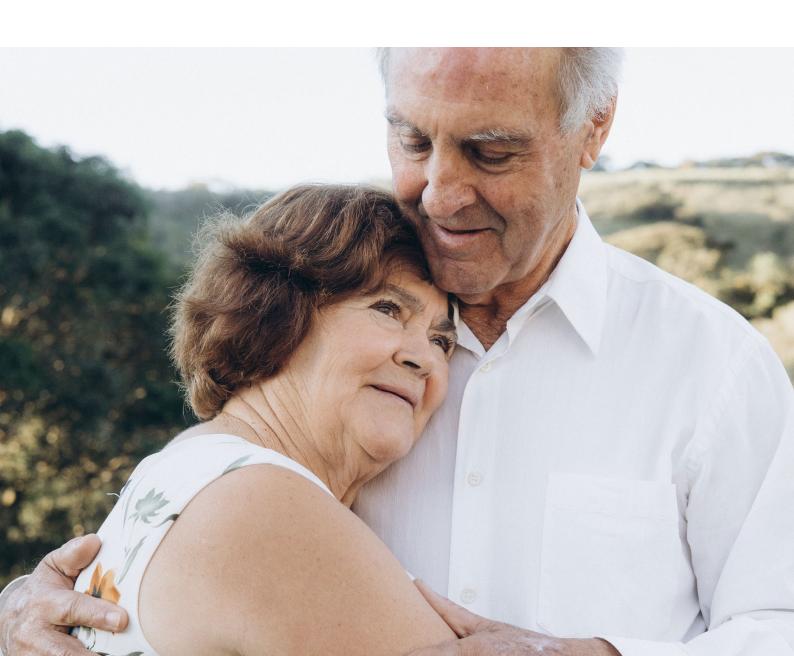


Carers of faith

Research report



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Introduction



This research report considers the experiences of carers of faith: i.e people who provide unpaid care to a family member, friend or neighbour, and who identify with a religion.

Methodology

State of Caring survey

The State of Caring 2023 survey ran from June 2023 to August 2023. Carers across the UK were invited to complete optional questions about their demographic characteristics, including their faith, at the end of the survey. The survey was published on the Carers UK website, publicised on Carers UK social media channels, and shared over email with Carers UK members, Carers UK affiliates (eg carers centres), carers who had previously completed Carers UK surveys, employers and Carers UK volunteers and campaigners.

LSE community engagement programme

Purposive sampling was used to recruit participants for interviews, in which carers of faith were invited to take part. All participants were identified and contacted through the Carers UK State of Caring 2022 or 2021 surveys. Only those who had given consent to be contacted about taking part in research were contacted.

Interviews were conducted by LSE students between January and March 2023. All interviews were conducted online over Zoom. All participants were sent consent forms to review and complete prior to the interviews. Interviews were recorded and transcribed. Thematic analysis was carried out, in which key themes were identified.

Summary

- A significant proportion of carers identify with a religion.

 The Census 2021 found that 49% of unpaid carers were Christian: the most common religion amongst unpaid carers in England and Wales. 56% of carers who completed the Carers UK State of Caring 2023 survey were Christian.
- Having a religion or faith can have a positive impact on carers'
 wellbeing. Carers UK State of Caring 2023 survey found that
 nearly a third (30%) of carers who identified with a religion said
 that having a faith or religion helped improve their health and
 wellbeing. Other research has also found that carers can find
 strength from their faith, leading to a more positive and less
 stressful caring experience.
- Having a religion or faith can influence how people view their caring roles and responsibilities. Some religions encourage a focus on the concerns and needs of others over the self.
 Qualitative research conducted by LSE volunteer students on behalf of Carers UK found that some carers felt that their religion influenced the way they saw their caring role.
- Faith organisations and groups, along with places of worship, can play an important role in supporting carers. Carers UK State of Caring survey found that only 7% of carers of faith received support with their caring role from a faith organisation or place or worship. The Archbishops' Commission on Reimagining Care recommended that there should be a greater role for and investment in communities (including faith communities) to provide support to carers.
- Some carers of faith may not be accessing support from healthcare services due to concerns around services not meeting their needs, a stigma around certain health conditions such as mental health issues, and concerns around discrimination. Health and social care services can help build trust by offering tailored support that considers the faith or religion of the person being cared for.



Data on unpaid care and faith

Census 2021

- 46% of the population in England and Wales said they were 'Christian' in 2021. Although this was a decrease from 59% in 2011, this remained the most common response to the religion question.
- The second most common response was 'no religion' (37% an increase from 25% in 2011).
- There was an increase in the number of people who described themselves as Muslim (6.5% an increase from 5% in 2011) and Hindu (1.7% an increase from 1.5%).
- In England, London was the most religiously diverse region, with over a quarter (25%) of residents reporting a religion other than 'Christian'.

Unpaid carers and faith

- The most common religion amongst unpaid carers was 'Christian' with 49% of carers in England and 46% of carers in Wales reporting this as their religion. This was similar to the pattern seen in 2011.
- In England, the least common religion amongst unpaid carers was 'Buddhist' (0.4%) and 'Jewish' (0.5%). In Wales it was 'Jewish' and 'Sikh' (0.1%).

Table 1: Unpaid carers by religion in England and Wales (Census 2021) Age-standardised percentage

Religion	Carers	Non-carers
Christian	48.5%	47.4%
No religion	35.6%	36.3%
Muslim	6.2%	6.1%
Hindu	1.4%	1.8%
Other	1%	0.6%
Sikh	0.9%	0.9%
Buddhist	0.4%	0.5%
Jewish	0.4%	0.4%

 In both England and Wales there has been an increase in the percentage of unpaid carers identifying with 'No religion' in 2021 compared with 2011. This pattern has also been seen in the usual resident population.

Carers UK State of Caring 2023 survey

• In State of Caring 2023 survey, we asked carers whether they identified with a religion or belief. Over 7,500 carers answered this question. Over half said they were Christian (56%).

Table 2: Unpaid carers by religion in England and Wales (State of Caring 2023)

Christian	56%	
No religion	32%	
Muslim	1%	
Buddhist	1%	
Hindu	0.5%	
Jewish	Less than 0.5%	
Sikh	Less than 0.5%	



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Impact of faith on caring

Carers UK research

- In our State of Caring 2023 survey, we asked carers what improved their health and wellbeing. Nearly a third (30%) of carers who identified with a religion said that having a faith or religion helped improve their health and wellbeing.
- Carers who identified with a religion were more likely to say they had very good or good mental health (27%) compared with carers who did not identify with a religion (20%).
- We also asked carers to tell us about any issues with their health and wellbeing. Carers who identified with a religion were less likely to say that caring made them feel stressed or anxious (77%) than carers who did not identify with a religion (83%). They were also less likely to feel lonely (49% compared with 54% of carers who did not identify with a religion) and less likely to feel depressed (47% compared with 55% of carers who did not identify with a religion).
- Carers who identified with a religion were slightly less likely to say they needed more support to be able to look after their health and wellbeing (62%) than carers who did not identify with a religion (65%).
- Carers who identified with a religion said that their faith could improve their wellbeing.
 - " My faith has made a huge difference. In times that are really hard it lifts me up to sing praise and worship songs."
 - "....being a catholic I found my strength in prayer."

Background

Increasing wellbeing and reducing stress

Religion and spirituality can have a positive impact on wellbeing, hope, optimism, meaning and purpose¹. Religion can provide resources for coping with difficult situations, such as giving meaning to difficult circumstances, providing a sense of purpose, and giving people a sense of control over events through prayer². Some research has found that people use religious beliefs or spirituality to cope with illness³, and experience less depression during illness⁴. It has been suggested that people who have high religious and spiritual involvement tend to give a more positive appraisal of their lives, despite the negative circumstances they may encounter⁵.

- 1 Koenig, H. (2012) 'Religion, spirituality and health: the research and clinical implications'. https://www.ncbi.nlm.nih.gov/ pmc/articles/PMC3671693/
- 2 Ibid
- 3 Koenig, H. Larson, D. and Larson, S. (2001) 'Religion and coping with serious medical illness'. https://pubmed.ncbi.nlm.nih. gov/11261534/
- 4 Mueller, P., Plevak, D. and Rummans, T. 'Religious involvement, spirituality, and medicine: implications for clinical practice'. https://www. mayoclinicproceedings.org/article/ S0025-6196(11)62799-7/pdf
- 5 Villani et al. (2019) 'The role of spirituality and religiosity in subjective wellbeing of individuals with different religious status'. https://www.frontiersin.org/articles/10.3389/fpsyg.2019.01525/full

Research has found that carers are more likely to struggle with poor health⁶. Religious belief can therefore play an important role in helping carers cope with the challenges of caring and the impact caring can have on health⁷. Some research has found that unpaid carers can find strength from their faith or culture⁸, including emotional strength and comfort, and a sense of taking control.⁹ A study with people caring for family members with serious mental illness found that carers who used religion as a means of coping reported having a positive caregiving experience¹⁰. Another study with people caring for a family member with a mental illness found that when other factors were controlled for, having religious feelings was associated with less depression and better self-esteem and self-care¹¹.

Perceptions of caring

Religion can also encourage compassion and support for others, and endorse strong family relationships¹². A study looking at the impact of religion on reducing carers' distress found that carers who used religious or spiritual beliefs to cope with their caring role had a better relationship with the person they cared for¹³. Another study found that adults who frequently attended religious services were significantly more likely to provide assistance to parents, as well as report higher quality relationships and more frequent contact with both parents¹⁴. The researchers suggested that this could be because religious teachings and values encourage a focus on the concerns and needs of others over the self. Another study found that Muslim carers viewed caregiving as an act of kindness and an opportunity to demonstrate faith in Allah¹⁵.

LSE community engagement programme

As part of the LSE community engagement programme, Carers UK commissioned volunteer students to conduct qualitative research to explore the impact of faith and culture on unpaid carers. The students conducted 11 semi-structured interviews with carers of faith from a range of ethnic backgrounds.

The research found that while carers of faith experienced many of the challenges faced by all carers, regardless of religious beliefs, there were some specific aspects of caring associated with their faith. For example:

- Some carers felt that their faith brough them peace and helped them
 to ground themselves. A Sikh carer felt that attending the temple
 gave them a sense of normality, while a Buddhist carer said that
 praying and chanting provided reassurance.
 - "My faith is very useful since it can be practised at home. It establishes a comforting practice to follow and a way of dealing with life."
- Some carers felt that their religion influenced the way they saw their caring role. A Christian carer talked about how the phrase 'love thy neighbour' was fundamental to their decision to become a carer, while a Sikh carer described the concept of 'sewa' (selfless service): that all Sikhs must do good for others without expecting it back.

"I think caring for my mum is my sewa in this life."

08

- 6 GP Patient survey (2023). https://gp-patient.co.uk
- 7 Rammohan, A., Rao, K. and Subbakrishna, D. (2002) 'Religious coping and psychological wellbeing in carers of relatives with schizophrenia'. https://pubmed.ncbi.nlm.nih. gov/11942942
- 8 Span et al. (2019) 'Challenges of combining work and unpaid care, and solutions: a scoping review'. https://onlinelibrary.wiley.com/doi/full/10.1111/hsc.12912
- 9 Health Talk 'Mental health: ethnic minority carers experiences' https://healthtalk.org/mentalhealth-ethnic-minority-carersexperiences/support-fromspirituality-and-religion
- 10 Pearce et al. (2016) 'Religious coping among adults caring for family members with serious mental illness.' https://www. ncbi.nlm.nih.gov/pmc/articles/ PMC 5636637
- 11 Murray-Swank et al. (2006) 'Religiosity, psychosocial adjustment, and subjective burden of persons who care for those with mental illness'. https://pubmed.ncbi.nlm.nih. gov/16524994
- 12 GANS, d., Silverstein, M. and Lowenstein, A. (2009) 'Do religious children care more and provide more care for older parents? A study of filial norms and behaviours across five nations.' https://www.ncbi.nlm.nih.gov/ pmc/articles/PMC4507809
- 13 Chang, B., Noonan, A. and Tennstedt, S. (1998) 'The role of religion/spirituality in coping with caregiving for disabled elders. https://pubmed.ncbi.nlm.nih. gov/9726133
- 14 King, V., Ledwell, M., and Pearce-Morris, J. (2013) 'Religion and ties between adult children and their parents'. https://www. ncbi.nlm.nih.gov/pmc/articles/ PMC3744048/
- 15 Seephom, S., Jittanoon, P., and Balthip, K. (2021) 'Muslim caregivers' experiences in caring for patients receiving peritoneal dialysis'. https://onlinelibrary. wiley.com/doi/epdf/10.1111/ jorc.12408?saml_referrer

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Supporting carers of faith and the people they care for

Carers UK research

- In our State of Caring 2023 survey, we asked carers where, if anywhere, they received support with their caring role. 7% of carers who identified with a religion said they received support with their caring role from a faith organisation or a place of worship.
- Some carers may find that private prayer or worship in their own home to be beneficial, without the need for further support. However, the low proportion of carers receiving support from a faith organisation or place of worship suggests that these organisations or buildings could play a greater role in supporting carers.
- Carers who said they were receiving support said that the help had been beneficial:
 - "My vicar set up a Carer's Home Group and Bible Study Group with volunteers to sit with our loved ones. This helped us to bond as carers and support each other."
 - "Local church runs a dementia cafe for persons with dementia and their carers, this provides a social focal point for a group with similar situations."

Background

Faith community

Places of worship and faith groups can play an important role in supporting carers by bringing people together, offering wellbeing activities and counselling services, and signposting to further resources for carers. However, some research has highlighted that some carers may need more support from their faith community. A qualitative study with Muslim carers of family members with dementia found that while Muslim faith played a pivotal role as a support mechanism for carers, the wider faith community and its leaders did not typically offer support, often due to a lack of awareness of dementia¹⁶. Similarly, a study with Sikh, Hindu, Bangladeshi and Pakistani carers found that many carers felt reluctant to seek help from wider social networks due to concerns about attitudes towards disability¹⁷.

- 16 Kevern et al. (2022) 'Religious influences on the experience of family carers of people with dementia in a British Pakistani Muslim community.' https://pubmed. ncbi.nlm.nih.gov/36611580/
- 17 Katbamna, S. et al (2004) 'Do they look after their own?
 Informal support for South Asian carers. https://onlinelibrary.
 wiley.com/doi/10.1111/j.1365-2524.2004.00509.x

Another study, with over 50 carers of faith, from a range of denominations, found that many experienced loneliness and that the support offered by churches was not always enough¹⁸. One of the researchers suggested that many carers have to drop out of church activities due to the demands of caring, and that church members should not give up on visiting people who are in danger of losing touch with their church¹⁹.

Archbishops' Commission on Reimagining Care

The Archbishops of Canterbury and York tasked the Commission with developing a vision for care and support, drawing on Christian theology. The Commission, led by Dr Anna Dixon, engaged with a wide range of people and organisations, including Carers UK, to inform their National Care Covenant for England, which was published in 2023.

The Commission's report suggested that:

- There needs to be a fundamental shift in the way care is viewed, and a greater public acknowledgement of the ways in which we all need and give care and support. Alongside this, there should be a shift in attitudes towards old age, disability and mental illness, with the church and faith leaders playing their part.
- A National Care Covenant should set out the rights and responsibilities of government, communities, families and citizens. As part of this, there should be greater role for and investment in communities (including faith communities) to provide support. There should also be more support for unpaid carers, enabling them to take a break and to combine caring with paid employment, as well as a government commitment to universal access to care and support.
- The social care system should be simple, consistent and person-centred, with people given the freedom to shape their care and support, and a long-term plan for the recruitment and retention of paid carers.
- 18 Jewell et al. (2017) The loneliness of the long-distance carer: the experience of primary carers of loved ones with dementia. https://www.tandfonline.com/doi/abs/10.1080/14704994.2017.1373473? journalCode=yrur20 Church Times (2017) Dementia
- 19 Church Times (2017) Dementia carers need more support to strengthen their faith, says report. https://www.churchtimes.co.uk/articles/2017/24-november/news/uk/dementia-carers-need-more-support-to-strengthen-their-faith-says-report



Health and social care services

Some studies have found that people from certain faiths may be less likely to seek support from health and social care services, particularly in relation to mental health issues. One study with Arab Muslims found that attitudes towards seeking formal mental health services were affected by cultural and traditional beliefs about mental health problems and perceived social stigma²⁰. A study with Muslim women in Scotland found that some women felt that 'spirit possession' can cause illness and that appropriate help should be sourced through a faith-based route rather than through medical services²¹.

Research has also found that carers can have concerns about health or social care services not meeting their needs or the needs of the person they care for. Carers UK's State of Caring 2022 survey found that 23% of carers said services not meeting needs was a barrier to accessing support²². Carers of faith may have concerns over the person being cared for having access to culturally and faith sensitive care services. Some people may have particular needs in relation to diet, medication, privacy and dress, and prayer and other daily practices. Research with Muslim women found there were certain barriers to using healthcare, including concerns about privacy and modesty, a preference to see female medical practitioners, concerns over maintaining religious practices while in hospital, preference for traditional remedies and fear of discrimination²³.

Evidence suggests that tailoring support services to religious requirements might be beneficial. One study found that when health care services asked about patients' spirituality, there were positive benefits, such as improving wellbeing and helping people feel connected from the health care system²⁴. Acknowledging someone's spirituality or religion can offer reassurance, enhance cultural sensitivity, and improve the relationship between the patient and the healthcare professional²⁵. Spiritual care can also be an important part of palliative care, when having a terminal illness can lead to people thinking about their lives in new ways²⁶.

NHS England offers <u>guidance</u> to NHS managers on how to offer high quality and inclusive chaplaincy services²⁷, while Care Quality Commission <u>suggests</u> some of the ways in which people can be supported to keep up with religious or spiritual practice while receiving care.

- 20 Aloud and Rathur (2009) 'Factors affecting attitudes towards seeking and using formal mental health and psychological services among Arab Muslim populations'. https://www.tandfonline.com/doi/abs/10.1080/15564900802487675#:~:text=The%20results%20 indicated%20that%20 Arab,use%20of%20informal%20 indigenous%20resources. https://www.tandfonline.com/doi/abs/10.1080/15564900802487675
- 21 Gunson et al. 'Spiritual beliefs and mental health: a study of Muslim women in Glasgow.' https://mwrc. org.uk/wp-content/uploads/2023/03/ amina-resources-Spiritual-beliefsand-mental-health-2019.pdf
- 22 Carers UK (2022) State of Caring https://www.carersuk. org/media/p4kblx5n/ cukstateofcaring2022report.pdf
- 23 Tackett et al. (2018). 'Barriers to healthcare among Muslim: a narrative review of the literature'. https://pure.johnshopkins.edu/en/publications/barriers-to-healthcare-amongmuslim-women-a-narrative-review-of-t
- 24 Balboni et al (2022) 'Spirituality in serious illness and health'. https:// jamanetwork.com/journals/jama/ article-abstract/2794049
- 25 Mueller, P., Plevak, D. and Rummans, T. 'Religious involvement, spirituality, and medicine: implications for clinical practice'. https://www. mayoclinicproceedings.org/article/ S0025-6196(11)62799-7/pdf
- 26 Marie Curie. 'Providing spiritual care'. https://www.mariecurie.org. uk/professionals/palliative-care-knowledge-zone/individual-needs/spiritual-care
- 27 NHS England (2022) NHS Chaplaincy guidelines for NHS managers on pastoral, spiritual and religious care. https://www.england.nhs.uk/long-read/nhs-chaplaincy-guidelines-for-nhs-managers-on-pastoral-spiritual-and-religious-care

Good practice examples

Derbyshire Carers

Derbyshire Carers have been reaching out to diverse groups of carers for several years, including running drop-ins and informal events in diverse communities. For over eight years they have run a monthly support group in partnership with a local Methodist Chapel. The group, which is called Carers Oasis, meet in South Derbyshire and is an opportunity for carers to come together and chat about their caring roles in a safe space. The group was previously held in a church, and now takes place in the Oasis Cafe space, alongside their fair trade shop. A Minister attends to provide support and faith guidance on situations, but although carers of faith attend, the group is open to all. Carers can attend with the person they care for, and there is no pressure to attend every session.

As well as opportunities to talk to one another, the group have also done a range of activities from arts and crafts to journalling and sharing poetry. Volunteers provide support with refreshments. Around 25 carers receive support from the group, with 12-15 attending at any one time. As well as the group meetings, there is also an online Facebook group, and many of the carers have formed friendships with people met through the group. The support worker also signposts carers to further advice and information if needed. Many of the carers have found the group beneficial:

- "My faith has always been a part of my daily life and especially now as life becomes more challenging. Also it's good to be able to relate to other people who have similar experiences."
- "We feel we get emotional support and a safe understanding environment. Where we can share our feelings privately. It helps our autism, in many ways. We are not judged."
- "Meeting with other carers of faith. I feel a sense of belonging with shared values and beliefs."
- "I do feel safe relaxed and feel I could talk about anything there."

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West London Synagogue

The West London Synagogue runs several support groups as part of its pastoral care, including a support group for carers. This group was set up in response to a clear need from the local community and is jointly facilitated by a social worker and a rabbi. The group provides an opportunity for carers to meet others and talk about any issues or challenges with caring.

Although the group has invited guest speakers to attend in the past to share advice and information about caring, it is the peer support that people have found to be most beneficial. Carers who attend have appreciated the spiritual advice and guidance offered by the rabbi, alongside the emotional support provided by the social worker. Carers have also found it beneficial to have a support group within their local synagogue. Many people feel attached to the synagogue, and have found solace and comfort there. During the pandemic, the group moved from being face-to-face to online. Although the group sessions are now less frequent, the social worker continues to offer 1:1 support to carers, including signposting and offering a listening ear.

Embracing Age

Embracing Age is a Christian charity which started offering support to carers during the COVID-19 pandemic to help people who were feeling isolated during this time. It runs two weekly online gatherings for carers (one during the day, and one in the evening) hosted by a facilitator, in which carers talk about caring and pray together. The facilitator also reads a poem or text during the session. Carers appreciate the opportunity to connect with other people who have an understanding of the challenges they face as carers, and who also share their Christian faith. Carers can attend as many sessions as they want, for as long as they want to – there is no pressure to attend every week. There is also a private Facebook group where carers can connect outside of the online sessions: many have developed new friendships and met up in person.

The charity has also produced guidance for churches on how to support carers, based on feedback from carers themselves. These guiding principles, available to download on the website, explain some of the issues faced by carers, with advice for churches on how to be inclusive and provide practical support. The charity has recently appointed a part time worker to support the carers project. It has also recently developed a course for churches in supporting carers of people with dementia, and training videos are available to download on its website.

Carers Centre Tower Hamlets

The Carers Centre Tower Hamlets has a Carers Wellbeing Academy which aims to improve carers' wellbeing through information workshops, artistic activities, and support ranging from counselling to carer retreats and physical activity classes. As the borough is very diverse, the centre aims to meet the needs of carers from different faith backgrounds by providing prayer rooms and prayer mats, scheduling activities to take into account prayer times, and acknowledging key religious festivals on its carers blog. The Carers Centre funds the London Buddhist Centre to provide retreats and mindfulness sessions for carers in need of a break, from all faiths. There is also a Bengali dementia carers group which incorporates art activities led by an Islamic pattern artist. In addition, to reach people who may not identify as carers, the Carers Centre carry out outreach work within the Somali community.

The Carers Wellbeing Academy Manager is a member of the Tower Hamlets Interfaith Forum and attends meetings and events to raise awareness about the carer services available. The Forum aims to facilitate communication between different faiths in the borough, and to celebrate the role that faith organisations can play in the lives of residents. Forum meetings are attended by a range of organisations, including Muslim, Christian and Jewish groups. The Carers Wellbeing Academy Manager has also delivered presentations to the Forum and provided referral forms for carer support services.

The Carers Wellbeing Academy Manager is also currently developing guidance for support services, victim support services and the police about how to support carers who have been the victim of a hate crime, including a religious hate crime. This work aims to embed questions about caring into the support that someone receives when reporting the crime.



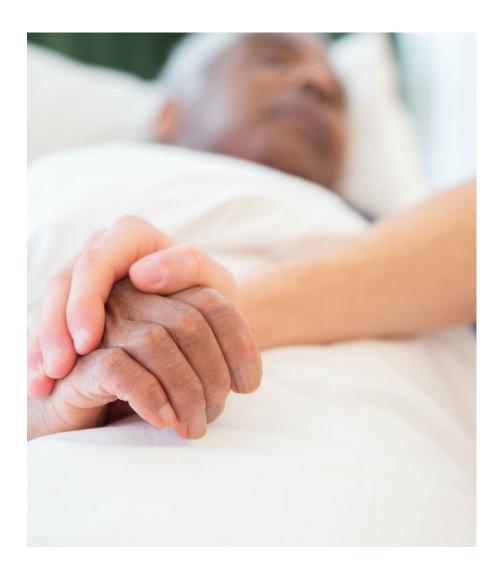
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Conclusion

This research demonstrates that a significant proportion of carers identify with a faith or religion. Many of those carers may gain comfort or support from their faith. As a result, faith organisations and places of worship can play an important role in supporting carers with their health and wellbeing. In some cases, faith organisations and places of worship may also be able to help identify carers and signpost them to help, advice and support services.

Recommendations

- Organisations supporting carers, such as carers centres or carers charities, could consider sharing resources on unpaid caring with faith leaders, to help faith communities identify and support unpaid carers. This might include distributing leaflets, holding training sessions, or meeting with faith leaders to discuss what unpaid caring is and the support available to unpaid carers.
- Support services such as social care services, should consider ways in which support could be tailored to people's religious requirements.
- Government should invest more in community-based programmes that aim to improve health and wellbeing, including those led by faith communities.
- Religious institutions and faith communities could consider ways in which unpaid carers could be supported, such as creating carer networks, providing opportunities for carers to meet other people, or offering volunteering opportunities that can be fitted around caring responsibilities.



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

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