meet their needs were identified as other key barriers. Gaddum and LGBT Foundation (2021) Can you see us? Igbt.foundation/ canyouseeus?\_cf\_chl\_f\_ tk=yAUpCE1Bh4nVYsiUP AvnNSGpwMLHvOodqtrlK EUxyzQ-1642508465-0gaNycGzNCWU There was a significant demand for services, with 58% responding that they would like to access mental health support such as counselling. 45% would like to access an LGBT peer support group, and 37% would like support online. Two-thirds (67%) of respondents thought that support services need to take steps to become more LGBT friendly.

Other research has highlighted that being lesbian, gay, bisexual or trans may be just one part of a person's identity, and other factors such as ethnicity, faith or disability may be just as relevant to their experience. The need for services to recognise multi-faceted identities, is highlighted as an expectation of a person-centred approach to services.<sup>8</sup>

A report by LGBT Health and Wellbeing in Scotland focused specifically on the experiences of carers of people living with dementia. It identified further barriers to accessing support and services that arose from issues around prejudice, worries that the carer role might not be recognised and supported, and tension with family members who may not even be aware of the extent of the relationship between the carer and the person they care for.<sup>9</sup>

It also highlighted the 'invisibility' of LGBT people, with some services reporting that they didn't have any LGBT people accessing their services. It is possible that some carers, particularly older LGBTQ+ carers who have experienced discrimination or stigma earlier in life, may be reluctant to use these services or to disclose their sexuality.

> 8 Social Care Institute for Excellence (2011) Personalisation: Working with lesbian, gay, bisexual and transgender people

www.scie.org.uk/ personalisation/specificgroups/lgbt

9 LGBT Health and Wellbeing (2020) Proud to Care LGBT Dementia Project (June 2018 – July 2020)

> www.lgbthealth. org.uk/wp-content/ uploads/2021/01/ Dementia-Impact-Report. pdf

# Summary of findings



Analysing data from State of Caring 2019, State of Caring 2021, Caring behind closed doors and Caring behind closed doors: six months on indicates that:

- Lesbian, gay and bisexual carers were more likely to be struggling financially and be unable to keep up with their bill or mortgage payments. Many were in, or had been in, debt as a result of caring and lesbian, gay and bisexual carers were more concerned about their financial situation in the pandemic than heterosexual carers. According to our most recent data from 2021, 50% of heterosexual carers feel anxious or stressed when they think about their financial situation, compared to 62% of lesbian and gay carers and 65% of bisexual carers. This is not surprising as bisexual (45%) and gay and lesbian (44%) carers were more likely than heterosexual carers (36%) to have seen their financial situation get worse because of the pandemic.
- Before the pandemic, gay carers were the most likely to report feeling lonely and isolated, with 2 in 5 (41%) identifying as chronically lonely. However, in our surveys during the pandemic, bisexual carers have emerged as the most socially isolated. In 2021, 48% of bisexual carers reported that they often or always felt lonely, compared with 45% of lesbian and gay carers, and 33% of heterosexual carers.

Percentage of carers who feel anxious or stressed when they think about their financial situation:

Bisexual	65%
Lesbian and gay	62%
Heterosexual	50%

(:..) 48% of bisexual carers

reported often or always feeling lonely, compared with 45% of lesbian and gay carers and 33% of heterosexual carers

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- Bisexual carers struggled the most with accessing supplies early on in the pandemic, with 88% of bisexual carers having some or significant problems accessing food and 50% having some or significant problems accessing medication.
- The closure of, or changes to, local care and support services disproportionately impacted lesbian and gay carers throughout the pandemic, with 11% of lesbian and gay carers telling us that they were getting a lower level of support from local charitable services (eg meals on wheels) than before the pandemic, compared to just 2% of heterosexual carers.
- The physical health of bisexual carers was suffering before the pandemic, with 37% rating their physical health as 'bad' or 'very bad' and 84% saying they were struggling to engage in as much physical activity as they would like to. This finding was replicated in 2021 when 41% of bisexual carers reported 'bad' or 'very bad' physical health, compared with 25% of heterosexual carers and 28% of gay and lesbian carers.
- Gay, lesbian and bisexual carers report lower average scores than heterosexual carers when asked about quality of life measures – general wellbeing, life satisfaction, happiness and anxiety. Carers have lower scores on average than the general UK population, yet we find that being part of a minority group within the carer population results in even lower scores.
- Bisexual carers entered the pandemic with poorer mental health and during the pandemic, continued to rate their mental health and wellbeing as worse across a number of factors than either heterosexual or lesbian and gay carers. In 2021, 57% of bisexual carers said their mental health was 'bad' or 'very bad', compared with 44% of gay and lesbian carers and 30% of heterosexual carers.
- Lesbian, gay and bisexual carers are more likely to care for someone with a mental health condition or problematic alcohol or substance use. In April 2020, over half (51%) of bisexual carers and 35% of lesbian and gay carers were caring for someone with a mental health condition compared to 31% of heterosexual carers. This is likely to present different challenges compared to caring for someone with a physical health condition.
- At the beginning of the pandemic, bisexual carers were more likely to be unable to work due to sickness or disability (12%) than heterosexual (5%), lesbian (0%) or gay (6%) carers. This finding was replicated in 2021, when bisexual carers were even more likely to say they were unable to work due to sickness or disability (16%) compared with gay/lesbian carers (10%) or heterosexual carers (6%).

## **XX** 41%

of bisexual carers reported bad or very bad physical health, compared with 28% of lesbian and gay carers and 25% of heterosexual carers

Percentage of carers who were caring for someone with a mental health condition:

Bisexual	51%
Lesbian and gay	35%
Heterosexual	31%

**†**††††††† 16%

of bisexual carers were unable to work due to sickness or disability compared to 10% of gay and lesbian carers and 6% of heterosexual carers

# Lesbian, gay and bisexual carers



The lesbian, gay and bisexual carers who responded to Carers UK's surveys varied from heterosexual respondents in several ways.

Across all four surveys, lesbian, gay and bisexual carers were younger than their heterosexual counterparts. According to our most recent data from 2021, 43% of bisexual carers and 24% of gay and lesbian carers were under the age of 45, compared to only 12% of heterosexual carers.

Across all three surveys conducted during the pandemic, lesbian, gay and bisexual carers were more likely to be disabled than heterosexual carers. 38% of lesbian and gay and 45% of bisexual respondents to the State of Caring 2021 survey stated they were disabled compared to 27% of heterosexual carers. During analysis, we are unable to control for these factors and each of these differences may be contributing to the different experiences reported by lesbian, gay and bisexual carers.

## Who do they care for?

In data collected before the pandemic, gay men were significantly more likely to be caring for a parent than any other group, with over half (52%) of gay men stating they are taking care of one or both of their parents. Lesbians, on the other hand, were significantly more likely to be caring for a partner or spouse (53%) than bisexual (33%) or heterosexual (36%) carers. Finally, heterosexual and bisexual carers were more likely to be caring for a child or a child-in-law, at 37% and 30% respectively.

The respondents surveyed during the pandemic were broadly similar. Data from 2021 confirmed that lesbian and gay carers were significantly more likely to be caring for a parent/parentin-law than heterosexual carers (50% of gay and lesbian carers, compared with 36% of heterosexual carers). Only 11% of lesbian and gay carers were caring for a child or child-in-law, significantly lower than bisexual carers at 36% and heterosexual carers at 33%. In addition, lesbian, gay and bisexual carers were more likely to be caring for a neighbour or friend than heterosexual carers.

The conditions of the people they cared for also varied. In the State of Caring 2021 survey, bisexual and gay/lesbian carers had the same likelihood of caring for someone with a physical disability (54%, compared with 47% of heterosexual carers), but bisexual carers were more likely to be looking after someone with a mental health condition (40% compared with 30% of gay/ lesbian carers and 30% of heterosexual carers) or autism (37% compared with 21% of heterosexual carers and 13% of gay/ lesbian carers).

This pattern was also reflected in April 2020, when over half (51%) of bisexual carers were caring for someone with a mental health condition compared to 31% of heterosexual carers and 35% of lesbian and gay carers. Additionally, 1 in 10 (10%) bisexual carers were caring for someone with alcohol or substance use, significantly higher than any other group. In September 2020, the number of lesbian and gay carers caring for someone with a mental health condition increased to almost half (48%) of those surveyed. This may be due to higher rates of mental health conditions and substance abuse amongst lesbian, gay and bisexual people.<sup>10</sup>

Caring for someone with a mental health condition is likely to involve different experiences and challenges compared to caring for someone with a physical health condition.<sup>11</sup> For example, many carers find they are not fully included due to strict confidentiality protocols and there is still widespread stigma around mental health conditions. To fully support lesbian, gay and bisexual carers, it is vital that services ensure carers of people with mental health conditions are adequately represented and supported. 10 National Institute of Economic and Social Research (2016) Inequality among lesbian, gay, bisexual and transgender groups in the UK: a review of evidence

> assets.publishing.service. gov.uk/government/ uploads/system/uploads/ attachment\_data/ file/539682/160719\_ REPORT\_LGBT\_evidence\_ review\_NIESR\_FINALPDF. pdf

11 Mind Caring for someone with a mental health problem

> www.mind.org.uk/ information-support/ helping-someone-else/ carers-friends-familycoping-support/ supporting-someonewith-a-mental-healthproblem/

## How much care are they providing?

Before the pandemic, heterosexual and bisexual carers were providing the most amount of care, with 47% and 43% respectively providing over 90 hours of care each week, compared to 38% of gay carers and 27% of lesbian carers.

This pattern was replicated in 2021, where we found that 51% of heterosexual carers and 48% of bisexual carers, were providing over 90 hours of care per week, compared with 33% of gay or lesbian carers.

This pattern of increasing amounts of care being provided across all groups was confirmed by our two surveys in 2020. For almost all carers, the amount of care they were providing increased during the pandemic. In April 2020, 67% of heterosexual carers, 64% of lesbian and gay carers, and 80% of bisexual carers were providing more care. By September 2020, this had increased again to 78% of heterosexual carers, 75% of lesbian and gay carers, and 86% of bisexual carers providing more care.

However, the reason for this change varied between the groups. By September 2020, lesbian and gay carers were significantly more likely to be providing more care as they were worried about the quality or safety of local services. Over 1 in 5 (22%) lesbian and gay carers had listed this as a concern compared to just 9% of heterosexual carers and 2% of bisexual carers. Bisexual carers, on the other hand, were significantly more likely to be providing more care due to a reduction in personal care provided by health and social care staff.

"Services have been non-existent and things my parents could have done a little have not been possible. Their increased worry and deterioration of their mental health due to isolation resulted in relapse and mental health services have not stepped in"



- Bisexual carer

# Employment and finances



## Employment

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Before the pandemic, bisexual carers were significantly more likely to be unable to work due to sickness or disability (12%) than heterosexual (5%), lesbian (0%) or gay (6%) carers. Bisexual carers were also the most likely to have given up work to care, with 2 in 5 (40%) stating their work had been affected in this way. Conversely, lesbian and gay carers were most likely to be in full- or part-time employment at 50% or 48% respectively compared to 34% of heterosexual carers and 31% of bisexual carers. However, over a third (34%) of lesbian carers stated that their job was negatively affected by caring, significantly more than either bisexual or heterosexual carers who were in work. This suggests that despite being in full-time work, lesbian and gay carers may be finding it more challenging to juggle work and care than their heterosexual and bisexual counterparts. In comparison, heterosexual carers were significantly more likely to be retired, which is likely to be due to the older age of the heterosexual carers surveyed.

These trends continued during the pandemic, with bisexual carers (16%) continuing to be significantly more likely to be unable to work due to sickness or disability compared to heterosexual carers (6%) in 2021. When asked how their employment situation had been affected by coronavirus, there were no significant differences between groups, indicating that carers had been equally affected regardless of sexual orientation.

"I have reduced my hours by purchasing extra leave to help compensate for reduced weekends due to caring. It also makes it difficult to get promotion in order to financially safeguard my future, as I am not performing as well as I would have done at work, and home emergencies show that I am less dependable"

- Lesbian carer, 2019

"When mum went wandering due to dementia, I had to leave work to go driving looking for her....this meant I didn't get paid or had to work the hours back"

- Bisexual carer, 2021

### Financial impact and support

Lesbian, gay and bisexual people are disadvantaged financially compared to their heterosexual counterparts. The National LGBT Survey found that 47% of respondents were earning less than £20,000 a year, below that year's median annual income of £23,474.<sup>12</sup> A YouGov survey of 4,000 workers across the UK in 2019 also found that LGBT workers earned on average 16% less than heterosexual workers, the equivalent of losing £6,703 annually.<sup>13</sup>

Our surveys confirm that caring is having a negative impact on the finances of lesbian, gay and bisexual carers. All three groups were more likely to state that they couldn't afford their rent or mortgage payments and that they are in or have been in debt as a result of caring than heterosexual carers. In 2019, gay men reported struggling the most financially, with over 1 in 10 (11%) reporting that they couldn't afford their rent or mortgage payments and almost 2 in 5 (38%) stated they were or had been in debt as a result of caring. By 2021, bisexual carers reported the most concerns, with 7% stating they couldn't afford their rent or mortgage, 30% in debt as a result of caring, and 44% struggling to make ends meet. In order to cope, this group was more likely to be cutting back on essentials like food and heating, as well as hobbies and leisure activities.

#### "Any savings we had between us we've now used up"

- Gay carer, 2019

"We are in a debt management plan due to financial difficulties we got into"

- Gay carer, 2019

12 Government Equalities Office (2018) National LGBT Survey, Research Report: assets.publishing.service. gov.uk/government/ uploads/system/uploads/

attachment\_data/ file/721704/LGBT-surveyresearch-report.pdf

13 You Gov (2019)

www.linkedin.com/news/ story/the-uk-has-anlgbtq-pay-gap-4702500/ The 2020 surveys point to the impact that the pandemic had on carers' finances. When asked in April 2020, 81% of heterosexual carers, 77% of lesbian and gay carers and 88% of bisexual carers stated they were spending more due to the coronavirus pandemic. Overwhelmingly, this increased expenditure was on food and household bills but some carers were also spending more on PPE, medical equipment and indoor entertainment for the person they were caring for. Finances were a worry for many carers but more so for lesbian, gay and bisexual carers. 37% of heterosexual carers were worried about their financial situation, compared to 43% of lesbian and gay carers and 50% of bisexual carers.

When asked what support would be most helpful, lesbian, gay and bisexual carers were significantly more likely to choose 'increased financial support' than heterosexual carers. Half (50%) of lesbian and gay carers and almost 6 in 10 (59%) of bisexual carers opted for increased financial support compared to around a third (34%) of heterosexual carers.

Finances are a concern for a large number of unpaid carers, but this is a more significant problem for lesbian, gay and bisexual carers and has only increased as a result of the coronavirus pandemic. When asked in 2021 about how their financial situation had changed since the start of the pandemic, bisexual carers were most likely to report that it had got worse (45%), closely followed by gay and lesbian carers (44%). Despite it being a lower figure of 36% for heterosexual carers, these figures highlight the extent to which all carers have been affected financially by the pandemic. Financial difficulties and worries about finances are likely to have a knock-on effect on carers' health, wellbeing and ability to cope and should not be neglected when considering how best to support carers.

#### "I am spending more on supplies and petrol and I also work and have been furloughed so only getting 80% of my wage as well"

- Gay/lesbian carer, April 2020

"My carers allowance for 35 hours a week is lower than the statutory sick pay for people who are self-isolating. I am being paid less for doing 35 hours work. How can this be right? I am unable to save or go on holiday, it makes me feel like my care isn't worth anything to the government and gives me low selfworth"

- Bisexual carer, April 2020

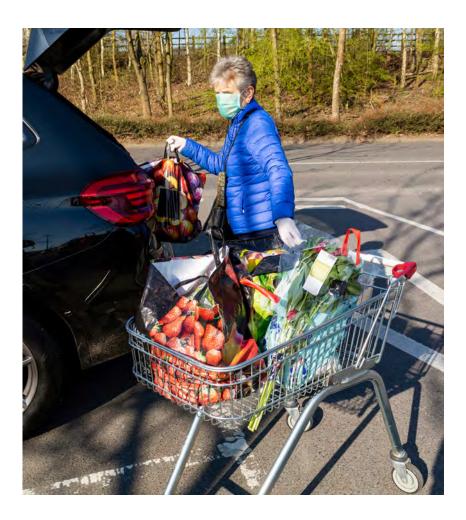
"I have no money in my bank at all"

- Bisexual carer, April 2020)

#### Carer's assessment

In our *State of Caring* survey in 2021, we asked carers if they had a carer's assessment in the last 12 months. Bisexual carers were less likely to have had an assessment (15%), compared with gay and lesbian carers (24%) and heterosexual carers (24%). Of those who hadn't received an assessment, gay and lesbian carers were most likely to say they didn't know what an assessment is (54%) compared with heterosexual carers (36%) and bisexual carers (28%). However, bisexual carers were most likely to say they didn't think an assessment would be beneficial (30%) compared to gay and lesbian carers (21%) and heterosexual carers (19%).

# Access to supplies and support



## Supplies

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Access to food, medication and cleaning supplies was challenging for everyone at the beginning of the pandemic in March and April 2020. However, the impact of this may have been more keenly felt by carers due to the increased importance of these items and the higher likelihood that they or the person they care for were shielding and unable to access their usual supplies. In April 2020, bisexual carers were consistently struggling the most to access supplies. 88% of bisexual carers were having some or significant problems accessing food, compared to 66% of gay and lesbian carers and 64% of heterosexual carers. Access to medication was marginally better with 50% of bisexual carers having some or significant problems with access compared to 41% of lesbian and gay carers and 38% of heterosexual carers. These difficulties with accessing supplies were likely caused by many factors, such as carers being ineligible for priority shopping hours or deliveries and the additional challenges that came with shielding.

While this limited access to supplies is likely to have reduced as the pandemic continued it speaks to the precarity of these carers and highlights how carers are often forgotten.

"I am unable to access the 'vulnerable' shopping hours offered by many supermarkets as I am not in that bracket myself, even though the person I care for is. This means I have to order food online and delivery spots are almost impossible to get. Our regular pharmacy is located within a supermarket, which means queuing and risking infection. The family and friends we have nearby are also shielding, as are many of our neighbours. One family member has been helping collect prescriptions and we wouldn't have managed otherwise"

- Bisexual carer, April 2020

#### Social support and loneliness

Feeling lonely or isolated was a common experience for carers even before the pandemic, when over 2 in 5 (41%) gay carers were chronically lonely (identifying as 'often' or 'always' feeling lonely), compared to 35% of heterosexual and bisexual carers and a quarter (25%) of lesbian carers. These numbers are markedly higher for carers than the general population, where only around 5% of people aged 16 or over in England are chronically lonely.<sup>14</sup> Loneliness has a profound impact on someone's health and wellbeing, increasing the risk of death, cognitive decline, dementia, coronary heart disease and stroke<sup>15</sup> and is likely to be contributing to the poor health of many carers.



14 Campaign to End Loneliness Facts on Loneliness: www.campaigntoendloneliness.org/the-factson-loneliness/

15 Ibid.

In April 2020, towards the beginning of the pandemic, carers were asked if they felt they had a network of people around to support them. Almost 3 in 10 (38%) of heterosexual carers agreed, significantly more than 27% of lesbian and gay carers and 18% of bisexual carers. When asked if they felt lonely and cut off from people, bisexual carers (30%) were significantly more likely to strongly agree compared to either heterosexual (16%) or lesbian and gay (28%) carers. This loneliness is likely to have exacerbated the strains of the pandemic and made it harder for these carers to cope, as well as impacting their health and wellbeing.

These feelings of isolation and lack of social support only worsened for carers as the pandemic continued but this was particularly challenging for bisexual carers. Responding to the State of Caring 2021 survey, 48% of bisexual carers reported that they often or always felt lonely, compared with 45% of lesbian and gay carers, and 33% of heterosexual carers. In September 2020, bisexual carers tended to disagree with the statement 'I feel I am able to keep in contact with neighbours, family members or local community' while lesbian, gay and heterosexual carers were all more likely to agree. Interestingly, in September, lesbian and gay carers (37%) were more likely to either agree or strongly agree that they had a network to support them compared to both heterosexual (30%) and bisexual (33%) carers. This feeling of support may have been a protective factor for these carers and enabled them to cope better with their caring role during the pandemic.

"Many people don't understand the burden of being a carer. They frequently give unhelpful advice such as 'just stop doing that' which isn't possible. Or they make you feel guilty for talking about how being a carer can affect you and your work. Being a younger carer for a young adult is also an unusual situation that other carers can struggle to understand. So in some ways it can be doubly isolating. Plus the difficulties that my sister faces are so complex, often people try to give me solutions when all I'm looking for is a space to talk about how I'm feeling"

- Bisexual carer, 2019

Isolation, loneliness, and a lack of social support are issues affecting all carers but are especially impacting bisexual carers and the knock-on effect of this on their health and wellbeing is deeply concerning. Increased isolation amongst bisexual carers may be because the bisexual carers who completed our surveys are likely to be caring for someone with a mental health condition, which may result in them feeling excluded from traditional carer support groups or social activities. In addition, some research suggests that bisexual people are less likely to be 'out' to the people in their lives, which may cause added stress or feelings of isolation.<sup>16</sup> Some carers may also feel that they are unable to access support due to previous negative experiences of services or concerns that services are not inclusive.

In 2021, we also asked carers the four standard Office for National Statistics questions on wellbeing, life satisfaction, happiness and anxiety. Carers could answer on a scale from 0 to 10 and the mean scores are summarised in the table below. This demonstrates how carers as a whole are less satisfied with their life, less happy and more anxious than the general UK population, and across all measures the scores are worse for gay, lesbian and bisexual carers than for heterosexual respondents.

## ONS Wellbeing Scores according to sexual orientation in the State of Caring survey 2021

Group	Life satisfaction	Life is worthwhile	Happiness	Anxiety
ONS UK average	7.55	7.78	7.52	3.04
Lesbian/gay	3.93	5.18	3.95	5.65
Bisexual	3.82	4.42	3.52	6.33
Heterosexual	4.42	5.63	4.46	5.32



0 = not at all satisfied/ worthwhile/happy/ anxious,

10 = completely satisfied/worthwhile/ happy/anxious

16 Pew Research Centre (2019) Bisexual adults are far less likely than gay men and lesbians to be 'out' to the people in their lives.

> www.pewresearch.org/ fact-tank/2019/06/18/ bisexual-adults-are-farless-likely-than-gay-menand-lesbians-to-be-outto-the-people-in-theirlives/

# The impact of the coronavirus pandemic on access to support

When the coronavirus pandemic began in March 2020, local care and support services across the country were impacted. Many had to close or move their services online and the risks of home-based care were judged by many carers and families to be too great. Consequently, carers across the board took on more care and received less support. However, the impact was greater for lesbian, gay and bisexual carers.

By September 2020, lesbian and gay carers were significantly more likely to be receiving reduced support from local charities than heterosexual carers, with 1 in 10 (11%) getting a lower level of support than before the pandemic compared to 2% of heterosexual carers. Even where services were open or available, access was reduced for lesbian, gay and bisexual carers. More than 1 in 5 (22%) of lesbian and gay carers were providing increased care as they were concerned about the safety or quality of local services compared to just 10% of heterosexual carers and 2% of bisexual carers. Bisexual carers, on the other hand, were more impacted by the reduction of personal care provided by health and social care staff as 1 in 10 (10%) were providing more care for this reason compared to 7% of heterosexual carers and just 2% of lesbian and gay carers.

#### "Mental health services have reduced enormously. Little help or willingness from them to help. Good support from MIND. I am a key worker and very stressed and exhausted doing both"

- Lesbian/gay carer, September 2020

"Social distancing and isolation has increased mental health issues with the person I care for who is now reluctant to leave the house for any reason"

- Lesbian/gay carer, September 2020

## Health and wellbeing



#### Physical health

Carers UK has undertaken more in-depth analysis of the 2021 GP Patient Survey including where possible, the experiences of lesbian, gay and bisexual carers.<sup>17</sup> This research found that 70% of lesbian, gay and bisexual carers reported a long-term condition, compared to 60% of heterosexual carers. Lesbian, gay and bisexual carers were more likely to have a mental health condition (36%) compared to heterosexual carers (13%).

Before the pandemic, bisexual carers were significantly more likely to rate their physical health as 'bad' than any other group. Almost 4 in 10 (37%) of bisexual carers rated their physical health as 'bad' or 'very bad' compared to 22% of heterosexual carers, 19% of gay carers and just 16% of lesbian carers. Going into the pandemic, bisexual carers were already suffering from worse physical health, and this is likely to have worsened over the past year.

The State of Caring 2021 survey confirmed these findings with 41% of bisexual carers reporting 'bad' or 'very bad' physical health, compared with 25% of heterosexual carers and 28% of gay/lesbian carers.

17 Carers UK (2021) Carers' health and experiences of primary care: Data from the 2021 GP Patient Survey www.carersuk.org/forprofessionals/policy/ policy-library/gp-patientsurvey-201 When asked in September 2020, 51% of heterosexual carers felt they had been unable to maintain their health and wellbeing, markedly lower than the 61% of lesbian and gay carers and 59% of bisexual carers. However, when asked if their physical health had worsened as a result of the coronavirus pandemic, 57% of heterosexual carers agreed or strongly agreed which was very similar to the rates of lesbian/gay and bisexual carers at 59% and 60% respectively.

"My depression and anxiety have rocketed, and I haven't been able to follow a healthy diet and I haven't had a chance to do any exercise and my depression has worsened and the lockdown has ruined so many things"

- Lesbian/gay carer, September 2020

"I have gained a lot of weight from stress and inactivity which has given me dangerously high blood pressure. I am now trying to scrape together the money for bariatric surgery or I will not live long"

- Bisexual carer, September 2020

Some of these disparities in physical health may be explained by differences in physical activity. Before the pandemic, carers were already struggling to engage in physical activity. 84% of bisexual carers stated they weren't able to do as much exercise as they would like to, compared to 81% of heterosexual carers, 78% of lesbian carers and 77% of gay carers.

These differences are due to a variety of factors. For instance, almost three-quarters (72%) of bisexual carers found their caring role so tiring they didn't have the energy to do more physical activity. This compares to just two-thirds (63%) of heterosexual, gay and lesbian carers. Bisexual carers were also significantly more likely to state that they feel out of place in a sports or fitness environment and that they worry about not being good at a physical activity than heterosexual carers. Our surveys also found that bisexual carers were more likely to be disabled and more likely to be struggling financially, which might affect participation in physical activity.

While there was no specific data collected by Carers UK, the pandemic is likely to have had a variable impact on carers' ability to exercise and participate in physical activity. For some, increased care will have impacted their already limited time but for others, working from home may have freed up time for exercise. Nevertheless, the issues of limited time, funds and energy are likely to be ongoing problems that prevent carers from participating in as much exercise as they would like to.

"Balancing full time work and being a carer means that there isn't enough time for me to exercise as I would like. There aren't enough hours in the day!"

- Bisexual carer, 2019

"Im too exhausted to exercise – some days even going out for a walk feels like too much. I tend to just go to work and then come home. I feel completely physically and emotionally drained and lack confidence in my ability to get out and take part in group activities because I haven't used my social skills 'properly' in so long I'm scared they've disappeared"

- Lesbian carer, 2019

### Mental health and wellbeing

LGBT people are consistently shown to have poorer mental health than their heterosexual counterparts. Stonewall found that over half (52%) of LGBT people had experienced depression in the past year and 13 per cent had attempted to take their own life.<sup>18</sup> As carers also tend to have worse mental health than those who aren't caring,<sup>19</sup> LGBT carers are likely to be at greater risk. Indeed, data from Carers UK's analysis of the GP patient survey in 2021 shows that over a third (36%) of lesbian, gay and bisexual carers had a long-term mental health condition compared to just 13% of heterosexual carers, making them almost three times as likely to be experiencing a long-term mental health condition.



18 Stonewall (2018) LGBT in Britain – Health www.stonewall.org.uk/ system/files/lgbt\_in\_ britain\_health.pdf

19 Carers UK (2019) Facts about Carers Evidence suggests that mental health substantially worsened as a result of the coronavirus pandemic.<sup>20</sup> While this will have had an impact across the entire population, lesbian, gay and bisexual carers were already dealing with poorer mental health and may therefore be feeling the effects more keenly.

The State of Caring 2021 survey showed the extent of poor mental health among bisexual carers in particular, with 57% reporting their mental health was 'bad' or 'very bad' compared to 44% of gay/lesbian carers and 30% of heterosexual carers.

When asked in September 2020 if their mental health had worsened as a result of the pandemic, bisexual carers were significantly more likely to strongly agree at 41%. However, almost a quarter of both heterosexual carers (24%) and lesbian and gay carers (22%) also strongly agreed.

This trend was reflected across both surveys conducted during the pandemic with bisexual carers rating their mental health and wellbeing as worse across a number of factors than either heterosexual or lesbian and gay carers.

"My health is continuing to deteriorate, I get no breaks, the state of our living environment deteriorates as time goes on, it's putting a huge strain on my relationship"

- Bisexual carer, September 2020

"I struggle with physical and mental health problems also winter is a particularly difficult time for me"

- Bisexual carer, September 2020



20 The Health Foundation (2020) Emerging Evidence on Covid-19's impact on mental health and health inequalities



"I am constantly exhausted, drained physically and emotionally and anxious. I am now myself on anti-depressants and the waiting list for high intensity CBT"

- Bisexual carer, September 2021

In April 2020, when asked if they felt able to manage their caring role, 10% of bisexual carers strongly disagreed compared to 7% of lesbian and gay carers and 5% of heterosexual carers. Similarly, a quarter of bisexual carers (25%) strongly disagreed with the statement 'I feel able to look after my own health and wellbeing'. Most concerningly, almost half (47.5%) of bisexual carers strongly agreed when asked if they felt overwhelmed and worried they were going to burnout in the coming weeks. They were significantly more likely to strongly agree than either heterosexual carers (23%) or lesbian and gay carers (28%) although the percentages agreeing are concerning in all three groups. By September 2020, when asked if they were reaching breaking point, almost a third (30%) of bisexual carers strongly agreed.

The particular challenges faced by bisexual carers require further investigation but may be linked to the greater isolation and lack of social support experienced by these carers as evidenced above. These findings also reflect other research that finds bisexual people have worse mental health<sup>21</sup> compared to both heterosexual and gay and lesbian people, in part due to the 'double discrimination' of homophobia and/or biphobia they face.<sup>22</sup>

21 www.rethink.org/adviceand-information/livingwith-mental-illness/ wellbeing-physicalhealth/lgbtplus-mentalhealth/

22 Oxford University Press. The Oxford Handbook of Sexual and Gender Minority Mental Health. (2020). United States

#### Breaks

In our *Caring behind closed doors* surveys we asked carers whether they had been able to take a break from caring. In September 2020, bisexual carers were most likely to say that they were providing more care because the people they usually relied on to give them a break were unavailable or unwilling to help (34%) compared with gay and lesbian carers (28%) and heterosexual carers (26%). However, it was heterosexual carers who were most likely to say they had been unable to take any breaks from their caring role (64%), compared with gay and lesbian carers (57%) and bisexual carers (52%).

#### "Sometimes I feel stir crazy and does affect my sleep and mental state and become unable to do anything apart from the absolute necessities"

- Gay/lesbian carer, September 2020

"It feels non-stop, every morning and evening, not even a joint break/holiday. I do get exhausted"

- Bisexual carer, September 2020

#### "I haven't had a break for 15 years"

- Bisexual carer, September 2021



## Conclusion



There are millions of unpaid carers across the UK and many of these carers are lesbian, gay or bisexual. While lesbian, gay and bisexual carers share many of the same concerns as heterosexual carers such as loneliness and isolation, poor health and the challenges of juggling work and care, our data indicate that lesbian, gay and bisexual carers are disproportionately impacted. Lesbian, gay and bisexual carers entered the pandemic with poorer mental health and with financial disadvantage that has only been exacerbated.

More research needs to be done with larger sample sizes, as well as more in-depth qualitative research, to substantiate these findings but this preliminary research highlights troubling differences between heterosexual and lesbian, gay and bisexual carers.

## Recommendations

We believe there are important steps that the government, NHS and local services can take to improve the lives of lesbian, gay and bisexual carers.

Improve the financial support available to carers. Lesbian, gay and bisexual carers have greater financial concerns than heterosexual carers, in particular bisexual carers who are more likely to be unable to work due to sickness or disability. The government should increase the rate of Universal Credit and implement a similar increase to Carer's Allowance, both of which will help to ease the financial pressure on lesbian, gay and bisexual carers. An increase to the earnings limit of Carer's Allowance will also enable more carers to effectively juggle work and care.

**2 Improve support for working carers.** Lesbian and gay carers are more likely to be in work but also experience greater problems juggling work and care. The government should bring forward legislative measures to introduce Carer's Leave at their earliest opportunity. Employers are encouraged to become early adopters and go one step further and provide this as paid leave making it more accessible.

Employers should recognise caring as part of their diversity and inclusion policies and practice and should look at how this intersects with other diversity groups. We would encourage employers to become part of Employers for Carers, Carers UK's good practice forum.

Employers should register with an appropriate carer confident benchmarking scheme such as Carer Confident in England and most of the UK and Carer Positive in Scotland and promote carer friendly policies in their workplaces. This may include carer awareness, access to paid carers' leave or carer support groups at work.

Improve the identification of carers at an early stage. While there is much good practice in health and social care when it comes to identifying carers, many are still slipping through the gaps and not being identified appropriately. The government should introduce a duty on the NHS to identify carers and to promote their health and wellbeing. This duty on the NHS would lead to a step change in culture, ensuring professionals take a holistic approach to their work that would make carers more visible in the system and would move towards carers as expert partners. The NHS should also increase training for frontline professionals to ensure they are able to identify, signpost and support carers when they encounter them.

4 Ensure that LGBTQ+ carers are included as part of health improvement and disparities work. Since caring has been identified as a social determinant of health, it's clear that this intersects with other determinants as well as equalities issues. By targeting support, this would help to decrease the health inequalities faced by LGBTQ+ carers.

**5 Provide targeted, meaningful support for carers of people with mental health conditions.** Lesbian, gay and bisexual carers are more likely than heterosexual carers to be caring for someone with a mental health condition. As many mainstream carers' services target or are attended by those caring for someone older or with a physical disability, lesbian, gay and bisexual carers may feel excluded as a result. Providing bespoke services for these carers will have positive consequences for health, wellbeing and support.

**Fund more research into the experiences of LGBTQ+ carers.** In order to have a more comprehensive understanding of the experiences of LGBTQ+ carers, more research is required. This research should focus on the experiences of trans carers and LGBTQ+ carers from ethnic minorities as their experiences are likely to be different from white British LGBTQ+ carers. By improving the data we have on LGBTQ+ carers, interventions and support can be designed to be more effective.

Development or education, information and training to ensure services are understanding of and welcoming to LGBTQ+ carers. Professionals working with carers should be understanding of the different needs and experiences of LGBTQ+ carers and empowered to meet these needs. This may include professionals being aware of different relationship structures or gender identities. It is also important for professionals to bear in mind that some LGBTQ+ carers may not want to discuss their sexuality or interact with other carers online, for a variety of reasons, and some carers may be unable to access online services, particularly those in remote or rural areas.

The experiences of lesbian, gay and bisexual carers during and beyond the COVID-19 pandemic

## About this research

The four surveys on which this briefing is based were conducted on the following dates:

- State of Caring: 24 February 20 May 2019
- Caring behind closed doors: 3 April 14 April 2020
- Caring behind closed doors, six months on: 11 September – 28 September 2020
- State of Caring: July September 2021

The number of respondents who identified as either lesbian, gay or bisexual is summarised in the table below. Due to a change in data collection, we are unable to disaggregate lesbians and gay men in the two Caring behind closed doors surveys and instead have analysed them together.

#### Sexual orientation of survey respondents

Group	State of Caring 2019	Caring behind closed doors – April 2020	Caring behind closed doors – Sept. 2020	State of Caring 2021
Lesbian	64	86	65	102
Gay	48	(3%)	(2%)	(2%)
Bisexual	67	40 (1%)	51 (2%)	67 (1%)
Heterosexual	4,719	2,981 (96%)	3,198 (96%)	4,585 (96%)
Total	4898	3107	3314	4754

In general, carers who respond to Carers UK surveys have been caring for longer and care for more hours each week than the caring population as a whole. In addition, they have identified themselves as carers and recognised their caring role.

As a result, they are more likely to be well connected to local support services and have greater access to support. It is also worth noting that the sample sizes of lesbian, gay and bisexual carers in all three surveys are relatively small. Caution should therefore be exercised when it comes to extrapolating Note that percentages may not add up to 100 due to rounding

these findings to lesbian, gay and bisexual carers as a whole. Further research is required to more thoroughly understand the experiences of lesbian, gay and bisexual carers both during and beyond the coronavirus pandemic.

#### About the project

This report forms part of our ongoing 'Making Carers Count' project. This is a three-year project alongside Carers Trust where we seek 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 services, including local authorities and charities, to improve access to and outcomes from support, information and advice for marginalised carers.

We would like to thank the members of our Expert Advisory Group on LGBTQ+ carers for their support and advice in producing this research report.



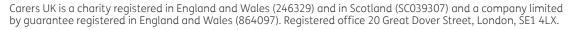
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