

The experiences of trans carers

Research report



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Introduction



This research report considers the experiences of unpaid carers whose gender identity is not the same as their sex registered at birth. It follows the Carers UK report ‘The experiences of lesbian, gay and bisexual carers during and beyond the Covid-19 pandemic’, which analysed carers’ responses to three Carers UK surveys. Unfortunately, due to sample sizes being too small, it wasn’t possible to include analysis about trans carers in that report. Carers UK therefore committed to undertaking further research to consider the experiences of trans carers.

This research explored the following three questions:

- **What, if anything, do trans carers find challenging about caring?**
- **What, if any, support do trans carers receive to help them with their caring role?**
- **Do carers feel that being trans has any impact on their caring role?**

Methodology

This report includes analysis of ONS Census 2021 data on gender identity and sexual orientation.

This research also consisted of semi-structured interviews with 4 carers, conducted between January and March 2023. Purposive sampling was used to identify participants in which carers who completed the Carers UK State of Caring 2022 and 2021 surveys were contacted if they had indicated their gender identity was different from the one registered at birth. Only those who had given their consent to be contacted about research opportunities were invited to take part. Carers UK also shared the opportunity to take part in this research with over 30 LGBT organisations.

Interviews took between 30 to 60 minutes and were conducted online over Zoom. All participants were sent consent forms to review and complete prior to the interviews. To protect carers' privacy, pseudonyms have been used throughout the report. Interviews were recorded and transcribed in full.

Background



Research with LGBTQ+ carers

Some research suggests that LGBTQ+ carers may face challenges in relation to health and wellbeing. Research by Gaddum and the LGBT Foundation found that 58% of LGBTQ+ carers said they would like to access mental health support such as counselling.¹ However, while some LGBTQ+ carers may need further support with health and wellbeing, evidence suggests there can be barriers preventing LGBTQ+ carers from seeking help. The research by Gaddum and the LGBT Foundation found that over a fifth (21%) of LGBTQ+ carers said that thinking that the service would not meet their needs as an LGBTQ+ person was a barrier.

Some studies have found that LGBTQ+ people may also face barriers in accessing support with their caring role. A report by LGBT Health and Wellbeing on the experiences of carers of people living with dementia found that people were concerned about prejudice, and worried that their carer role might not be recognised and supported.² Similarly, research by Switchboard found that LGBT carers face additional pressures due to a tendency of some professionals and family members to devalue their relationship to the person being cared for.³ As a result of these barriers, LGBTQ+ carers may be less likely to seek support with their caring role.

- ¹ Gaddum and LGBT Foundation (2021) *Can you see us*
lgbt.foundation/can-you-see-us
- ² LGBT Health and Wellbeing (2020) *Proud to Care LGBT Dementia Project (June 2018 – July 2020)*
lgbthealth.org.uk/wp-content/uploads/2021/01/Dementia-Impact-Report.pdf
- ³ Switchboard (2018) *LGBTQ+ Communities and Dementia*
switchboard.org.uk/wp-content/uploads/2018/09/LGBTQ-Dementia-Report_Final.pdf

Research with trans people

While little research has considered the experiences of trans carers, research suggests that a significant proportion of trans people experience mental health problems. Research by Stonewall and YouGov found that two thirds of trans people (67%) had experienced depression in the past year.⁴ A survey conducted as part of the EHRC Transgender Research Review and Scottish Evidence Review found that 88% of trans people had suffered from depression, 80% from stress and 75% from anxiety.⁵ Trans people who are also carers may face additional challenges due to the demands of caring, and limited opportunities to take a break. Research has found that carers are more likely to have poor mental health. The GP Patient Survey 2023, for example, found that 16% of carers had a mental health condition, compared with 12% of non-carers.⁶ Carers UK's State of Caring 2022 survey found that a third of carers reported bad or very bad mental health.⁷

However, trans people can face barriers when accessing support services, and may not be getting the support they need. For example, an investigation by the London Assembly Health Committee into the challenges faced by trans and gender-diverse people in accessing healthcare found that training of NHS staff is patchy, resulting in people not wanting to book GP appointments because they have faced misgendering and misunderstanding.⁸ Trans people who are carers may be even less likely to seek support due to the demands of their caring role. Carers UK's State of Caring 2023 survey found that many carers delayed or cancelled their health appointments, or did not seek help for health conditions, because they were too busy caring. Similarly, the GP Patient Survey 2023 found that 58% of carers had avoided making an appointment, compared with 50% of non-carers.⁹

Many studies have found that certain factors can lead to improved wellbeing, including social and family support.¹⁰ Trans people can experience loneliness and social isolation, particularly if they have experienced discrimination, prejudice, or marginalisation. One study, for example, found high prevalence rates of loneliness and social isolation amongst trans people.¹¹ Research by Stonewall and YouGov found that two in five trans people (41%) have experienced a hate crime or incident because of their gender identity in the last 12 months.¹² Loneliness may be exacerbated for trans people who have caring responsibilities. Carers UK's research has found that many carers feel lonely or isolated, often because they are unable to spend time with family or friends, or because they feel their caring role is unrecognised by society. Carers UK's State of Caring Survey 2022 found that 29% of carers felt lonely often or always.¹³

- 4 Stonewall and YouGov (2017) *LGBT Health in Britain Health report*
stonewall.org.uk/system/files/lgbt_in_britain_health.pdf
- 5 Scottish Government (2013) *Scottish Government Equality Outcomes: Lesbian, Gay, Bisexual and Transgender Evidence Review*
gov.scot/publications/scottish-government-equality-outcomes-lesbian-gay-bisexual-transgender-lgbt-evidence-review/pages/4/
- 6 GP Patient survey (2023)
gp-patient.co.uk
- 7 Carers UK (2022) *State of Caring 2022*
carersuk.org/media/p4kblx5n/cukstateofcaring2022report.pdf
- 8 London Assembly Health Committee (2022) *Trans health matters: improving access to healthcare for trans and gender diverse Londoners*
london.gov.uk/sites/default/files/health_committee_-_report_-_trans_health_matters.pdf
- 9 GP Patient survey (2023)
gp-patient.co.uk
- 10 Aldridge et al. (2022) *Understanding factors that affect wellbeing in trans people 'later' in transition: a qualitative study*
link.springer.com/article/10.1007/s11136-022-03134-xa
- 11 Hajek et al. (2023) *Loneliness and social isolation among transgender and gender diverse people*
ncbi.nlm.nih.gov/pmc/articles/PMC10217806
- 12 Stonewall and YouGov (2018) *LGBT in Britain: Trans report*
stonewall.org.uk/system/files/lgbt_in_britain_trans_report_final.pdf
- 13 Carers UK (2022) *State of Caring 2022*
carersuk.org/media/p4kblx5n/cukstateofcaring2022report.pdf

Research has also shown that being in employment can improve wellbeing. However, trans people can face challenges in the workplace. Some trans people can experience discrimination in the workplace: a survey of employers found that 1 in 3 employers said they are 'less likely' to hire a transgender person and nearly half (43%) were unsure if they would recruit a transgender worker.¹⁴ Trans people who also have caring responsibilities may face additional barriers to being in employment, due to the demands of their caring role. Research suggests that 2m carers have reduced their working hours, and 2.6m have given up work to care.¹⁵

Best practice in supporting LGBTQ+ carers

To help ensure that LGBTQ+ carers are getting the support they need, Carers UK published a good practice briefing on supporting LGBTQ+ carers, highlighting examples projects and organisations supporting LGBTQ+ carers, and recommending actions that organisations can take to be more inclusive to LGBTQ+ carers.



¹⁴ Crossland Solicitors (2018) *Transgender discrimination in UK workplaces*
[crosslandsolicitors.com/site/hr-hub/transgender-discrimination-in-UK-workplaces](https://www.crosslandsolicitors.com/site/hr-hub/transgender-discrimination-in-UK-workplaces)

¹⁵ Carers UK (2019) *Juggling work and care*
[carersuk.org/media/no2l-wyxl/juggling-work-and-unpaid-care-report-final-web.pdf](https://www.carersuk.org/media/no2l-wyxl/juggling-work-and-unpaid-care-report-final-web.pdf)

Census data on unpaid care, sexual orientation and gender identity



Background

In 2021, for the first time, the Census included questions on sexual orientation and gender identity. The data for England and Wales shows that:

- 1.5 million people (3% of the population aged 16 or over) identified as LGB+ (i.e. Lesbian, Gay, Bisexual or Other sexual orientation).¹⁶
- 262,000 (0.5% of the population aged 16 and over) said the gender they identify with is not the same as their sex registered at birth. In England, the region with the highest percentage of people who said their gender identity was different from their sex at birth was London (0.9%).¹⁷

¹⁶ ONS (2022) *Sexual orientation, England and Wales: Census 2021*
ons.gov.uk/peoplepopulationandcommunity/culturalidentity/sexuality/bulletins/sexualorientationenglandandwales/census2021

¹⁷ ONS (2022) *Gender identity, England and Wales: Census 2021*.
ons.gov.uk/peoplepopulationandcommunity/culturalidentity/genderidentity/bulletins/genderidentityenglandandwales/census2021

LGBT+ unpaid carers

The Census also asked people whether they provided unpaid care or support to someone. The data for England and Wales shows that 5 million people in England and Wales are providing unpaid care (an Age Standardised proportion of 9%).

- 147,405 unpaid carers identified with a lesbian, gay, bisexual, or other (LGB+) sexual orientation.¹⁸
- More unpaid carers aged 16 or over identified with a LGB+ orientation in both England (4%) and Wales (4%) compared with non-carers (3% in both countries)
- 25,355 unpaid carers said their gender identity is different from the sex registered at birth¹⁹:
 - » 10,028 unpaid carers said their gender identity is different from their sex registered at birth, but did not give a specific identity
 - » 5,409 unpaid carers identified as a trans woman
 - » 4,541 unpaid carers identified as a trans man
 - » 5,377 unpaid carers gave another identity
- Of the carers who said their gender identity is different from their sex registered at birth:
 - » 10,983 are providing 19 or less hours a week of unpaid care
 - » 7,924 are providing 20 to 49 hours a week of unpaid care
 - » 6,448 are providing 50 or more hours a week of unpaid care.

¹⁸ ONS (2023) *Unpaid care and protected characteristics, England and Wales: Census 2021*.
ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/socialcare/articles/unpaidcareandprotectedcharacteristicsenglandandwales/census2021#unpaid-care-and-sexual-orientation-16
Census 2021

¹⁹ ONS (2023) *Gender identity by unpaid carer status*.
ons.gov.uk/datasets/RM191/editions/2021/versions/1/filter-outputs/bc5c3481-592c-43ee-bd7c-fad6731f492a#get-data

Interviews

Interviewees

A total of 4 unpaid carers were interviewed:

- **Sam** has been caring for his wife, who has a long-term illness, for several years, and became a full-time carer about five years ago. He identifies as gender queer and said he is having 'a bit of a manly phase at the minute' but could also 'go to the other extreme of putting on a wig and dressing completely as female'. He has recently started hormone replacement therapy which he hopes will 'get rid of my facial hair and help with my dysphoria'.
- **Charlie** has been caring full time for 6 years for his partner who has a range of diagnoses. Charlie identifies as non-binary trans. Charlie transitioned about several years ago, and started the process of medically transitioning in 2020 with his first gender appointment taking place shortly before the first COVID-19 lockdown.
- **Rachel** was born intersex and initially lived as a girl, before starting school as a boy, and then living as a man, getting married and becoming a parent. For health reasons, she had to stop receiving testosterone injections, and went into female puberty as a result. After a couple of years, she could 'no longer hide that female body successfully' and because it was illegal for two women to be married in her country at that point, she had to go through the process of having her marriage annulled in order to have her gender identity recognised. She cares for her now ex-wife.
- **Gabi** leaned towards self-identifying as a boy and felt more comfortable with male friends as a child. They now use Mx or unidentified as their title because they don't want people making judgments or assumptions about them, based on their gender. They feel that being a white person who looks like an older woman means they can be labelled as old fashioned, conservative and well-off, when actually they are 'very alternative' and 'very progressive'. Gabi cares for their partner who has a mental health condition.

Thematic analysis



Support with caring in general

None of the carers were receiving support from paid care workers, but some had joined local carers groups. Rachel said she doesn't receive any support from services as she is caring part-time and is able to arrange alternative support from neighbours if she is unable to carry out her caring role. She attends weekly relaxation meetings for carers which she finds 'extremely helpful'. Sam also said he attended social activities for carers and found it 'really quite therapeutic' to speak to other carers who are experiencing the same issues. However, he also felt that support groups and activities were only 'mildly helpful', particularly during the pandemic when 'everything had shut down' and his social life 'dwindled to absolutely nothing'. In contrast, Gabi found that during the pandemic, when events at their local carers centre moved online it became easier for them to connect with others: 'I think more hybrid sort of attendance should be generally more available for everyone'.

Charlie said he had been 'meaning to access' some support groups, but there were various barriers preventing him doing so, such as the groups being 'too far away', a lack of confidence in using technology for online meetings, difficulty maintaining attention in online meetings, and group meetings clashing with other responsibilities such as childcare. He also said that because of the changing needs of his partner, he needed to 'be able to just drop things at the drop of a hat'.

Accessing support as a trans carer

Sam said he had been ‘very open’ about his identity and that he’d ‘never had any problems’ with support services. He said the local carers team had been ‘absolutely great’: when he went to an event ‘in full girl mode, nobody batted an eyelid, no comments, no looks, nothing’. However, Charlie talked about some of the issues he had faced when accessing support as a trans carer. He said it is important to him that his pronouns are respected, but when attending medical appointments with his partner, he is often mis-gendered, despite telling people he is their husband: ‘a good 75% of people that we’ve seen misgender horribly...it’s not always blatant discrimination but it’s very subtle’. He said this was ‘upsetting’, ‘invalidating’ and ‘frustrating’.

Social support, including support from the LGBT community

Gabi said they had joined an LGBT group which was welcoming: ‘I said will I get accepted if I say I’m asexual, they said ‘oh yeah, sure, join us, happy to see you. I like getting welcomed and not being stigmatised just because I look like some sort of mature woman.’ However, Sam said he didn’t always feel comfortable in LGBT+ specific groups: ‘I’ve never really gotten into any groups... those sort of specifically targeted groups, I’ve never ever felt comfortable in any of them, in any circumstances throughout my entire life’. He said that his autism affected his ability to join groups and to socialise with others. Charlie also felt that some LGBT groups ‘aren’t always t-friendly’ and that people make judgements based on his appearance: ‘even though I’m 8 years into my transition I haven’t had anything medically done so I still very much outwardly present as being female, even though I’m not.’ He also said that some trans groups are not always supportive and that ‘gatekeeping can be anywhere’.

Some carers felt that other people did not always accept or acknowledge their gender identity. Sam described how he previously lived in a rural area which was ‘very very conservative’ and he ‘went quite far back into the closet’. He said that after coming out, his friends were ‘absolutely superb’, but his family were not supportive: ‘sadly it meant I lost my parents, I’ve not spoken to my father since and have a very loose relationship with my mother’. Charlie described how attending AA meetings were important in maintaining his health and wellbeing as well as his sobriety, allowing him to fulfil his duties as a carer. He said that his partner ‘tries ‘not to have a bad time’ during his meetings, because they recognise how important those meetings are: ‘my sobriety always comes first, because if my sobriety doesn’t come first, everything comes last’. However, he had to stop going

to some AA meetings because ‘they’re just not supportive’ of his gender identity. He said that a lot of what he shares in meetings are to do with his gender identity and sexuality as his ‘addiction was rooted in being in the closet’, yet he was asked to ‘minimise’ what he shared on this.

Lack of recognition of unpaid carers

Sam felt there is a lack of understanding from others around caring, and that ‘a lot of people are quite ignorant’ about what carers have to do on a daily basis. However, he felt that understanding amongst medical professionals has improved, in terms of him being able to attend medical appointments with his wife. In contrast, Rachel said she found it ‘extremely frustrating’ that because she isn’t in receipt of Carer’s Allowance she isn’t recognised by some organisations as a carer: ‘the assumption by some companies or organisations or departments is if you’re not getting Carer’s Allowance, you’re not really a carer’. She said that sometimes she was unable to support her ex-wife because certain organisations, like banks or hospitals, wouldn’t give her access to certain information.

Gabi said that although they moved to the UK with their partner because their home country were ‘so backwards’ in dealing with mental health problems, they still felt that mental health issues are not very well understood: ‘people say oh you’re just making it up, come on, get over it... they keep on thinking it’s just in your mind, but it can be just as bad or even worse than a physical disability because a physical one is actually more accepted in society’. Gabi felt that their local carers centre was very supportive: they said they had had several Carers Assessments and has received some financial support through those, which they have used to buy art materials: ‘it’s appreciation, it’s nice people appreciate you’.

Impact of caring on finances

Sam said that he and his wife were ‘struggling’ with the increase in the cost of living, and that ‘what little money’ they had to spare each month was being spent on additional costs: ‘we are using things like heating sparingly, so it’s definitely affecting us quite badly’. Rachel said she is not eligible for Carer’s Allowance because she is also in receipt of a pension. As a result, financially she has ‘no support whatsoever’ and because she doesn’t live with her ex-wife, she has to use her own personal expenses to cover the cost of travel. As the cost of fuel has ‘rocketed’ this can be expensive: ‘at one point it was costing me maybe over £100 a month in fuel for the caring role.’

Impact of caring on health and wellbeing

Because he is not receiving ‘anything practical’ to help with his caring role, such as support from paid care workers, Sam is providing full-time care, and ‘would quite like a break’. He also experienced a ‘huge autistic burnout’ about 5 years ago, after he lost his job, and has ‘never really recovered from that since’. Sam described some of the ways in which his autism affected his caring role: he said his ‘executive functioning is appalling’, and that issues with memory meant that he could forget to do certain things, like making appointments, which was ‘very very challenging.’ Sam also said he was diabetic and had to make some lifestyle changes, resulting in losing weight and becoming ‘a lot healthier’. However he found it difficult to keep physically active due to the cost of gym membership and because it was ‘hard to get the motivation’ without people to be active with.

Charlie said it ‘very isolating’ when they were shielding during the pandemic: during this ‘really tricky time’, his anxiety and depression were exacerbated because he missed being around people. However the pandemic also gave him an opportunity to think more about his plans for medically transitioning: ‘I was able to pick myself apart kind of thing and start understanding me and where I wanted to go in my transition’. Charlie said although his wellbeing is now ‘getting back to where it was, the lack of exercise over the last few years has meant he has gained weight and is now ‘classed as obese’.

Gabi felt the most challenging aspect of caring was that ‘you don’t have your own life’. They said that they ‘have to be [on] call any time, at night, day’ and that their partner’s complex needs means that ‘everything is complicated...I have to open doors for him, help him go to the toilet because he can’t touch anything’. Despite these challenges, Gabi felt that had got used to it over the past 40 years: ‘if you were a paid carer and you had to do all this stuff, I think they probably would run away immediately, for me I’ve got the habit of it, I’m able to do it.’

Impact of caring on relationships

Sam said that some of his relationships had been affected by his caring role because he was ‘very difficult to make plans with’, and sometimes had to cancel plans because he needed to look after his wife. Charlie said that the most challenging thing about caring was ‘the unpredictability of it’ and, like Sam, described how he sometimes had to cancel plans because his partner was having a bad day. Gabi said they hadn’t had a visitor to the house in nearly 4 years, and have ‘missed out on all social life’. They said their sons were reluctant to visit and bring their partners and children to the house: ‘nobody will ever come to

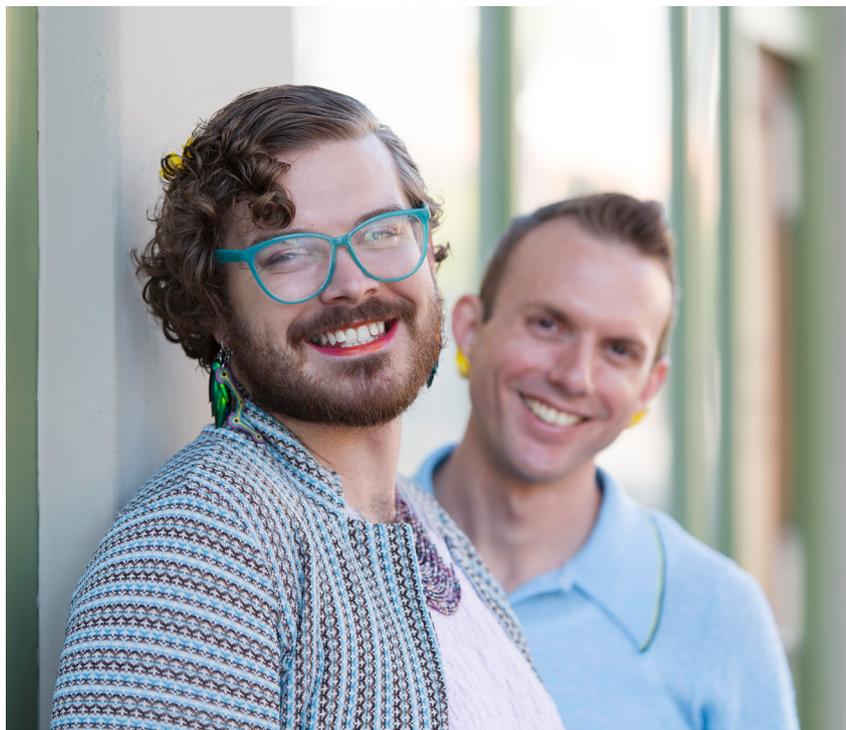
this house... it's something that I can't change, but you still feel frustrated, you feel like a failure in one way or another'.

Rachel felt that although she was 'forced down this particular pathway' of living as a woman due to health reasons, she has experienced 'transgender guilt'. She said her wife 'wouldn't accept' her 'living with her as a woman', still sees her as her husband, and refers to her by her previous name and pronouns. Rachel also talked about 'survivor guilt', which she felt has influenced her caring role: 'I would actually probably bend over backwards to facilitate rather than try and delegate or abdicate my caring responsibilities'. Rachel said that caring has had a positive impact on her relationship with her daughter: 'the fact that I still have a permanent caring responsibility and relationship with her mother is a positive'. However, she said that some of her friends felt that because her marriage is over, she should no longer provide so much care: 'they feel like I give way more than I should'.

Coping with the challenges of caring

Charlie said he has one day off a week where he goes shopping or meets friends, and it was important to him to have that time to himself: 'I need a balance, not just for me and my friendships but I need it for my sobriety and I need it for being a human being'. However, he didn't take any longer breaks because he felt he'd be too worried about his partner and not enjoy it. Rachel said she is 'very active' and finds walking 'very energising and very helpful'. She also meditates in the evening, which has helped her sleep. Gabi said that they coped with the challenges of caring by using humour: 'I try to beat it and get on top of it by being really humorous, keep on cracking jokes and being funny'. They are also a trustee for a few organisations and enjoy campaigning and lobbying for more support for carers and disabled people: 'this keeps me going, actually, to be able to support others'. They said that being able to use their lived experience to help other people 'is a big incentive' and improves their wellbeing: 'it makes me feel more positive really, as long as I can just have a voice, it makes me feel more positive'.

Conclusion



Many studies have found that unpaid carers can face challenges around health and wellbeing, making ends meet, and balancing employment and care. Trans carers may experience additional difficulties, particularly around accessing support – both from support services, and from the wider community. Several studies have shown that trans people can often face discrimination and prejudice, resulting in isolation and poor mental health, and a reluctance to seek help due to previous negative experiences.

This report, based on analysis of the Census 2021, and interviews with carers whose gender identity is not the same or does not sit comfortably with the sex registered at birth, follows Carers UK's research report on LGB carers, published in 2022. It aims to address a current gap in the research by focusing on the experiences of trans carers.

As outlined in the Methodology section, Carers UK contacted over 30 LGBTQ+ organisations as part of the interview recruitment process. Carers were also invited to take part through the Carers UK State of Caring survey. Four trans carers were able to take part in this research and we are extremely grateful to those carers for taking the time to share their experiences with us.

Although it is difficult to draw any conclusions from this research, or make any recommendations for policy and practice, due to the small sample size, this research is helpful in providing an insight into four individuals' experiences of caring. Many of the challenges that the carers experienced were not necessarily related to their gender identity. However, there were important issues raised which did relate to gender identity. For example, one carer described their experiences of being misgendered by health and social care staff. It is vital that health and social care services are inclusive to all carers, regardless of background.

For more detailed advice and information about supporting LGBTQ+ carers, please refer to the [Carers UK LGBTQ+ good practice guide](#).

About the project

Carers UK, in partnership with Carers Trust, has received funding from the Covid 19 Support Fund to support the “Making 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, ethnic minority 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, 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.



Contact

We would like to thank our LGBT Carers Advisory Group for their support.

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