



EXPERIENCES OF OLDER ADULT UNPAID CARERS IN SCOTLAND

MARCH 2023

**CARERS
TRUST**

SCOTLAND

ACKNOWLEDGEMENTS

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About Carers Trust Scotland

Carers Trust works to transform the lives of unpaid carers. It partners with its UK-wide network of local carer organisations to provide funding and support, deliver innovative and evidence-based programmes, raise awareness, and influence policy. Carer's Trust vision is that unpaid carers are heard and valued, with access to support, advice and resources to enable them to live fulfilled lives.

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INTRODUCTION

In recent years Scotland, like many developed nations, has seen a demographic shift in its population. Since 2000, the number of people aged 65 and above in Scotland has increased by a third whilst the number of children has fallen by 6% (Age Scotland, 2022). In 2020, it was reported that there was an estimated one million Scottish residents aged 65 and above and by 2040, this is expected to rise to 1.4 million equating to approximately 25% of the total population (National Records of Scotland).

The Scottish Government is dedicated to making Scotland a fairer place for older adults and have made improving the quality of later life a National Outcome. In 2019, the Scottish Government published 'A Fairer Scotland for Older People' which is a national framework developed to challenge the inequalities older adults face as they age and to celebrate older people in Scotland. In 2022, a consultation was held regarding the Health and Social Care Strategy for Older People and how the Scottish Government can develop this. From the 127 responses, some of the key issues highlighted in the consultation were loneliness and social isolation, having better access to GPs and other healthcare professionals, and support surrounding palliative, or end of life care. As well as feeding these responses into the development of the new strategy, it is important that these issues be considered in the creation of the National Care Service. There are estimated to be over one million unpaid carers aged 65 and above across the UK (Elder website, 2017). A recent report on unpaid carers in Scotland found that 28% of participants were aged 65 and above and 26% were retired (Carers Scotland, 2022). However, in recent years, there has been a lack of national discussion regarding older adults who have unpaid caring responsibilities.

With Scotland's ageing population, the future of unpaid care across the country will become increasingly pertinent to older adult unpaid carers and therefore critical that we have a deeper understanding of their experiences and challenges. This report explores the key findings and makes recommendations based on the experiences provided by research participants. By understanding these and the needs of this age demographic of unpaid carers, we will be able to better support local carer organisations in reaching more unpaid carers and ensuring they are best supported as possible.

KEY FINDINGS FROM OLDER ADULT UNPAID CARER RESPONDENTS

80%

said their physical health had been affected by their caring role.



87%

said that their mental health and wellbeing had been affected by their caring role.



65%

said that they experience feelings of loneliness some of the time, and a **further 19% said they often felt lonely.**



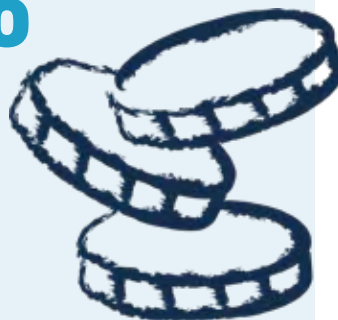
18%

feel as though they have no time for themselves.



82%

felt as though their caring role has financially impacted them.



In past 12 months,

37%

have used less gas and electricity in their homes as a way to save money, and **19% have skipped meals in the past 12 months.**



RECOMMENDATIONS

1. Prioritise financial support and funding for older adult unpaid carers across Scotland. We ask that:

- Scottish Government extend Carer Support Payment to older adult unpaid carers with underlying entitlement who are receiving State Pension. Alternatively, a specific recognition payment for older adult unpaid carers with underlying entitlement to Carer Support Payment should be introduced.
- UK Government urgently extends the Warm Home Discount scheme to include financially vulnerable unpaid carers.
- All local authorities work collaboratively with local carer organisations to provide additional funding and physical spaces to allow respite services to open back up to relieve some of the pressure facing unpaid carers, especially in rural communities.



2. Ensure that the physical and mental health and wellbeing of older adult unpaid carers is robustly supported through decision making at local and national levels. We ask that:

- Health and Social Care Partnerships and local authorities provide ringfenced funding to local carer organisations dedicated to providing physical and mental health support for older adult unpaid carers.
- Health and Social Care Partnerships and local authorities work collaboratively with local carer organisations and third sector organisation stakeholders to develop specific programmes aimed at combatting social isolation and loneliness amongst older adult unpaid carers, such as setting up peer support groups and befriending phone calls.



- All healthcare professionals undertake mandatory Unpaid Carer Awareness Training to ensure all unpaid carers, including older adult unpaid carers, are identified, signposted to local services and informed on what support they are entitled to.

3. Ensure that all pre-existing national and local support outcomes are maintained, and that with any future policy and decision-making where unpaid carers may be stakeholders, older adult unpaid carers are at the forefront of these decisions. We ask that:



- Local authorities ensure that all older adult unpaid carers have an emergency plan and future plan in place as per the requirement of Carers (Scotland) Act 2016.
- Scottish Government ensures there is a dedicated section on unpaid carers in the upcoming Dementia Strategy, with particular focus on where to turn to for support.
- Through their Self-Directed Support plans, all local authorities ensure that all unpaid carers, including older adult unpaid carers, understand the entitlement to Self-Directed Support, the options of support available and that all options are appropriately funded.
- With the creation of the National Care Service, the Scottish Government ensures a sustainable workforce is created which sees unpaid carer support staff as a professional role, properly valued, increased pay, improved working conditions and enhanced training for all staff, in particular Dementia training.
- Scottish Government creates a dedicated section in the Older Adult Framework on older adult unpaid carers.
- Scottish Government introduces a new, dedicated National Outcome on Care to fully value and invest in those experiencing care and all of those who provide it in Scotland, and ensures that the personal and financial wellbeing of unpaid carers across Scotland is fully included within the measures identified to track progress achieved.



- Local authorities and health boards work collaboratively to ensure parents of children with learning or physical disabilities are supported throughout all stages of their child's life including adulthood, with dedicated support to maintaining employment.
- National Carer Organisations ensures the involvement of older adult unpaid carers in any future influencing and campaign work, with older adult unpaid carers being co-producers of future work.

FINDINGS

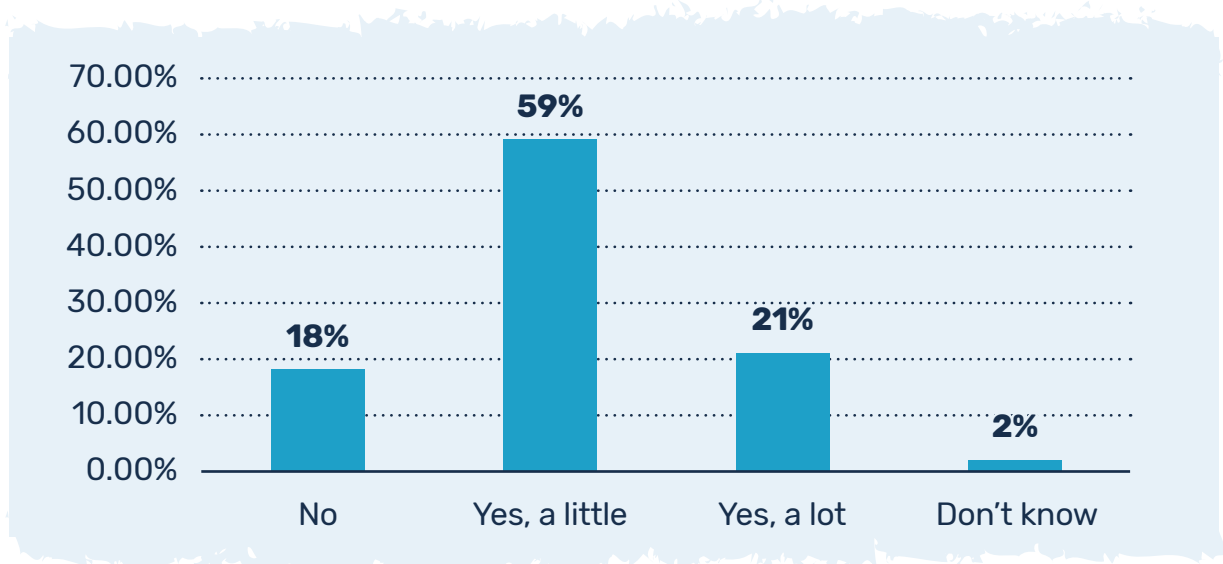
Survey Findings

Health and Wellbeing

In the survey, we asked older adult unpaid carers about their physical and mental wellbeing, as well as discussing issues such as loneliness and isolation.

80% of respondents agreed that their physical health had been affected by their caring role, of which 21% said it had been affected greatly. This response was seen in both female and male older adult unpaid carers. However, across the different age groups, respondents aged 70 and above reported higher levels of being physically impacted by their caring role.

Has your physical health been affected by your caring role?



“ Just exhausted all the time, affects my patience.

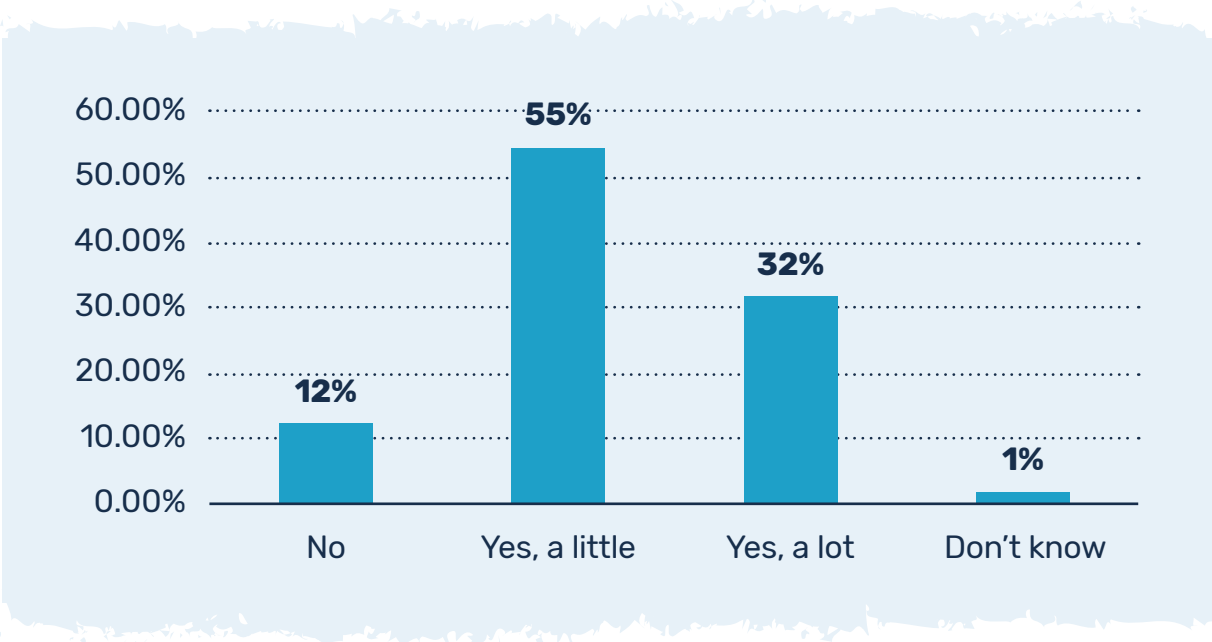
“ My health is deteriorating quite rapidly and I am afraid as to what may happen to loved ones should I die.

“ I am quite surprised how tired I have become looking after my wife who has severe mobility issues and recently being diagnosed with a form of dementia. I recognise my duty of care is essential for her well-being. However, I feel trapped being 24/7 on call and know my own mental health suffers as a result.

“ Although I am still quite fit, as I get older and as my husband's physical ability gets worse, I do worry about how I will manage in the future.

87% of all respondents agreed that their mental health and wellbeing had been affected by their caring role, of which 32% reported that it had been affected greatly. This trend was similar between male and female older adult unpaid carers, and, similarly to physical health, respondents aged 80 and above reported the highest levels of being affected greatly.

Has your mental health and well-being been affected by your caring role?



“ I have felt very stressed with being on constant alert and anxiety about my husband’s actions. And injured myself trying to assist him.

“ I have been caring for my mother who has mobility issues for a number of years but in the last 7 years her general health has significantly deteriorated too. This has had the most impact on my emotional health as my mother struggles to cope with her limitations and needs to express her frustration and it is my role to listen and talk over possible solutions. On a bad day I can find this very depressing.

“ The despair about getting information and help is overwhelming at times and you don’t know where to turn to get help.

“ Just life is more difficult and my mood is not good. I feel cheated of years which should have been happy for us. Now I struggle to be nice to my husband who is like a child instead of a support.

Whilst many older adult unpaid carers have noted feeling that their caring role has had a negative impact on their mental health, many reported that the services provided by local carer organisations have been able to successfully support them and relieve some of negative impact.

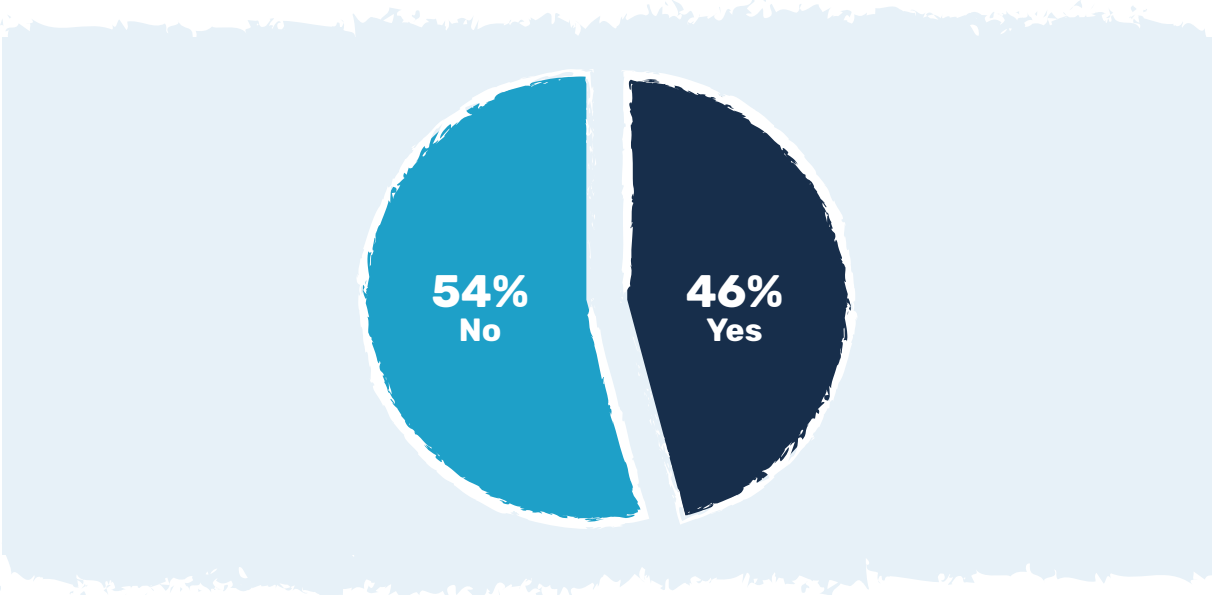
“ If not for Connecting Carers arranging some counselling sessions, I don’t know how I would’ve got through last year. My mental and physical health reached rock bottom and I honestly felt I couldn’t go on any longer. My mother had become very mentally and emotionally abusive. My brother and his family would only help very occasionally when I simply could not go on.

“ Being an unpaid carer is difficult at the best of times, even worse now with the cost of trying to pay for massive increases for gas, electric and everyday living expenses. The support offered by PKAVS has been very good, helped me keep in contact with others, have a short break and basically helped me maintain my mental health status.

Whilst the data collected is not demographically representative of all older adult unpaid carers across Scotland, it does suggest that the older you become, the more likely you are to experience a negative impact on your physical and mental health due to your caring role.

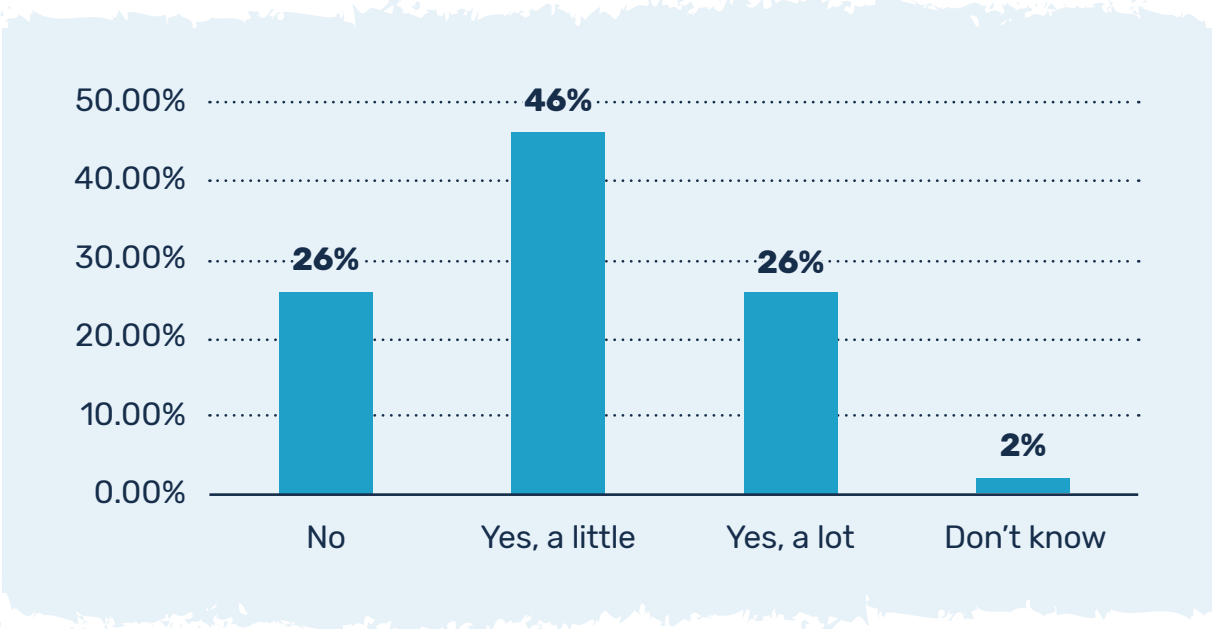
Over the past 12 months, 46% of all respondents had missed some form of health appointment due to their caring role. Male respondents reported higher levels of missing health appointments compared to female respondents, and respondents in their 60s were more likely to miss an appointment than unpaid carers aged 70 and above.

Missed health appointments (GP, hospital etc) in the past 12 months due to caring role



72% of all respondents agreed that their health, physical and/or mental, can affect their ability to carry out their caring role, of which 26% strongly agreed.

Do you feel that your health (physical and/or mental) can affect your ability to carry out your caring role?



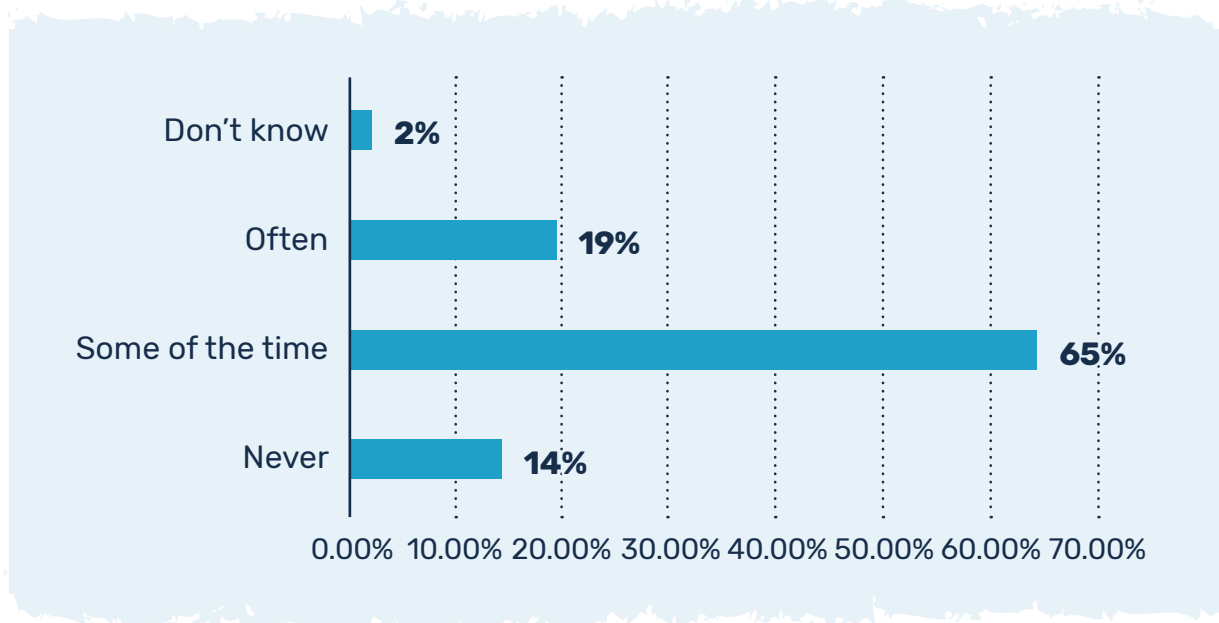
Respondents in their 60s and 70s reported higher levels of being slightly affected. Respondents aged 80 and above had more even distributed answers, reporting higher levels in their ability of being greatly affected but also with some saying they felt their health did not affect their ability at all.

“ I had to give up my career as my own health and wellbeing was impacted with my role. I also had to give up my home and move to a council flat. My whole way of life was changed.

“ I don't know what to do because my husband only wants me to care for him but my health is deteriorating too.

We asked older adult unpaid carers about their experience of feelings of loneliness and isolation. 65% of all respondents reported experiencing feelings of loneliness some of the time, and a further 19% saying they often felt lonely. Unpaid carers aged between 65-69 and 70-79 were more likely to report feelings of loneliness some of the time. However, unpaid carers aged 80 and above had more evenly distributed responses with 38% saying they never experienced feelings of loneliness. When asked whether their caring role had contributed to feelings of loneliness, 65% of all respondents agreed that their caring had done so, of which 21% reported it had greatly contributed to feelings of loneliness.

How often do you experience feelings of loneliness?



“ I care for both my husband and mother... their needs are so different from each other and neither believes they need help nor will accept any external help. Neither of them has much insight into how they are or what their needs are and both of them believe that they are quite independent whereas neither of them would be able to live independently if I didn't look after them. Neither is able to recognise the demands placed on me, no fault of their own. Because they are both quite frail and have mental disabilities too, I often feel the lack of having proper conversation and I don't have enough time just to go for a long walk. It can be frustrating and lonely.

“ Own social life ends- loneliness and stigma is still around us.

“ The loneliness and isolation have really impacted during this time. I have felt despair at not knowing what to expect or who to turn to for advice. I have felt depressed and exhausted in every way, mentally, physically, and emotionally, and not known who to turn to. I have occasionally had thoughts of suicide.

We asked older adult unpaid carers what support could help them feel less lonely, providing multiple choice responses. The most popular answer was having regular breaks from their caring role and accessing support from local carer services (both 47%), followed closely by being able to talk to friends or family (46%) and being able to meet up with other unpaid carers (43%). Female respondents were more likely to want to speak to family and friends and have regular breaks from their caring role, whereas male respondents were more likely to want to meet up with other unpaid carers and access support from local carer organisations to help feel less lonely.

Support

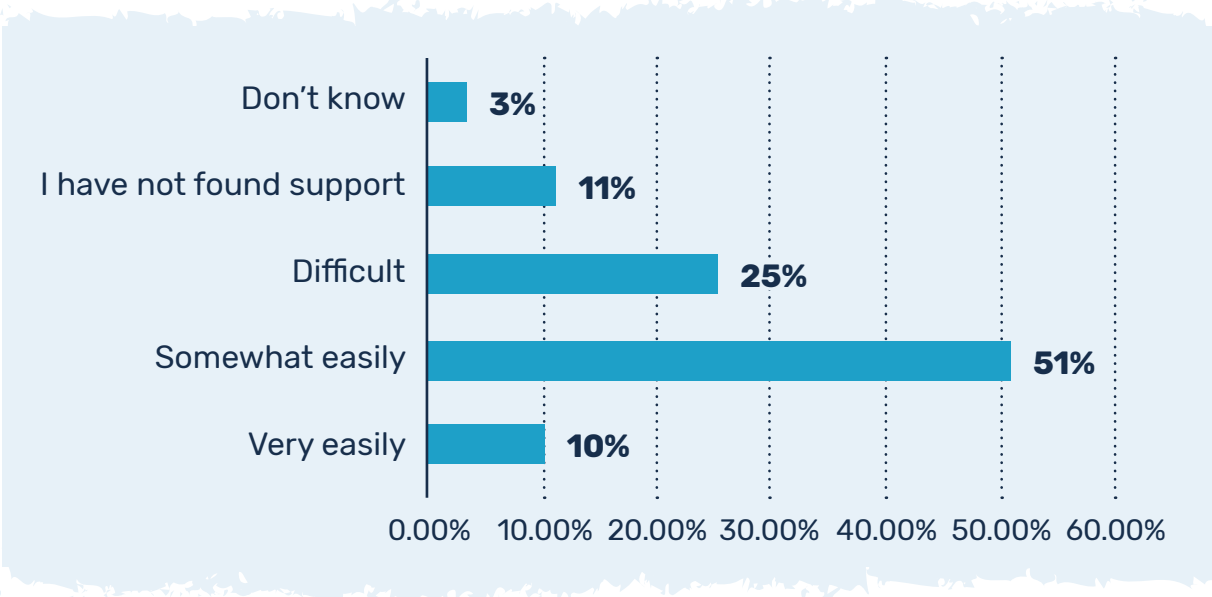
We asked older adult unpaid carers how easily they have been able to find the support they need as an unpaid carer.

- 51% of respondents said that they had found the support they need somewhat easily. A further 10% noted that they could very easily find the support they need.
- 25% of respondents reported having difficulty being able to find the support they need as an unpaid carer.
- 11% reported that they had not yet found support.

When breaking down the different age groups from the data sample, unpaid carers aged 80 and above found it more difficult to find support compared to unpaid carers in their 60s and 70s.

Older adult unpaid carers were asked how much time they are able to find for themselves on average each week. 37% reported they had a couple hours a day, 40% of respondents said they had a couple hours a week, and 18% felt as though they have no time for themselves.

How easily have you been able to find the support you need as an unpaid carer?



This trend was seen with female and male unpaid carers, as well as with unpaid carers in their 60s and 70s.

Keeping with the theme of having time for yourself, we asked older adult unpaid carers if in the past 12 months they have been able to take any break from their caring role. This could be in the form of a weekend away, a holiday, spending time with friends, having time for themselves to do the things they enjoy etc, away from their caring role.

- 40% of older adult unpaid carers said that they had taken a break but that it was not enough time to rest from their caring.
- 18% reported that they had tried to take a break but had not been able to.
- 12% noted that they had not been able to organise a break as they felt it was too stressful to organise.
- 7% reported that they felt they did not need a break from their caring role.

The most common response amongst both female and male unpaid carers was that they had taken a break but felt as though it was not enough time to rest, and females reported higher numbers of satisfactory breaks.

“ My husband is 88 and is sharp as a needle, therefore, he would be hurt if I left him to take a break. I am 14 years younger and greatly appreciate the mental support of Quarriers to enable me to find the strength.

When asked what support would be required in order to have a break, older adult unpaid carers were asked to choose from a multiple choice list, as well as provide their own answers. To facilitate a break, 43% said that they required support from friends and family, 36% would need to arrange a holiday for the person(s) they care for, and 31% would need short-term residential care.

Answer Choices	Response Percentage
Live-in care	16%
Short-term residential care	31%
Arrange a holiday for cared-for person	36%
Support from friends and family	43%
Respite day services	25%
None of the above	7%
Other	10%

*Respondents were given option to choose multiple answers so total response number is over 100

“ It would be nice to have a carer to live-in while I had a longer break.

“ I would need someone else in the family to come with me to help with my wife and look after her for a few hours so I could get some time to myself and not have to be worrying about my wife, who understands that keeping my wife’s dignity is very much part of the process.

We further asked what barriers, if any, prevented them from being able to take a break, with the most common response being services still being closed due to Covid (31%), cost of services being too expensive (27%) as well as being worried about the quality of care being provided (27%).

Answer Choices	Response Percentage
Services difficult to access	23%
Services still closed due to Covid-19	31%
Cost is too expensive	27%
Worried about the quality of care being provided	27%
Shortage in paid care workers	21%
No transport available for my cared-for person	21%
I don’t know about local services available in my area	25%
There are a lack of services available in my area	21%
Services in my area do not meet our care needs	16%
There are no barriers	8%
Other	11%

*Respondents were given option to choose multiple answers so total response number is over 100

“ Have found it difficult to get anyone to look after the person I look after but realise Covid has decimated services.

“ There have been eight companies providing carers in the last twelve years but none of them were able to provide the support or experience needed for my daughter’s severe learning disability which is why I am the only person she will allow to do her personal care.

Discussions with older adult unpaid carers through focus groups and interviews found that many unpaid carers struggle to organise a break for themselves and respite services due to the person they care for not wanting external support from outside the household. This has put additional stress on older adult unpaid carers as they do not want to upset the person they care for yet feel as though they need a break.

“ I’m not sure how my husband would react to going away, even if I went with him which would defy the point of him going. His one experience of being in a care home was one he found upsetting and hated, and he has refused to consider a day care centre. Respite services are also something he won’t consider.

“ Ideally it would be live in care but my husband, who I support, would hate this. He would benefit from some respite but it is unlikely he would accept this.

“ It’s really hard as the person I care for is a highly intelligent, autistic person with physical disabilities who doesn’t want to be dependent on me and my husband but has a desperate need for constant reassurance and someone to talk things through. She phones up umpteen times a day and talks to me. She has low self-esteem and misinterprets people (including us), taking the worst view of things that have been said. She monopolises conversations and shows off her esoteric knowledge as though everyone should know it. I’m exhausted. The only peace that I can foresee comes in the form of a coffin- though I doubt I’d actually take that way out deliberately.

“ Rely on friends to check on son, but often not available. Son won’t accept help from someone he doesn’t know. Keeps door locked and won’t answer whilst I am away.

“ It’s difficult if cared-for person wouldn’t except another care giver.

Finances

Carer’s Allowance

Carer’s Allowance, soon to be reformed as Carer Support Payment in Scotland, is the main benefit for unpaid carers who provide at least 35 hours of care per week. However, older adult unpaid carers who are in receipt of a full State Pension are not eligible to receive Carer’s Allowance.

33% of respondents were currently in receipt of Carer’s Allowance, and 21% previously were in receipt and now receive other benefits or State Pension.

Unpaid carers who are, or were previously, in receipt of this benefit discussed the financial positives of receiving Carer’s Allowance in enabling them to carry out their caring role. However, many noted that despite being pleased they qualified, they felt as though the amount was not sufficient enough.

“ Carer’s Allowance was extremely useful enabling us to do things together. Additionally it provided the funds we required to be able to do things like keep fit (Fit-Life Moray) which we can no longer afford.

“ When I had Carer’s Allowance for the years I was an unpaid carer for one parent then the second, it was so useful as I had a long train trip to be there 4 days a fortnight.



“ It works out at less than £2 an hour less tax-based on the minimum 35 hours a week care. I do caring 24/7/365. I will stop receiving Carer’s Allowance when I get my state pension-why? I will have to carry on caring.



Some older adult unpaid carers noted that they were able to start receiving Carer’s Allowance only because they had been forced to give up employment due to taking on caring responsibilities.

“ I was granted Carer’s Allowance when I took early retirement from my job as my husband needed my help full-time.

“ I had to give up work to look after my husband and was disappointed that the Carer’s Allowance was such a small amount each week.

“ I care on my own for an adult son with additional needs. My ability to work was hugely impacted by my role as a carer, and thus my ability to save for a private pension. Carer’s Allowance was far too little and now I don’t even get that. More and more parent carers will face this situation as children with disabilities survive longer into adulthood than before. This urgently needs to be addressed.

“ Caring has cost so much financially, emotionally and physically, and robbed me of a successful career but no one factors in the impact that has had and will continue to have on me as a carer. Having no choice but to take on caring responsibility has meant so much of normal family life has been sacrificed to the extent my marriage is in jeopardy of failing so potentially having to face being alone when my caring role ends. It seems that it’s acceptable to those who set social care policy that the carer is a disposable resource.

Many older adult unpaid carers discussed through the interviews and focus groups the topic of not receiving Carer’s Allowance when in receipt of a full State Pension. Unpaid carers felt as though it was unfair that due to receiving a State Pension they no longer qualified for Carer’s Allowance.



“ Anger, sheer anger, that I do not qualify for Carer’s Allowance. Just because I receive a state pension – seemingly I’m not entitled. If ever a government could make my role and me as a person feel worthless, lonely and taken for granted, this demonstrates it. I worked 44 years to earn my state pension- it bears no relationship to my relentless role as a 24/7 carer. Excuses!

“ The loss of Carer’s Allowance due to reaching state pension age is a joke. It is an entitlement that I have paid towards since the age of 16. It is not a benefit in my humble opinion, but an earned right.

“ Used to get Carer’s Allowance but not since I got my pension. How is that fair?

“ Not getting Carer’s Allowance is shocking. I care 24/7 non-stop. I would get State Pension anyway caring or not. Pension is not a benefit. When one needs the funds for caring it stops. State Pension is there for me not to supplement the caring role. I have not had Carer’s Allowance in 15 years.

“ Because I cared for my Mum for one year, I lost out on a pension therefore I do not get the full State Pension. Now I find myself caring again for my husband. I had to give up work and worry everyday about money, especially since I have had to use the little I managed to save for making our home and garden wheelchair friendly. My husband has bone cancer which causes him to feel cold all the time. He also has dementia which brings a whole lot of other issues. Not to complain but just making a point that the health of a loved one brings its own worries.

Whilst discussing the topic of Carer’s Allowance, many unpaid carers also mentioned how they felt as though the UK Government and the Scottish Government were not understanding and supportive enough of unpaid carers within this age group.

“ Not enough to live on so claim income support too. Still not enough to live on. Cruel, rotten, disgraceful to claim to value carers then pay them benefits which guarantee poverty. Ditto with the loss of Carer’s Allowance if you earn more than £132 per week. Again, guarantees poverty for providing care for a loved one. Horrible, terrible people/world/governments who can do this.



“ Governments make you feel lonelier by ignoring and failing to recognise the 24/7 role we do. They acknowledge we work hard as carers but choose to take us for granted. I suspect ageism is part of it too. We are an easy target to take for granted and to write off. It’s disgraceful to not be rewarded for the hardest job of my life. Perhaps governments should consider just how much we financially save local authorities by taking on the full-time relentless care of our loved ones ourselves.

“ Lack of support from government. No proper recognition of the strain unpaid carers experience.

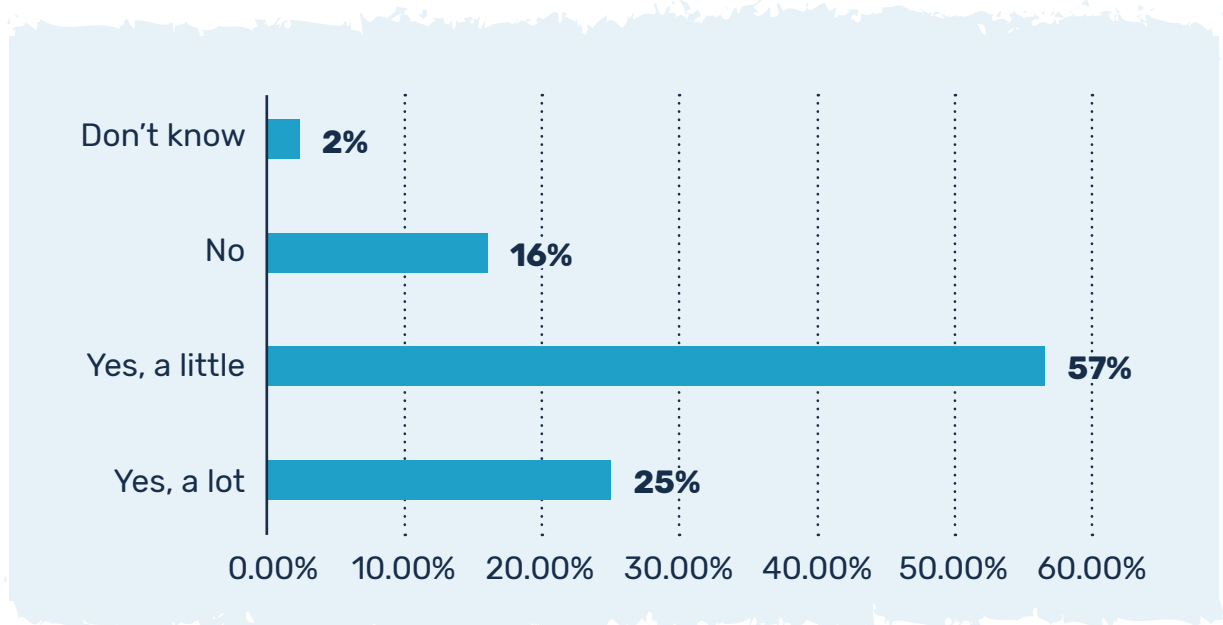
“ It is a very challenging, stressful job, woefully underfunded, undervalued. There does not seem to be an overall cohesive plan guaranteeing an equality of service wherever you are. There is no recognition by the local or national government of the desperate need. It is so short sighted or dishonest perhaps, to expect carers to care 24 hours a day, seven days a week for years and years and expect there to be no cognitive, psychological, physical impact on the carers. If successive governments were honest enough to say they recognise the impact, it would allow an open dialogue to begin. There are some medical, mental health professionals who do vocalise their despair at the shortage of services.

Financial Impact of Unpaid Caring

Through the discussions surrounding Carer’s Allowance, in particular those regarding having to give up employment due to caring responsibilities and not being able to receive Carer’s Allowance due to State Pension overlap, we asked unpaid carers to also discuss the potential financial impact of caring.

82% of all respondents agreed that their caring role had financially impacted them, of which 25% felt as though it had greatly impacted them. This response was shared amongst the different age groups and also between male and female unpaid carers.

Do you feel that your caring role has financially impacted you?



Cost of Living

Since late 2021, the UK has been in a cost-of-living crisis due to the prices of many essential items, such as food and energy bills, having increased rapidly over a short period of time and much faster than the average household income. This has meant that thousands of households in Scotland suddenly find themselves struggling to pay for basic items due to rapid price increase.

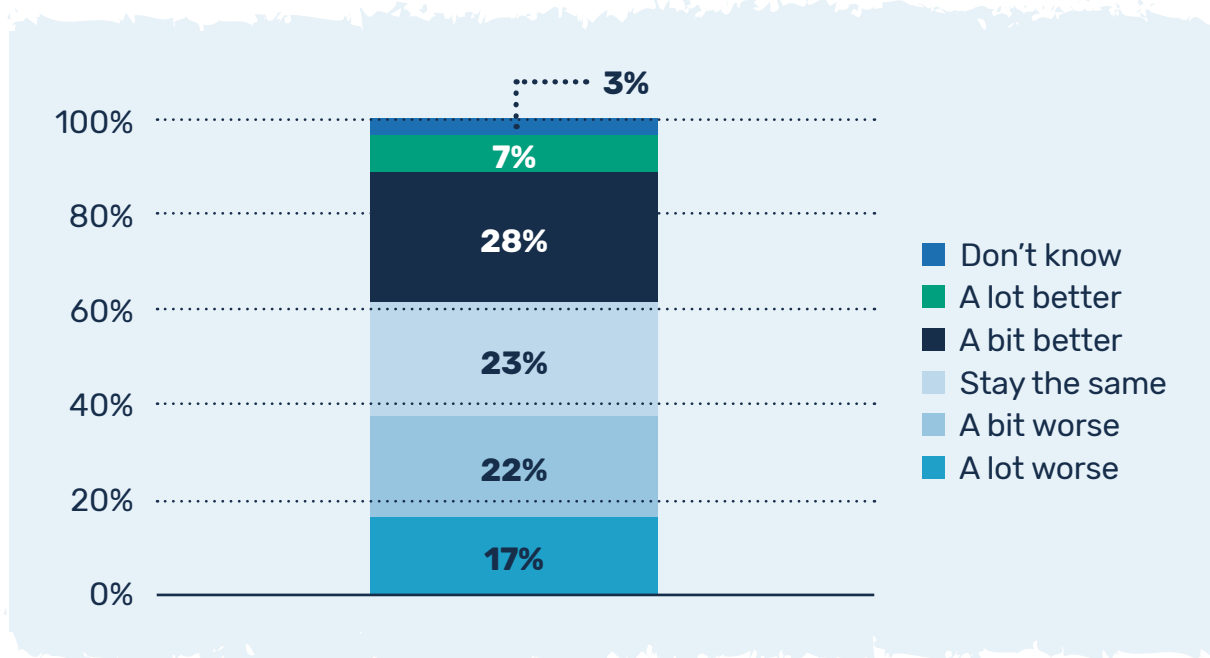


We asked older adult unpaid carers to think about their current financial situation and to compare it to 12 months before which, would have been in the early months of the cost-of-living crisis when prices started to increase. 60% of respondents felt they were financially about the same now as to the year before, however 25% reported they felt financially worse off now.

Similarly, we asked older adult unpaid carers to think about the coming year and how they think they will financially feel in 12 months' time. 17% of respondents felt that they would be a lot worse off while 22% felt they would be slightly worse off next year. 28% thought that they would be slightly better off next year.

As previously mentioned, the cost-of-living crisis has placed enormous pressure on thousands of households in terms of paying more expensive bills whilst their household incomes have stayed the same. We asked unpaid carers how likely, or unlikely, they thought they would struggle to pay a form of household bill. 49% of older adult unpaid carers said that it would be likely that they could struggle to pay a bill, of which 12% said it was very likely.

Thinking about your financial situation over the next 12 months, how do you expect it to get?



Finally, we asked older adult unpaid carers about ways they had been trying to save money over the past 12 months. The most popular response was using less gas and electricity in their homes (37%). Many unpaid carers had stopped subscriptions or memberships, for example for online streaming or for the gym (37%), and a high proportion of respondents also reported cutting back on essentials (35%). Furthermore, 16% of respondents said that they had used a food bank, and 19% had skipped meals in order to save money.

In the past 12 months, which of the following have you had to do? (Please tick all that apply)	Response Percentage
Use less gas/electricity in your home	37%
Skipped meals	19%
Cut back on essentials	35%
Used a food bank	16%
Stopped subscriptions/memberships (Netflix, gym etc)	36%
Given up hobbies or interests due to their cost	23%
Use personal savings for everyday expenses	30%
Used your pension pot for everyday expenses	27%
Borrowed money from a friend or family member	18%
Taken out a loan	5%
Used a credit card for everyday expenses	11%
None of the above	9%
Other	5%

“ I have used savings to make me and my mum’s houses more suitable for us as I have a disability and my mum is 90 and used a rollator in her house, such as installing a chairlift and adapting my bathroom. My mum is also now paying for an alert bracelet.

“ I am disabled and can’t access my local food bank. Even if I could, in a remote rural area where many people want to know everyone else’s private business, I would rather starve.

Whilst these statistics are deeply concerning, discussions held with older adult unpaid carers through interviews and focus groups showed that not all unpaid carers were as concerned with the current cost of living. Many older adult unpaid carers in these discussion noted a significant increase in household bills and had to make cutbacks in spending. However, some noted that they had lived through multiple recessions and financial instability so felt that would be able to find a way to manage this current financial period.



“ My husband and I have always been poor and we have always cut our cloth accordingly.

“ We try to be prudent, always have, and don't spend money unnecessarily. Because of Covid, we've not been going out to eat, etc as we did before, nor have we taken lengthy car journeys as my husband no longer enjoys a nice drive in the car.



THEMES FROM INTERVIEWS/ FOCUS GROUPS

Whilst it was important to gather statistical data from older adult unpaid carers across Scotland, it was of equal importance to ensure we also spoke with older adult unpaid carers to get a more detailed picture of their experiences. From the interviews and focus groups held, we were able to discuss some topics which did not come up in the survey.



Feelings of guilt/resentment

Older adult unpaid carers spoke at length of caring for someone they love and care about and many discussed how they were happy to continue in their caring role as they would prefer they carry out the caring responsibilities than someone else. However, many older adult unpaid carers mentioned the wide range of emotions felt due to their caring role, with many expressing feelings of guilt if they wanted a break from their role.

“ Along with the feeling of relief from having a break came the feeling of guilt for leaving him.

Furthermore, some older adult unpaid carers expressed feelings of anger and resentment at the situation in which they found themselves in. Many unpaid carers who expressed that they felt these emotions said that it could negatively impact their mental health and wellbeing.

“ I was being driven mad by these trivial things which were making me very, very angry and I was really hard on him which I feel awful about.

“ I find I get resentful for the things we can't do.



Emergency and Future Planning

Having an emergency plan, as well as planning for the future, are both extremely important for unpaid carers of all ages. It is a requirement of local authorities to ensure all adult unpaid carers are offered an Adult Carer Support Plan in which unpaid carers can make professionals aware of their caring role in case there is an emergency where they are unable to continue caring.

Through speaking to older adult unpaid carers in interviews and focus groups, the majority did not have an emergency plan in place. Many expressed feelings of worry when they have thought about the future and if they are no longer able to continue their caring role. Some older adult unpaid carers when asked about organising an emergency plan did not have one in place, and in a few instances, did not know what they were.

“What is going to happen when we are not here. My husband and I are both 72 so how much longer can we keep doing this. We can't... Where is the future? We cannot see a future for her, and that is very, very worrying and it is quite hard to deal with every day that there is no future for her without us. I mean, really, the best answer would be that she dies before we do.

“Another worry I have is that if I took ill in the middle of the night, which has happened before, I have to phone the medics and they have to take me to the hospital, what would happen to my husband? I am not concerned about what will happen to me but I worry about him being left alone.

Relationships

Some older adult unpaid carers we spoke with discussed the relationships they have with the person they care for. There was a wide range of different relationships, with some caring for their parents, their partner, or their adult child. For those who were caring for their partner, some older adult unpaid carers expressed that they were initially hesitant to identify themselves as an unpaid carer as they felt they were the person's partner and shouldn't need support to care for them.



“I didn't want to be seen that I needed to be paid to look after my husband. I was far too proud. The fact that we had never claimed benefits of any kind before, I had no idea how to either, but coming here (local carer organisation) makes you realise you are being silly and should accept help.

“There is a difference maybe between caring for a child and caring for your partner because your relationship does change in lots of ways, but that is what you sign up for isn't it.

Some also mentioned about the pressure that can be placed on relationships when undertaking a caring role.

“ I feel I have made the transition from wife to carer. Really that is what it boils down to...I resent it. I try not to feel that as I know I shouldn't. I do still love him but it is very hard.

Parent Carers

As mentioned above, we spoke to many older adult unpaid carers who care for different family members or friends. Through the interviews and focus groups conducted, we could identify that many shared similar experiences in access to support and concerns they have over their role. However, through speaking with some older adult unpaid carers who care for their adult children, some within this group feel they should be recognised as a separate group of unpaid carers.

“ Parent carers are a totally different group because you are supporting someone from birth through to adulthood if you are lucky they survive. There are carers who become carers later on in life say for a parent or for their husband or wife but it is not quite the same. They haven't had such restrictions on their movements and employment.

Some older adult unpaid carers who care for their adult children told of how they had to either give up employment or were unable to have the career path they had hoped for, as when their child was younger there was a lack of awareness for their disability and support. Whilst highlighting that there is better awareness and support for children with learning or physical disabilities now, concern is still held by many parent carers over support for adult children, and their families, are receiving.



METHODOLOGY

Between August 2022 and January 2023, unpaid carers across Scotland aged 65 and above were invited to take part in the research through the completion of surveys, focus groups and one-to-one interviews. A mixed-methods approach was used to integrate qualitative research with quantitative data in order to better understand the challenges and unique experiences of this demographic of unpaid carers.

The survey was widely shared with participants through professional networks, including Carers Trust Scotland’s network of local carer organisations, and through our social media platforms. As well as being available to complete online, paper copies of the survey were also made available to participants upon request.

The survey was also used as a recruitment technique for follow-up interviews with unpaid carers who wanted to share more detail on their experiences as an unpaid carer. Furthermore, focus groups were conducted through a number of local carer organisations across Scotland.

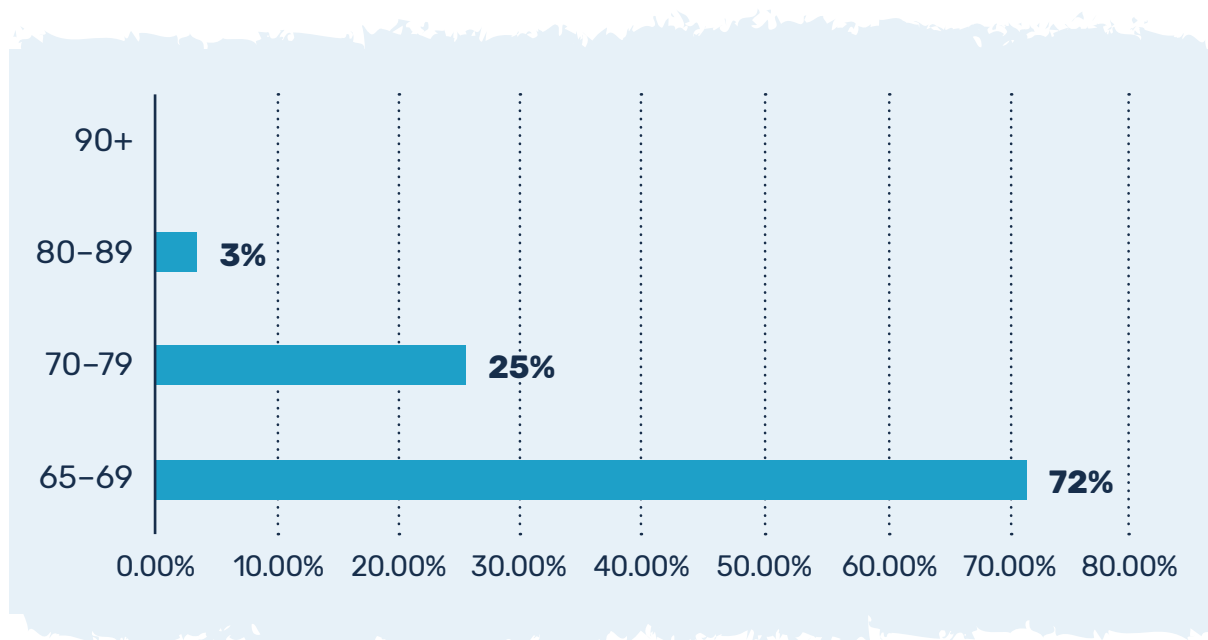
Participants	Survey	One-to-One Interviews	Focus Groups	Total
Unpaid Carers	396	13	56	465

The sample size from this research project is statistically relevant for Scotland, however we must note that this sample size is not demographically representative. We have been able to breakdown quantitative data between the sex of respondents, as well as between the majority of different age groups within the sample. However, we are unable to make statistical comparisons between unpaid carers’ race and ethnicity, sexual orientation and location in Scotland due to demographic sample size. Further research should be conducted to better understand these under-represented groups in our sample.



PARTICIPANT DATA

How old are you?



What race/ethnicity best describes you?	Response percentage
White: Scottish, English, Welsh, Northern Irish	76%
White: Irish	5%
White: Gypsy or Irish traveller	1%
Any other white background	4%
Asian/Asian British: Indian	2%
Asian/Asian British: Pakistani	2%
Asian/Asian British: Chinese	1%
Asian/Asian British: Bangladeshi	2%
Any other Asian/Asian British background	1%
Arab	1%

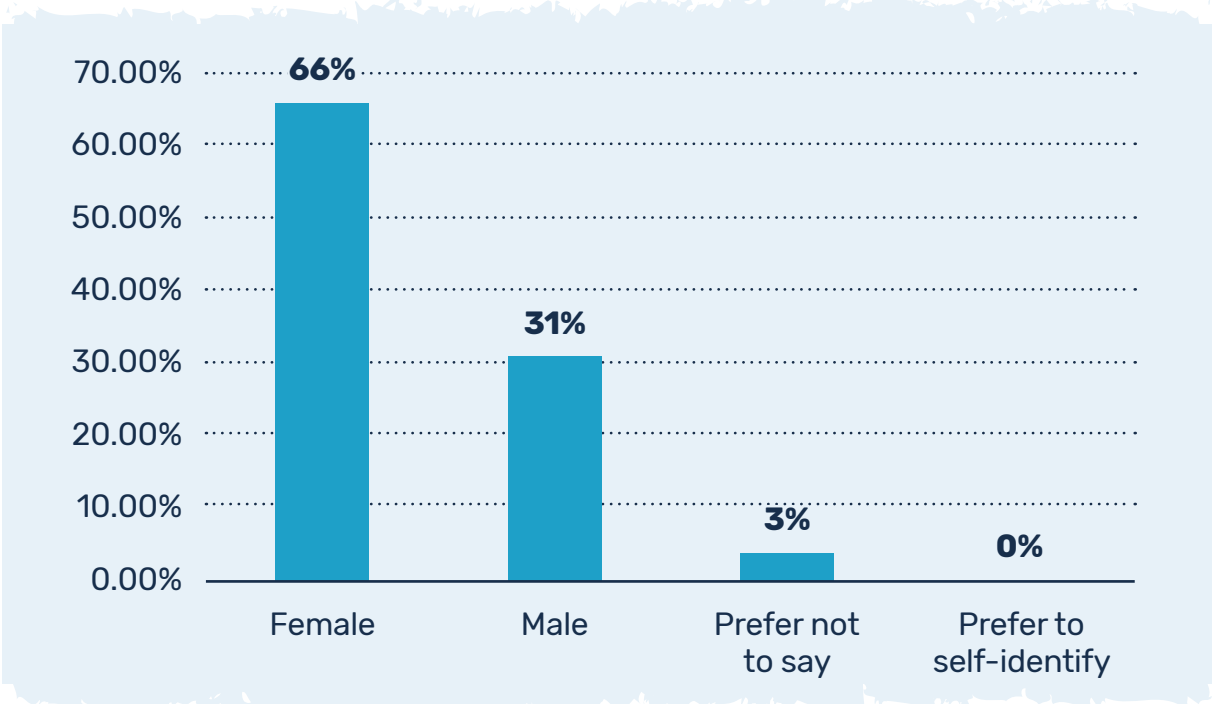
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What race/ethnicity best describes you? (cont.)	Response percentage
Black/Black British: African	1%
Black/Black British: Caribbean	1%
Any other Black/Black British background	0.0%
Mixed/multiple ethnic groups	0%
Prefer not to say	2%
Another race or ethnicity	1%

How do you identify?	Response percentage
Female	66%
Male	31%
Self-identify	0%
Prefer not to say	3%

Is your gender identity the same as the gender you were given at birth?	Response Percentage
Yes	94%
No	3%
Prefer not to say	3%

How do you identify?



Which of the following best describes your sexual orientation?	Response percentage
Heterosexual	79%
Bisexual	6%
Gay or Lesbian	7%
Other sexual orientation	1%
Prefer not to say	7%

What is your current employment status?	Response percentage
Caring full-time	24%
Working full-time (35+ hours per week)	12%
Working part-time (less than 35 hours week)	12%
Retired	37%
Self-employed	3%
Unemployed (currently looking for work)	4%
Unemployed (not currently looking for work)	6%
Student	1%
Not working due to disability or long-term health condition	1%
Other	0%

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