

# Making caring the 10th protected characteristic

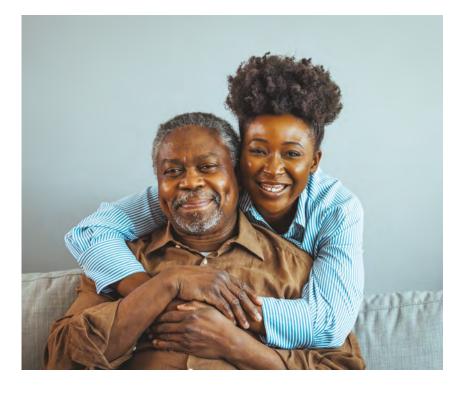
**Research report** 



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## Summary



- Across the UK, millions of people provide unpaid care for an ill, older or disabled family member or friend. Recent Census data suggests that there are 5.7m carers across the UK.
- **Carers can experience a number of challenges.** They are more likely to have poor mental and physical health, and more likely to be living in poverty. Many carers have to give up paid employment to provide care which can lead to financial difficulties.
- Many carers have experienced discrimination or harassment. Carers UK research found that a fifth of carers (19%) said they had been treated unfairly or unfavourably by the general public, and 22% of carers in paid employment said they had been treated unfairly or unfavourably at work. Nearly a quarter of carers in employment (24%) said that they had difficulties meeting their employer's requirements because of their caring role.
- The Equality Act 2010 makes it unlawful to directly discriminate against or harass someone who is associated with someone with a protected characteristic. This means that carers should not be treated less favourably or unfairly because they are associated with someone with a protected characteristic, such as disability or age. However, the law is complex and not widely understood, and caring is not specifically mentioned within the legislation.

- Carers UK is calling on the Government to review the Equality Act 2010 and introduce caring as a protected characteristic, with the same change delivered to Section 75 of the Northern Ireland Act. This campaign is a fundamental part of Carers UK's Vision 2025 strategy as we believe it could transform awareness and support for carers and help combat discrimination and inequality.
- Carers UK research suggests that carers often feel invisible, overlooked and undervalued. 55% of carers need better understanding and recognition of unpaid carers from the general public. Making caring a protected characteristic would increase awareness of caring in society, making caring more visible and more widely understood.
- Making caring a protected characteristic would ensure that public bodies, businesses, and employers promote equality for carers, and treat carers fairly. Carers can experience a number of challenges in relation to their caring role, yet many are not receiving the support they need. 46% of carers need better recognition from the local council of their needs as a carer, and 42% need better recognition from the NHS of their needs as a carer. More support and consideration given to carers would help carers to improve their health and wellbeing, their financial situations, and their ability to juggle care with paid employment.

## Background



Across the UK millions of people provide unpaid care for an ill, older or disabled family member or friend. Census data suggests there could be over 5.7m people providing care across the UK. Carers UK own research indicates that this is a significant underpresentation – polling in 2023 found that there could be 10.6m carers in the UK.<sup>1</sup> Caring can happen to anyone at any time. It can happen overnight, through an accident or illness, or it can develop gradually over several years due to declining health or increasing frailty. Research by the Centre for Care found that between 2010-2020, 4.3 million people became unpaid carers every year – 12,000 people a day.<sup>2</sup>

### Carers' challenges and needs

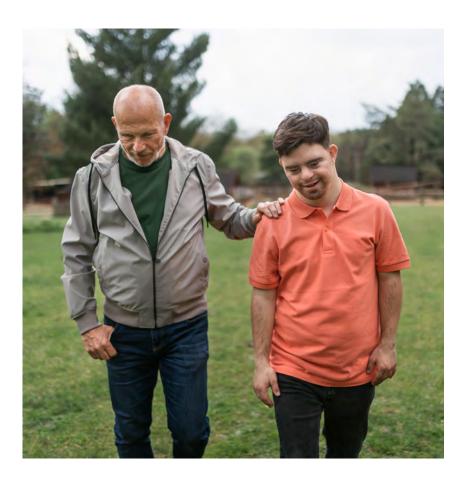
Carers can experience a number of challenges. They are more likely to have poor mental and physical health: the 2023 GP survey in the UK found that 64% of carers said they had a longterm physical or mental health condition, disability or illness, compared to 54% of non-carers.<sup>3</sup> For example, carers were more likely to have arthritis or an ongoing problem with back or joints, compared to non-carers.

Carers have an increased risk of mortality. A longitudinal study in the US found that after controlling for demographic factors, carers reporting mental or emotional strain had mortality risks that were 63% higher than non-carers.<sup>4</sup> Research by Public Health England has shown that caring should be considered a social determinant of health.<sup>5</sup>

- 1 carersweek.org/media/ yqkdkodx/carers-weekreport-2023.pdf
- 2 centreforcare. ac.uk/wp-content/ uploads/2022/11/ CUK-Carers-Rights-Day-Research-Report-2022-Web.pdf
- 3 gp-patient.co.uk/ analysistool
- 4 pubmed.ncbi.nlm.nih. gov/10605972
- 5 assets.publishing. service.gov.uk/ media/60547266d-3bf7f2f14694965/ Caring\_as\_a\_social\_determinant\_report.pdf ukmedia/60547266d-3bf7f2f14694965/Caring\_as\_a\_social\_determinant\_report.pdf

Many carers find that their friendships and relationships are impacted by caring, with less time to spend with family and friends. This can lead to loneliness and isolation. Carers UK's State of Caring survey 2023 found that 50% of carers feel lonely.<sup>6</sup> Carers are often providing many different types of care, from clinical tasks to dealing with medication, and providing practical and emotional support. Juggling several caring tasks, alongside other priorities such as paid employment or childcare, can be stressful for some carers. Carers UK's State of Caring 2023 survey found that over three quarters (79%) of carers feel stressed or anxious.<sup>7</sup>

Carers are more likely to be struggling financially than noncarers. Research by the Joseph Rowntree Foundation found that 29% of carers were living in poverty compared to 20% of those without caring responsibilities.<sup>8</sup> Carers in receipt of Carer's Allowance – the lowest benefit of its kind – are even more likely to be struggling. The Department of Work and Pension's Family Resources Survey 2020/21 found that 1 in 5 households in receipt of Carer's Allowance reported living in food insecurity – nearly three times the rate of the general population.<sup>9</sup> Many carers providing high levels of care are also struggling financially. The New Poverty Institute found that the poverty rate among working-age carers increases with the number of hours they care for, with 37% of working age adults caring for at least 20 hours of care living in poverty.<sup>10</sup>



- 6 carersuk.org/reports/ state-of-caring-survey-2023-the-impact-of-caring-on-health
- 7 Ibid.
- 8 jrf.org.uk/work/uk-poverty-2023-the-essentialguide-to-understandingpoverty-in-the-uk
- 9 gov.uk/government/ statistics/family-resources-survey-financial-year-2020-to-2021
- 10 npi.org.uk/ files/2114/6411/1359/ Carers\_and\_poverty\_in\_ the\_UK\_-\_full\_report.pdf

People with caring responsibilities are less likely to be working and more likely to be working part-time.<sup>11</sup> Caring is a significant and growing reason for employees leaving the labour market. Many people cut back their working hours in order to care, while others feel they have to leave their employment or reduce their working hours if flexible working or unpaid care leave isn't available or supported.

Carers UK research in 2019, based on polling, found that 2.6m people have given up work to care, and 2m people have reduced their working hours to care.<sup>12</sup> The Carers UK's State of Caring 2023, which is largely drawn from the experiences of carers providing substantial care, found that 40% of carers had given up work to care, and 22% had reduced their working hours to care.<sup>13</sup> Some carers also find that they are unable to progress in their careers: research by the University of Sheffield found that 36% of working carers said they had turned down a job offer or promotion, or decided not to apply for a job, because of their caring responsibilities.<sup>14</sup>

Within certain groups of carers, there can be significant challenges. According to the Census 2021, 120,000 children aged 5-17 are providing care in England and Wales;<sup>15</sup> other research has found that there are far more young carers than this, with a total number of at least 800,000.<sup>16</sup> Many of these children are providing substantial levels of care, which can lead to lower educational attainment,<sup>17</sup> with some young carers missing school and experiencing educational difficulties. Caring can also restrict access to education amongst young adults: according to the Office for Students caring responsibilities may prevent many young people from entering further and higher education, while those who do progress often experience struggles and hardships.<sup>18</sup>

Within the adult population, women are more likely to provide care, with those aged between 55-59 providing the most care.<sup>19</sup> Many women are also providing care for dependent children. Research by the Office for National Statistics found that women who care for both sick, disabled or older relatives and dependent children are more likely to report mental illhealth, feel less satisfied with life, and struggle financially.<sup>20</sup> Carers from ethnic minority backgrounds,<sup>21</sup> carers of faith,<sup>22</sup> and LGBTQ+ carers<sup>23</sup> can also experience challenges, particularly in accessing support with caring.

- 11 academic.oup.com/ eurpubarticle/30/4/799/ 5851091?login=false
- 12 carersuk.org/media/no2lwyxl/juggling-work-andunpaid-care-report-finalweb.pdf
- 13 carersuk.org/media/hiekwx0p/carers-uk-crd-employment-report-2023\_final.pdf
- 14 cipd.org/globalassets/media/comms/news/a1supporting-working-carers-2\_ tcm18-80339.pdf
- 15 ons.gov.uk/peoplepopulationandcommunity/ healthandsocialcare/socialcare/articles/unpaidcarebyagesexanddeprivationenglandandwales/ census2021
- 16 actionforchildren.org.uk/ blog/young-carers-whoare-they-and-how-arethey-impacted/
- 17 childrenssociety. org.uk/sites/default/ files/2020-10/young-carers-and-school.pdf
- 18 officeforstudents.org.uk/ advice-and-guidance/promoting-equal-opportunities/effective-practice/ carers/
- 19 ons.gov.uk/peoplepopulationandcommunity/ healthandsocialcare/ socialcare/articles/ unpaidcarebyagesexanddeprivationenglandandwales/census2021#:~:text=In%20England%20 and%20Wales%20 there,over%2C%20 age%2Dstandardised).
- 20 ons.gov.uk/peoplepopulationandcommunity/ healthandsocialcare/ healthandwellbeing/ articles/morethanoneinfoursandwichcarersreportsymptomsofmentalillhealth/2019-01-14
- 21 carersuk.org/reports/ the-experiences-of-blackasian-and-minority-ethnic-carers-during-and-beyond-the-covid-19-pandemic/
- 22 carersuk.org/reports/ the-experiences-of-carers-of-faith/
- 23 carersuk.org/reports/ the-experiences-of-lesbian-gay-and-bisexual-carers-during-and-beyond-the-covid-19-pandemic/

## **Current legislation**



The Equality Act 2010 aims to prevent discrimination and encourage equality. In the Equality Act there are nine protected characteristics: age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex, and sexual orientation. It is against the law to discriminate against anyone because of these characteristics. These are largely mirrored in Section 75 of the Northern Ireland Act, which imposes a duty on government and public authorities to have due regard for the need to promote equality of opportunity between protected groups. This entails not just the elimination of discrimination, but proactive action to address inequality and promote equality of opportunity.

Although caring is not a protected characteristic, carers are protected against direct discrimination or harassment under the Equality Act. This is because under Section 13 of the Act, it is unlawful to directly discriminate against or harass someone who is associated with someone with a protected characteristic. In other words, carers should not be treated less favourably or experience harassment because they are associated with someone with a protected characteristic, such as disability or age.

**Direct discrimination.** If a carer is treated less favourably because they are caring for older or disabled person, this is direct discrimination under the Equality Act 2010. An example of this might be an employer refusing to offer a job to a carer because of their caring responsibilities, or a carer being discouraged to use a service because they care for someone who is disabled.

**Harassment.** If a carer experiences unwanted behaviour which creates an intimidating, degrading, or offensive environment, because they are caring for older or disabled person, this is harassment under the Equality Act 2010. An example of this might be a shop assistant making a negative remark about wheelchair users which a carer finds offensive or upsetting.

The inclusion of associative discrimination in the Equality Act 2010 followed a successful case brought by Sharon Coleman, a Carers UK member, in Coleman vs Attridge Law in 2008. Coleman, who cared for her disabled son, brought a case of unfair dismissal against her employer. Coleman argued that her employer treated her unfairly by not offering her the same flexible working hours as colleagues, and by making abusive comments when she requested time off. After the European Court of Justice found that Coleman could claim direct discrimination and harassment, even though she was not disabled herself, a provision was included in the Equality Act 2010 which made it unlawful to directly discriminate or harass someone associated with someone with a protected characteristic.

Under the Equality Act a person is protected from discrimination in the workplace, when using public services like healthcare or education, when using businesses and other organisations providing services and goods, when using transport, when joining a club or association, or when having contact with public bodies such as a local council or government department.

## Examples of where carers have successfully claimed associative discrimination

In Coleman vs Attridge Law in 2008, Coleman, who cared for her disabled son, brought a case of unfair dismissal against her employer. Coleman argued that her employer treated her unfairly by not offering her the same flexible working hours as colleagues, and by making abusive comments when she requested time off. The European Court of Justice found that Coleman could claim direct discrimination and harassment because of her association with her son who had a protected characteristic.

In Price v Action-Tec Services Ltd t/a Associated Telecom Solutions in 2011, Price successfully claimed direct discrimination and harassment. Price, who was caring for her disabled husband who had leukaemia, claimed that her manager commented that he wouldn't have taken on her on had he known about her husband's illness. Price, who was also disabled herself, was dismissed by her employer. A tribunal found that the employer had unfairly treated Price because of her association with her disabled husband.

In Bainbridge v Atlas Ward Structures Ltd in 2012 Bainbridge claimed that his fixed term contract was not renewed by his employer because of the time he had taken off to care for his disabled wife. A tribunal found that the employer was unable to explain why Bainbridge's contract had not been renewed. As a result, the tribunal found that the employer had treated Bainbridge unfairly because of his wife's disability.

In Follows v Nationwide Building Society in 2020. Follows – a carer for her disabled mother – argued that she had experienced indirect discrimination when her employer made it mandatory for employees to work in the office. When her request to work from home was refused, Follows was made redundant. The Employment Tribunal decided that Follows could bring a claim for indirect discrimination by association.

In Bellini v Italy in 2022, Bellini – who cared for her disabled daughter – lost her job after a working from home policy was revoked. She took legal proceedings to challenge the fact that the Italian social system provides no legal recognition or support for unpaid carers, with the only state assistance being a very low disability allowance. Bellini argued this was a violation of the UN Convention on the Rights of Persons with Disabilities. Although this convention provides no rights for carers, the Committee found that "the rights of persons with disabilities cannot be realised without the protection of family caregivers" and that as a result, carers should have the right to state protection. It concluded that the lack of support provided to Bellini was associative discrimination.

## Where there are gaps in the current legislation



## The concept of discrimination by association is not widely understood

The law in relation to direct discrimination by association is not widely known or understood. This may be partly due to the wording of the Equality Act 2010. While it is clear that it is unlawful to discriminate against someone because of the nine protected characteristics, the provision in relation to associative discrimination is less explicit. The Act describes direct discrimination as:

A person (A) discriminates against another (B) if, because of a protected characteristic, A treats B less favourably than A treats or would treat others.

The phrase 'because of a protected characteristic' implies that person B may not necessarily need to have the protected characteristic themselves. This means that this important protection for carers and other family members is only suggested through the inclusion of one word – 'a' – i.e that it is 'a characteristic' and not person B's characteristic which has resulted in the unfair treatment. Many employers are likely to be aware of the law around direct discrimination. It is less likely that they will be aware of the law around discrimination by association. If employers are unaware of the legal protections for carers, carers are more likely to experience unfair treatment in the workplace. Moreover, if carers themselves are unaware of the law, it is less likely they will feel confident in challenging any unfair treatment. As the law is not explicit about associative discrimination, it is not always covered in basic equalities training for employers and employees.

There is also a lack of awareness in relation to how widely the law can be applied. Much of the guidance in relation to associative discrimination is targeted to employers. This is perhaps unsurprising as the concept of associative discrimination was introduced in legislation as a result of the Coleman vs Attridge Law case, which – as explained previously – found that an employer had discriminated against a carer. While discrimination can occur in the workplace, the Equality Act 2010 also protects carers against direct discrimination and harassment when accessing goods and services, yet few references are made to discrimination in this context.

## The law is unclear in relation to indirect discrimination by association

As the section above explains, carers already have protection under the Equality Act 2010, which makes direct discrimination by association unlawful. However, the wording of the Equality Act 2010 does not expressly allow claims for associative discrimination for what is known as indirect discrimination. An example of indirect discrimination is when an employer applies a new practice to all employees which places a particular group of employees at a disadvantage due to their protected characteristic.

Historically, indirect discrimination claims have required the claimant to have the protected characteristic themselves. More recently, this has not always been the case, as seen in Follows v Nationwide Building Society in 2020, where Follows – a carer for her disabled mother – successfully made a claim for indirect discrimination by association. However, while Follows' claim was upheld, other tribunals may not interpret the legislation in the same way. This means that carers who experience indirect discrimination by association might find it difficult to challenge employers.

## Examples of discrimination experienced by carers



## Carers UK research with carers

Carers UK asked carers about their experiences of discrimination in the State of Caring 2022 survey. Working in partnership with the Disability Law Service, we provided the following definitions of discrimination:

- Associative discrimination where you are treated unfairly because you are connected to someone who has a protected characteristic such as a disability.
- **Direct discrimination** where you are treated unfairly because you are disabled or have another protected characteristic.
- **Indirect discrimination** where someone (such as an employer) has a policy which applies equally to everyone, whether or not they have a protected characteristic, and may disadvantage people with such a characteristic.
- **Harassment** where someone behaves in a way which makes you feel threatened, and their behaviour is because you are disabled or have another protected characteristic.

Carers were asked whether they had been treated unfairly or unfavourably as a result of their caring responsibilities in various different contexts. Many carers felt they had been treated unfairly or unfavourably by the general public, from their employer, or when accessing goods or services.

#### Table 1: Discrimination experienced by carers

Context where carers had been treated unfairly or unfavourably	% of carers who responded saying they had been treated unfairly or unfavourably
By the general public	19%
At work	15%
When receiving public services from the NHS	13%
When receiving public services from the local council	10%
When receiving public services from the Department for Work and Pensions/local Jobcentre/Department for Communities in Northern Ireland/Social Security Scotland/ HM Revenue and Customs	10%
When receiving financial services – eg banks, building societies	8%
When using businesses, on the high street, or online	6%
When renting housing/receiving housing services	5%

## Unfair or unfavourable treatment from the general public



Just under a fifth (19%) of carers said they had been treated unfairly or unfavourably by the general public.

Some carers were more likely to say they had been treated unfairly or unfavourably by the general public. For example:

- Over a quarter (28%) of carers who were disabled said they had been treated unfairly or unfavourably by the general public compared to 15% of carers who were not disabled.
- LGB+ carers were more likely to say they had been treated unfairly or unfavourably by the general public than heterosexual carers (28% compared with 18%).

Carers who were looking after the home/family/dependents full-time or unable to work due to sickness/disability were more likely to say they had been treated unfairly or unfavourably by the general public compared with carers in employment (27% compared with 17%). Many of these carers said that members of the public believed they were unfairly claiming financial benefits because of their caring role.

"Some have judged me for accessing the benefit system, for not working, have made me feel like a scrounger and just look at me differently when they realise I am an at-home carer."

"Some people are judgemental when I say I'm a carer for my son. They even say that I'm a lady of leisure..."

"The DWP have been contacted a number of times by people accusing me of "doing the double" because my neighbours were convinced I must be working. I've had neighbours harass me so frequently that I installed CCTV for my own protection and ended up using it to prove I wasn't the aggressor when they called the police on it."

Several carers felt that members of the public treated them unfavourably because they didn't understand the needs of the person being cared for, particularly if the person cared for had mental health issues or learning disabilities.

"Invisible disability means people often think we are skipping queues."

"My husband has hidden disability – won't use white stick so people don't realise he needs help and think he/we are rude or using blue badge inappropriately."

### Unfair or unfavourable treatment at work



22% of carers in employment said they had been treated unfairly or unfavourably at work.

We asked carers what type of unfair or unfavourable treatment they had experienced at work, which we set out in Table 2.

#### Table 2: Discrimination experienced by carers in employment at work

Issues experienced at work	% of carers in employment who responded
I have difficulties meeting my employer's requirements because of my care responsibilities	24%
I have been treated unfavourably compared to colleagues because I need to provide care for someone	17%
I have been excluded at work because of my care responsibilities	13%
My employer has rules or policies (eg regarding working hours) which I cannot comply with because of my care responsibilities	9%
My employer has refused my request for changes to be made at work to help me with my caring responsibilities	9%
I have felt bullied at work due to the fact that I have caring responsibilities	9%

Nearly a quarter of carers in employment (24%) said that they had difficulties meeting their employer's requirements because of their caring responsibilities. 9% of carers in employment said that their employer had rules or policies (eg regarding working hours) they couldn't comply with because of their caring role. For example, some carers said they were unable to travel to meetings, or work in the office, and that they sometimes faced criticism from colleagues because of this.

"During the pandemic my department had to be redeployed (I was working in the NHS)...was told that I would have to be redeployed with my colleagues, but because of the place and hours expected to work I was unable to comply. Rules and policies in place meant that I had to either resign or face disciplinary action."

"With a previous employer, my caring responsibilities meant that I was unable to attend business meetings involving longdistance travel. This affected how I was viewed by senior managers, who were well aware of my caring commitments."

"During the pandemic I was permitted to work from home which made my caring role easier. However my employer wants full time return to the office soon. This will greatly impact my ability to care."

"Expectation I can be at work for 8.45 start is difficult when my child has to wait for a special needs bus for school. I can miss meetings scheduled early and know work colleagues frown on this."

9% of carers in employment said that their employer had refused their request for changes to be made at work to help them with their caring responsibilities. Several carers said their employers had not allowed them to adjust their working patterns or working hours to juggle work and care.

"Unless managers have similar caring responsibilities they don't understand what's involved in caring for others, I have asked previously to reduce my working hours and was declined."

"I needed to start work later each morning when my mother fell and fractured her pelvis, my employer wasn't sympathetic and didn't agree to this willingly."

Some carers said that requests for leave had been turned down, or that there was a lack of understanding around the need to take time off.

"I asked for a career break to care for my elderly parents but was told it was only an option for staff with young children."

"Told I will have a warning for being late, despite giving the valid reason of having to look after someone." "I was being harassed by my manager for a sick note when my father was dying. I tried to get out of on-call work due to caring but wasn't allowed. I often had to answer out of hours calls at the hospital."

Many carers said had had to give up work, because they didn't receive the support they needed to juggle work and care.

"When I worked for a previous employer, they refused to reduce my working hours to under 30 per week and so they told me I had to make a choice to stay or go."

"I had flexible working hours due to my caring responsibilities but my line manager continually ignored my contract hours resulting in me having to take out an internal grievance which was extremely stressful and eventually I left my employment after 26 years service as my employer would not abide by my flexible hours contract."

"I had made a request for reduced hours, however this could not be accommodated, therefore I had no option other than to retire. I therefore have to wait 6 years to wait for my state pension."

"Following re-organisation, my post (mainly afternoon and evening work), I was offered redeployment to a role that required very early morning starts and was based a further 5 miles from my home. My employers had previously been happy to accommodate my needs and had made reasonable adjustments for my care responsibilities but I could not meet these requirements and they could not be adjusted. I had to take voluntary severance."

Other carers said they had been sacked or made redundant because of their caring role.

"I was made redundant because I couldn't work full time and I couldn't work full time because of my caring responsibilities."

"I was sacked by my employer because of my caring responsibilities."

"My employer didn't care about the reasons why I was often late or had to leave early or had to take calls during work or had appointments or was worried about mum so I was sacked during my probation so there wasn't even a process in place to appeal to."

"Dismissed from a job due to taking time off for caring responsibilities."

17% of carers in employment said they had been treated unfavourably compared to colleagues because they needed to provide care for someone. Several carers felt that they hadn't been given the same opportunities as other carers, or that they were viewed differently to other workers because of their caring roles.

"Passed up for promotion because I couldn't work full time."

"In previous jobs i have been passed over for extra responsibilities because I cannot work enough hours."

"I was overlooked in promotion as the manager said: 'you have so much on your plate already.""

"When I returned to work briefly following my sabbatical the team had undergone changes and I'd effectively been demoted. Since leaving they have supplied a reference to a prospective employer focussing entirely on the issues around the time I was caring which resulted in the job offer being rescinded."

13% of carers in employment felt excluded at work because of their care responsibilities.

"My employer organises staff get togethers outside of my normal working hours which I am unable to attend because of my caring responsibilities. This makes me feel left out and means I miss important gatherings."

"Can't go to work outings such as Christmas dinner as they are in the evening and I've no-one to look after my mum so that I can go."



9% of carers in employment felt bullied at work due to their caring responsibilities.

"My previous line manager was very unsupportive and just told me that I should put my family member in a nursing home."

"My previous job told me I wasn't dedicated enough and needed to stop using excuses or accept that I couldn't do the job."

"In my previous job, my employer would use the fact that he had given me time off for caring to essentially blackmail me into doing impossible work within impossible deadlines, and when I couldn't do it, he would refuse to give me time off to care even though I would make up for the lost hours."

Some carers had challenged discrimination with the support of their Union or through seeking legal advice, or by raising concerns or grievances.

"I had to get the Union involved in the fact that I wanted to reduce my hours for a caring role. I felt degraded and it cause me a lot of stress and anxiety that I had to go to a meeting with my Line Manager and bring a Union Rep with me to fight for something that had and has been given to other members of staff both before and after me. The whole process for me was degrading."

"A previous line manager used my health issues and caring responsibilities against me to instigate disciplinary action for poor performance despite me fulfilling all my work obligations, receiving positive feedback from peers and not having taken any sick leave. It resulted in an appeal which I won, disciplinary action against the line manager and I moved to a new job role."

"I left my job in June 2011 after 6 months sick leave and while caring for our son who was still at school during this time. His home to school transport required me to meet him just before 5pm daily. This conflicted with my work schedule as my wife had a fixed work schedule which required me to leave work each day at 4pm in order to meet him from his school transport. My employer sought to force me to work later hours which was impossible given my circumstances. I firmly believe that they sought to force me out and in doing so I took legal advice and obtained financial compensation for their actions. I did however have to sign a non-disclosure agreement as a result of obtaining this compensation."

### Debbie's experience<sup>24</sup>

Debbie, who cared for her father, had 28 years' experience working in the NHS. When her father's condition deteriorated, she had serious concerns about the quality of social care services he was receiving, meaning she had to look after him herself. She had to cancel several shifts at work as a result.

Debbie had been working in temporary roles within the NHS, but had been trying to find a permanent role within the NHS Trust that would allow her to do her caring role. However, when she applied for a permanent job, her application was turned down because of her caring role, with the employer stating that due to the 'unpredictability' of her caring role, it would not be appropriate to offer her a permanent role. Debbie was not informed her application had been unsuccessful, and only became aware of this when the new starter was appointed.

After her application for the job was unsuccessful, Debbie felt bullied by colleagues, and a complaint was raised about her performance. The employer also cancelled all the further shifts that Debbie was due to work. As the Trust will not give her a permanent job, Debbie is struggling financially, nearly lost her house, and is currently in debt.

#### **Nick's experience**

Nick cares for his mother, and had been working for his employer for a few years. As a manager within the organisation, he had previously received very positive feedback in relation to his performance.

During the COVID-19 pandemic, Nick's mother needed more care and support. Although Nick's employer had indicated that they were supportive of employees who were caring, Nick found that when he needed to take time off to care, his employer began to treat him as a 'massive inconvenience'. His employer also suggested that he took time off sick or used his holiday entitlement to carry out his caring role.

Nick was keen to resolve the situation and requested a meeting with HR in which he requested a different shift pattern. Due to his caring role, he found it very difficult to start shifts early in the morning. As a result, he requested later shifts – which the members of his team were supportive of. The employer stated that if they honoured Nick's request, he would become a more junior team

24 To protect the privacy of individuals, the names and some identifying details have been changed. member, with a considerable reduction in salary, as well as a reduction in hours. Nick did not want to reduce his working hours; he wanted more flexibility with the shift pattern.

Nick submitted a formal appeal, but this was rejected. Following this, Nick felt that managers were trying to 'performance manage him out of the organisation', by finding fault with his performance and claiming that his performance was 'slipping'.

Due to the negative impact this was having on his mental health, Nick resigned from the organisation. He contacted a solicitor specialising in employment law who filed a claim with a tribunal on the basis of associative discrimination. The matter was then settled out of court.

Nick is now working for another organisation who are supportive of his caring role.

### Lucy's experience

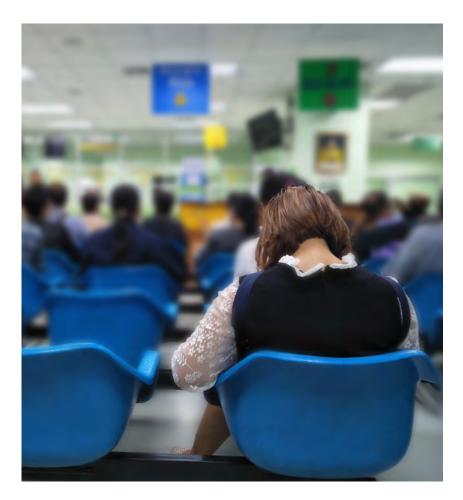
Lucy had been working for employer for 13 years, and was caring for her mother throughout that time. She enjoyed the job and wanted to work while caring. However, there were occasions where she was unable to work or finish her shifts because she needed to support her mother. This was often when her mother was experiencing pain caused by her catheter, with Lucy needing to present when nurses attended. As the waiting times for the nurses were uncertain, it was difficult for Lucy to know how long she needed to be at home for.

Lucy felt her employer was not understanding of her caring responsibilities. When she needed to provide support for her mother, she was asked to take this as her own sick leave. She was also asked to provide medical records to prove that her mother was unwell. Because Lucy was exceeding the amount of sick leave that the employer considered reasonable, she was given several verbal warnings, as well as written warnings. In contrast, Lucy noticed that employees with childcare responsibilities were able to leave shifts to provide childcare.

Lucy tried to resolve the matter, and changed her shift pattern to working days rather than nights. She also tried to arrange any appointments for her mother during her own time. However, she still experienced the same lack of support when she needed to provide care. Lucy felt the employer were 'relentless' in pursuing action against her,

resulting in her spending significant time in meetings which she found stressful. Because she had received warnings over taking sick leave to support her mother, when she was ill herself she went to work despite feeling unwell. Due to the negative impact that this was having on her mental health, Lucy resigned from the job. This had a 'crippling' financial impact, as well as an impact on her health and wellbeing.

### Unfair or unfavourable treatment from the NHS



13% of carers said they had been treated unfairly or unfavourably when receiving public services from the NHS. Some carers said that there was a lack of recognition within the NHS about the demands of caring, and that there was little flexibility in making and attending appointments.

"I was 12 minutes late for my podiatry appointment because of my caring responsibilities, they were dismissive, would not see me and were unsympathetic when I explained and apologised." Some carers were more likely to say they had been treated unfairly or unfavourably when receiving public services from the NHS. For example:

- LGB+ carers were more likely to say they had been treated unfairly or unfavourably by the NHS than heterosexual carers (24% compared with 12%).
- Carers who had been caring for over 50 hours a week were more likely to feel they had been treated unfairly or unfavourably by the NHS (16% compared with 10%).

Other experiences of unfair or unfavourable treatment (local council, Government, financial services, businesses and housing)



10% of carers said they had been treated unfairly or unfavourably when receiving public services from the local council.

10% of carers said they had been treated unfairly or unfavourably when receiving public services from the DWP/local job centre/Department for Communities in Northern Ireland/ Social Security Scotland/HM Revenue and Customs.

"Before Covid, I was sent to several work related seminars and threatened with benefit loss if I did not attend. As soon as I would arrive and tell them I'm a full time carer, they would tell me to go home, I was exempt. Then I would get an angry call threatening my benefits for not showing up. I learned to take a short video of the instructor sending me home. They have since stopped asking me after a made a complaint."

8% of carers said they had been treated unfairly or unfavourably when receiving financial services, including from banks or building societies, and 6% said they had been treated unfairly or unfavourably when using businesses on the high street or online. 5% said they had been treated unfairly when renting housing or receiving housing services.

"My being an unpaid carer is not viewed as being employed. People don't recognise my role or appreciate how much of my time it takes up. I lost my home due to domestic abuse and found it incredibly difficult to find an alternative home because I am not classed as being in employment. Private landlords discriminate against people like me, they won't accept us."

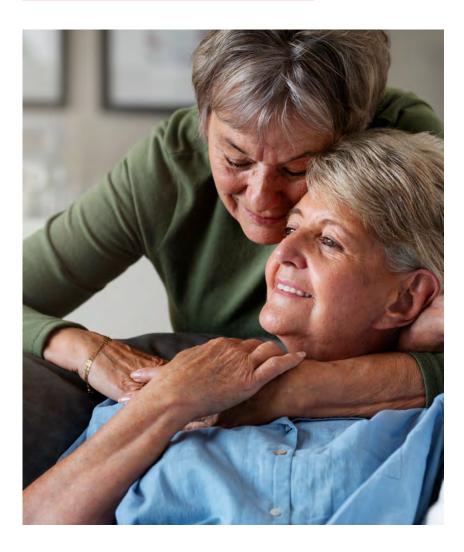
"I have had to cancel appointments due to my carer role. There's been no flexibility. Our mortgage advisor acted affronted when I had to bring my disabled child with me. Others have tried to take financial advantage due to us being so exhausted."

"Some companies are very slow to recognise/accept Lasting/ Enduring Power of Attorneys and refuse to deal with you at all until all they have had and accepted all the paperwork. In some situations, like when trying to sort out electricity to heat the home, it can make a difficult situation vastly worse."

One carer said that they had been discriminated against when going through the process of adoption.

"We are trying to adopt and are not being matched due to my husband's health and the assumed level of support that I require to provide (meaning we can't fully meet at child's needs allegedly!)"

## Why caring should be a protected characteristic



Carers UK believes that unpaid caring for disabled, ill or older relatives or friends should become the 10th protected characteristic. Although having a protected characteristic is not a panacea, it would still be valuable in helping carers to overcome challenges in relation to finances, health and wellbeing, loneliness and isolation, and juggling work and care. It would also make it easier for employers and service providers to recognise carers/caring situations and take steps to avoid discrimination and unfair treatment.

Carers UK is calling on Government to review the Equality Act and introduce caring as the tenth protected characteristic to improve the visibility and equality of carers in our society.

## Increased visibility of caring

Making caring a protected characteristic would transform the way that caring is perceived, making it more visible and more widely understood.

Although carers are protected against discrimination in the Equality Act, caring is not mentioned specifically. Many carers already feel invisible or overlooked, and public awareness of caring is low. Carers UK's State of Caring Survey 2023 found that 55% of carers need more recognition from the general public.

Including caring as a protected characteristic would raise awareness of caring. This could also help reduce the stigma which many carers can experience, for example when taking time off work to provide care or when claiming benefits such as Carer's Allowance. Some carers can feel guilty about asking for help, particularly if they feel that caring is their duty as a family member.

### Increased value of caring

Making caring a protected characteristic would demonstrate that carers are valued by society. If organisations providing support services asked people whether they have caring responsibilities, this would indicate an understanding of the challenges that carers can face, helping carers to feel more valued and improving carers' wellbeing as a result. 59% of carers said that being valued as a carer would improve their wellbeing.<sup>25</sup>

### Earlier identification of carers

Making caring a protected characteristic would lead to more people identifying themselves as carers and accessing support.

Many carers do not recognise themselves as carers until they have been caring for quite some time. Carers UK's State of Caring Survey 2022 found that half of all carers (51%) took over a year to recognise their caring role, with over a third (36%) taking over three years to recognise themselves as a carer.<sup>26</sup>

Many people consider caring as part and parcel of family life and see themselves primarily as a partner or spouse, son or daughter, parent, sibling, cousin, or a close friend. Carers Week research in 2023 found that nearly three quarters of people who are providing, or have provided, unpaid care said they do not identify as or call themselves a carer.<sup>27</sup> Nearly half of those who took longer to identify themselves as a carer (46%) said they missed out on financial support as a result of not knowing they were a carer.

- 25 carersuk.org/media/ xgwlj0gn/soc23-healthreport\_web.pdf
- 26 carersuk.org/policy-and-research/our-areas-of-policy-work/identification/#~:text=Key%20 techniques%20like%20 Carer%20Passports,physical%2C%20mental%20 and%20wellbeing%20 needs
- 27 carersweek.org/media/ yqkdkodx/carers-week-report-2023.pdf

Making caring a protected characteristic would raise awareness of what caring is and what caring can involve, leading to more people identifying themselves as carers. When people identify themselves as carers, they are more likely to look into what support services might be available.

## Better data on carers, leading to more evidence-based decisions

Making caring a protected characteristic could lead to more employers actively keeping track of employees' caring situations, by asking new employees to complete optional monitoring forms as part of the recruitment process, or asking employees whether they are carers within optional equalities sections of staff surveys. Gathering data on employee's caring situations would provide employees with a more detailed picture of staff demographics, leading to more consideration being given to carers – and other employees with protected characteristics – when new policies or practices are introduced.

#### **NHS Staff survey**

In 2020, the NHS included a question in its annual staff survey for the first time to identify carers amongst its workforce. The survey found that one in three of NHS employees are carers – demonstrating that there is a clear need for the NHS to consider how its policies in the workplace might affect employees who are carers.

Many NHS employers have improved their support for carers. For example, one of the values of South West Yorkshire Partnership NHS Foundation Trust is that families and carers matter – so much so that in their mandatory training they include carers as their tenth protected characteristic as an additional consideration alongside those protected under the Equality Act. Carers are a core part of the work at the Trust, included in equality impact assessments for polices and strategies. There are also carer champions embedded in services, and specialist training. Carers are also supported through schemes such as carers passports, a staff network and therapeutic funding.

If more people recognise themselves as carers as a result of caring being made a protected characteristic, this would improve the accuracy of national surveys such as the Census, where currently there is an underpresentation of the number of carers, with many people not reporting that they are carers.

Data from the Census is vital in providing policy makers with accurate data on the prevalence of unpaid caring across the UK, and supporting organisations like Carers UK to campaign on behalf of carers.

#### **GP** patient survey

The GP Patient Survey assesses patients' experience of healthcare services provided by GP practices, including experience of access, making appointments, the quality of care received from healthcare professionals, patient health, and experience of NHS services when their GP practice was closed.

The survey now includes a question asking people whether they provide unpaid care. As a result, the survey provides us with a hugely rich data source, enabling us to compare carers' wellbeing and experiences of the NHS with noncarers, as well as giving us data on carers by local area. The survey has shown, for example, that carers are more likely than non-carers to have a long-term health condition.

### Better support from employers

Many employers, including those who part of Employers for Carers, are already carer-friendly. Support from employers, such as offering opportunities for flexible working and leave can help carers to juggle work and care and reduce stress and anxiety.<sup>28</sup> Some forward looking employers who recognise the business benefits of supporting and retaining carers in their workforce are also already treating caring as a protected characteristic, eg by including carers within their Diversity, Equity and Inclusion policies and guidance, or giving employees the opportunity to self-identify as carers via workplace surveys or HR systems. New legislation giving carers the right to take unpaid care leave came into force in April 2024, supporting even more carers to combine caring with their paid employment.

However, with 600 people a day leaving work to care,<sup>29</sup> more can be done to help carers to juggle work and care. Although the Equality Act protects carers from associative discrimination, it does not – for example – make it compulsory for employers to consider reasonable adjustments for carers. If caring was to be made a protected characteristic, many more employers would also voluntarily adopt the kinds of approaches which can help carers juggle work and care, from offering flexible working hours to providing opportunities to work from home, and to take paid or unpaid carers leave.

28 carersuk.org/media/hiekwx0p/carers-uk-crd-employment-report-2023\_final.pdf

29 carersuk.org/media/no2lwyxl/juggling-work-andunpaid-care-report-finalweb.pdf

Creating an inclusive culture, based on supportiveness, could result in more employees sharing their caring responsibilities with their employer, with more open discussions around what support might be needed to allow them to juggle work and care. This would help improve staff retention, and boost carers' wellbeing in the workplace. Leading companies, such as Centrica, have demonstrated strong business benefits to supporting carers and have suggested that, cumulatively, UK companies could save up to £4.8 billion a year in unplanned absences and a further £3.4 billion in improved employee retention by adopting flexible working policies to support those with caring responsibilities.<sup>30</sup>

Carers UK research found that 57% of carers who are employees said that an understanding line manager helps them balance work and care, and 53% said that flexible working is helpful.

"My current employer is supportive. This is so important. It's difficult juggling work and care, it can be expensive and stressful. In previous years (2010) when caring for a different family member I had an unsympathetic line manager and the difference this makes is highly significant."

#### **Carers Together**

Carers Together recognise that being a carer is an aspect of a person's identity and should be acknowledged as a 'Protected Characteristic'. Following consultation with carers, they have highlighted this within the Core Principles of the Equality, Diversity and Inclusion Policy, ensuring carers are not disadvantaged and are free from discrimination.

Carers Together also wanted to ensure that carers were protected in key areas of employment and developed their Recruitment Policy to reflect this. They expanded on their existing Carers Policy, identifying their commitment to carers and the associated Management Practices that would be implemented. A Carers Charter was also developed and promoted throughout the service. This work has resulted in positive feedback from carers, with several carers stating that they feel more confident and comfortable discussing their individual needs. It has also advanced the development of a positive and inclusive culture within the workplace.

> 30 carersuk.org/media/no2lwyxl/juggling-work-andunpaid-care-report-finalweb.pdf

### **Surrey Heartlands ICS**

For Surrey Heartlands ICS, unpaid carers are a key area of focus, acknowledged as one of the priority populations in Surrey with some of the poorest health outcomes. Surrey Heartlands ICS want to make sure carers are recognised, valued, and supported in their caring roles and as individuals. They know that around a third of their workforce could be an unpaid carer who is juggling work and caring responsibilities. As a result, they are working hard to improve line managers, staff, and volunteers' knowledge of what an unpaid carer is, with consistency in decision making around carers leave and flexible working arrangements, and ensuring employees make the time to attend the staff carers networks to look after their own wellbeing and gain the support they may need from peers and carers team members.

Within Surrey Heartlands, there is an Independent Carers Lead who brings lived experience of caring to the heart of the work they do for unpaid carers in the community and within their workforces. The Carers Lead is part of the ICB's staff carers network which has had a positive impact on carers.

Surrey Heartlands ICS' local authority partner, Surrey County Council, have introduced five days paid leave for their employees who have unpaid caring responsibilities which has had a big impact on the wellbeing of carers in the workforce. There is now a lower number of carers using their annual leave for emergencies and planned appointments relating to caring for a loved one. Surrey Heartlands ICB are hoping to align with their partner this year.

As mentioned previously in this report, the law on associative discrimination is not widely known or understood. If employers do not understand the law, they are at risk of legal and financial challenge. Making caring a protected characteristic would make things much clearer and more manageable for employers, ensuring that they actively consider how inclusive the workplace is for carers, and look very carefully at their recruitment criteria and flexible working policies.

### Better support from public bodies for carers

Under the Equality Act, there is a duty on public bodies to remove or minimise disadvantages experienced by people who share a relevant protected characteristic. If caring was made a protected characteristic, this would lead to more public bodies considering the specific challenges that carers might face when carrying out equality impact assessments or when reviewing support services. This would help ensure that services meet carers' specific needs, as well as reducing any unfair treatment experienced by carers.

As caring is not a protected characteristic, carers' needs are not always considered in the development of new policies. For example, the Department for Education recently issued new guidance setting out local authorities' duties in relation to travel to school. The guidance states that a child will not be eligible for free travel to school on the grounds of their special educational needs, disability or mobility problem if they were able to walk to school if they were accompanied. The guidance indicates that if a child is able to walk, the parent should accompany them or make other suitable arrangements. Cerebra have argued that the pressures on parents of disabled children are different because their children will need to be accompanied to a much higher age than non-disabled peers.<sup>31</sup> As a result, this policy has a disproportionate and discriminatory impact on parents of disabled children, many of whom have already had to reduce working hours or give up work to be available for the school run.

Currently, carers have certain rights, in line with the Care Act 2014 and Health and Care Act 2022. Local authorities have a legal obligation under the Care Act 2014 to review carers' needs by conducting a carer's assessment. However, many carers who have had an assessment are unsatisfied with the service provided. For example, Carers UK research found that 28% of carers who had an assessment said that the assessment had not properly considered the support they need to look after their own health.<sup>32</sup>

NHS hospital trusts also have a legal duty to carers. Under the Health and Care Act 2022, NHS Trusts must involve carers when plans for a patient's discharge are being made. However, many carers are unaware of this right, and many are not consulted during the discharge process. Carers UK research in 2023 found that 36% of carers who had experienced hospital discharge disagreed they were involved in decisions about discharge, and 60% disagreed they were asked about their ability and willingness to care.<sup>33</sup>

Making caring a protected characteristic would be a means of checking that local authorities and hospital trusts are meeting 31 School Transport: what will the Department for Education's updated guidance mean for disabled children and their families? – Cerebra

- 32 carersuk.org/media/ p4kblx5n/cukstateofcaring2022report.pdf
- 33 carersuk.org/media/ xgwlj0gn/soc23-healthreport\_web.pdf

these obligations. These could then be addressed through Equality Impact Assessments. If carers feel they have equal opportunities to non-carers, and that they are treated fairly, and not discriminated against, this is likely to improve carers' health and wellbeing. Carers UK research in 2023 found that 46% of carers needed better recognition from the local council of their needs as a carer, and 42% needed better recognition from the NHS of their needs as a carer. Currently, many carers feel unsupported and unrecognised, and this can affect health and wellbeing.

Increased support could be provided to carers through, for example, health services providing more flexibility for carers when making appointments, allowing carers to get the help they need at a time that fits in with the demands and requirements of their caring role. The Carers UK State of Caring 2023 survey found that 44% of carers said they had put off health treatment because of their caring role.<sup>34</sup> 74% of carers said they would like systems that make managing appointments and speaking to health professionals easier. Ensuring that carers get the help they need to improve their health and wellbeing at the earliest possible stage would result in carers being less likely to need treatment further down the line.

"I am unable to sit for hours in the morning on the phone and then wait for a call back. Then drop everything to go to an appointment."

"We need to be able to make appointments online not spend ages on the phone at an inconvenient time ie in the morning when we have to get the person we care for up, dressed, fed, toileted etc."

The needs of carers should also be considered by daycare service providers, holiday play schemes, and breaks services, when those services consider making any changes to their provision.

### Herts Valleys CCG

As part of their Carers' Strategy, Herts Valleys CCG decided to add carers as a protected group. This was due to a recognition that carers can face health and economic inequalities, and the ruling in the Coleman v Law case showing that carers can be discriminated against by being associated with someone with a protected characteristic.

Adding caring as a protected characteristic has ensured that any discussions related to major policy or services fully consider the impact on carers.

34 carersuk.org/media/ xgwlj0gn/soc23-healthreport\_web.pdf

## Better support from education providers

Some young carers miss school or are unable to complete homework or coursework due to their caring responsibilities, and experience educational difficulties as a result. Children's Society research has found that young carers have significantly lower educational attainment at GCSE level.<sup>35</sup>

Currently, many young carers are not supported at school: a survey by the University of Nottingham found that 42% of young adult carers who were still at school said there was not a particular person at school who recognised them as a carer and helped them. Carers UK research has also found that carers can struggle to balance their caring responsibilities with further or higher education.

### "I was doing a PhD at university, but had to quit due to my caring responsibilities as the university was unwilling to help or compromise."

Making caring a protected characteristic would result in education providers taking action to tackle any challenges faced by carers, helping them to progress in their education and reach their full potential.

### Office for Students Equality of Opportunities Risk Register

The Office for Students Risk Register recently added young carers to their Equality of Opportunities Risk Register. The register sets out a range of risks to equality of opportunity across the higher education sector. The Office for Students suggest that unpaid carers are likely to experience a number of those risks, including not having an equal opportunity to develop knowledge and skills; having a limited choice of course type and delivery model; and experiencing increased cost pressures.

The risk register helps universities in England to consider the ways in which young carers may be at risk of not having equality of opportunity. This will enable more universities to consider the needs of young carers, as well as improving identification and support for students with caring responsibilities.

> 35 young-carers-and-school. pdf (childrenssociety.org. uk)

## Better support for carers from providers of goods and services

Making caring a protected characteristic would ensure that businesses treat carers fairly when providing goods or services, as well as providing better support for carers. That might include, for example, businesses flagging carers on their records so they know the background when dealing with any issues in relation to goods or services.

### **British Gas**

British Gas has a carers' flag on client records so that they know if they are acting on behalf of a disabled person.

They also have information and resources for carers on their website at britishgas.co.uk/about-us/making-adifference/carersuk.html.

Their 'Share That You Care' conversation aims to get people talking and help carers find the support they need.

### Contact

For further information about this briefing, please contact the policy team at policy@carersuk.org

Carers UK, 20 Great Dover Street, London, SE1 4LX

T 020 73784 4999 | E info@carersuk.org | carersuk.org



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