Midlothian Carers Survey 2023: Report

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Midlothian
Health & Social Care
Partnership

1.0. Introduction

The Midlothian Carers Survey is undertaken every two years to understand the views and experiences of unpaid carers locally. The survey also assesses satisfaction with services currently offered and gathers feedback on the development of future support for unpaid carers. The findings presented in this report will be used to inform the Midlothian Carers Strategy, improve carer support services and shape the future development of services. Thank you to all carers who took the time to share their views and experiences, and to our partners for their support in distributing the survey and enabling carers to take part.

The 2023 Midlothian Carers Survey was funded by Midlothian Health and Social Care Partnership (MHSCP) and led by VOCAL (Voice of Carers Across Lothian) on behalf of organisations that support unpaid carers in Midlothian. It builds on surveys conducted by VOCAL in 2021, 2017 and 2015. The research was conducted by Scotinform, an independent research agency.

Based on the findings, it is evident that unpaid carers are facing unprecedented challenges, with many experiencing health and wellbeing crises, as well as significant financial strain, with no opportunity or ability to take a break from caring. The survey highlights the urgent need for improved resources and support systems to address these issues, ensuring that carers can continue in their roles effectively. Implementing the recommended actions will be crucial in providing the support carers require and improving carers' wellbeing.

2.0. Unpaid carers definition

The Scottish government defines an unpaid carer as someone who is providing care and support to family members, friends and neighbours. The person or people they care for may be affected by disability, physical or mental health conditions, frailty or substance use. A carer does not need to be living with the person they care for. Anyone can become a carer at any time in their life and sometimes for more than one person at a time. Carers can be any age from young children to older people.

3.0. Recommendations

1(a) Recommendation: MHSCP will continue to invest in carers support organisations and in the training of health and social care staff to promote carer's rights. (Key Findings 1)

1(b) Recommendation: Review uptake of Adult Carer Support Plans (ACSP) and Young Carer Statements (YCS) across MHSCP and VOCAL to identify specific areas where there are gaps in uptake and identify potential root causes. (Key Findings 5.2)

2. Recommendation: MHSCP continue to support interventions to reduce the financial impacts associated with caring. This includes income maximisation, welfare rights and targeted initiatives such as the Carer Assistance Fund. (Key Findings 4.2, 5.4)

3. Recommendation: MHSCP should continue to support a range of services to facilitate breaks from caring including: providing formal, personalised respite support; investing in easy access breaks through short break fund; supporting community-based supports for carers. (Key Findings 4.3, 5.5)

4. Recommendation: MHSCP, with partners, and in line with national carer strategy, continue to commit to the provision of services and supports that aim to mitigate the impact of caring on carers' health, wellbeing, employment and finances. (Key Findings 5.3)

5. Recommendation: MHSCP will work in partnership with statutory and third sector agencies to ensure that carers are identified early. (Key Findings 5.6)

6. Recommendation: Care package reviews should include an offer of an Adult Carer Support Plan (ACSP) where a carer is identified, alongside information, advice and referrals for further support. Carers, as equal partners in care, must be involved in the planning of care for the person they care for. (Key Finding 5.7)

7. Recommendation: Ongoing engagement with carers about the type and location of opportunities to access support, ensuring support offered is tailored to carer need and what is offered meets carer demand. This may include more traditional and emerging formats, such as: face to face; digital solutions, etc. (Key Findings 7.0)

4.0. Key findings

4.1. Recognition of carers and carer rights

The 2023 survey highlights a shift in carer demographics, with 70% of respondents being of working age. It reveals that parent carers constitute the largest group, indicating a growing number of individuals who will take on lifelong caring roles.

Awareness of carers' legal rights including Adult Carer Support Plans (ACSP) remains low, resulting in a significant gap in the uptake of ACSPs and Young Carers Statements (YCS). There were slight improvements since 2021, with the findings illustrating the positive impact of engagement with and investing in carer support organisations to enhance carers' understanding and utilisation of these vital rights.

4.2. Financial support and income maximisation

Many carers continue to face significant financial insecurity, with little improvement since 2021. Concerns about future care costs and low awareness of available support further exacerbate these challenges, highlighting the urgent need for tailored resources and support.

4.3. Taking a break

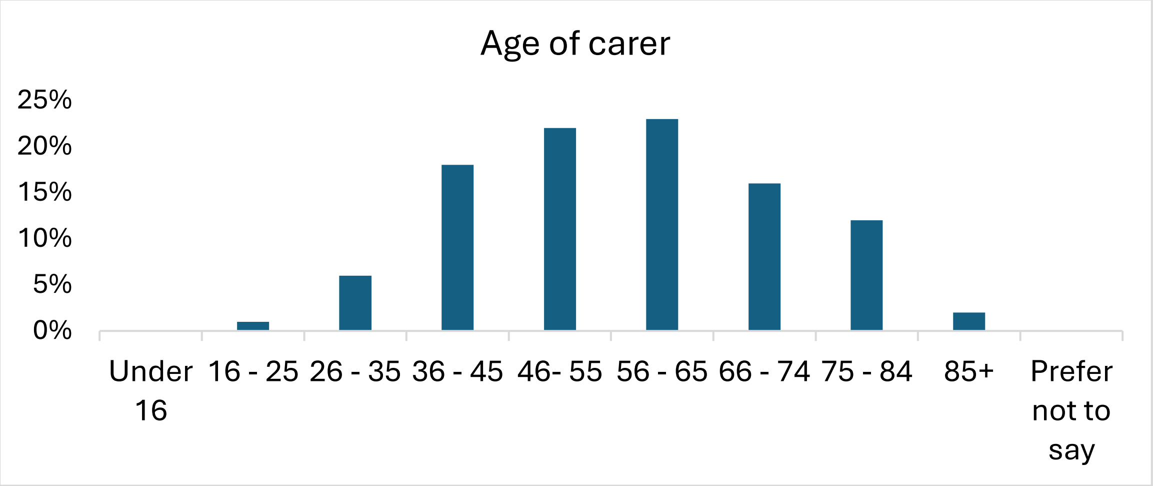
The survey reveals that while many carers recognise the importance of taking breaks, significant barriers such as stress, guilt, and a lack of respite and replacement care options prevent them from doing so. Carers need better resources and support systems to facilitate meaningful breaks, allowing them to rest, recharge and improve their wellbeing.

5.0. Detailed findings by theme

5.1. Demographics

The 2023 survey reveals a profile similar to 2021, with a notable shift toward younger respondents. The pressures identified on caring in 2021 have not eased.

Approximately 3 out of 4 respondents were female. Compared to the 2017 and 2021 surveys, the profile of respondents has changed to include more younger carers. 70% of respondents were of working age and 7% were under 35.



Nearly one-third were not in employment, education, or receiving a pension. Health concerns persist, with one in five reporting poor or very poor health, consistent with earlier surveys.

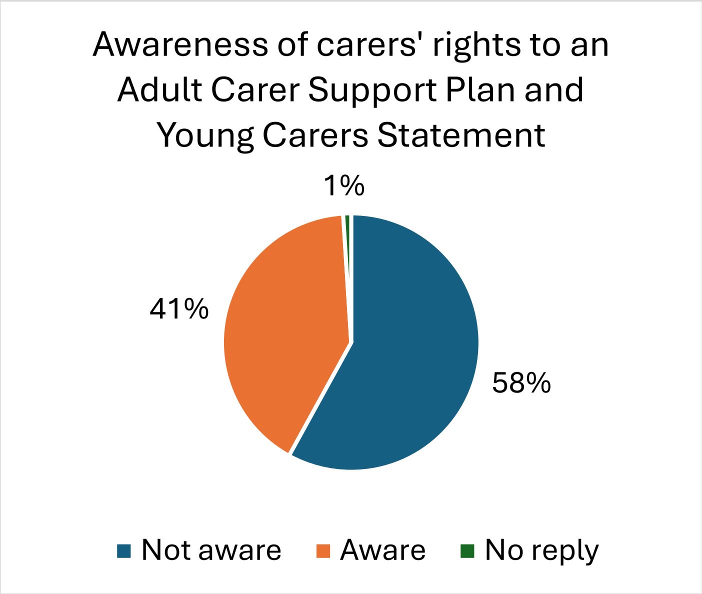
40% of respondents were caring for their son/daughter, 35% for their spouse/partner, and 27% for their parent. Carers were more likely to be caring for someone with a physical health condition, mental health condition, Alzheimer's/dementia, or for someone who is neurodivergent.

A significant 75% of respondents lived with the person they care for, and 62% had been caring for over five years. 15% had been caring for more than 20 years. More than half of respondents provided over 50 hours of care per week, a rise since 2021, while 30% cared more than one person.

Notably, 42% of respondents cared for someone aged 75 and over, down from 49% in 2017, while those caring for individuals aged 25 and under increased from 19% to 36%. There are differences in the caring experience depending on the age of the person being cared for. In general, respondents looking after someone aged 25 and younger were more likely to be living with the person they care for, to have been doing it for longer, and to be caring for more hours per week. They were also more likely to be caring for people with conditions that will require long-term support e.g. learning disabilities, neurodivergence, or substance use. The support required for these carers is likely to be quite different from the support needed for carers of older people.

5.2. Carers’ rights to an Adult Carer Support Plan and Young Carers Statement

Awareness of carers' legal rights to an Adult Carer Support Plan and Young Carers Statement remained low, with 58% unaware of their rights. Consequently, 66% of respondents have never been offered, requested, or completed an Adult Carer Support Plan or Young Carers Statement, with only 17% having been offered one. While awareness and uptake have slightly improved since 2021, there is evidence that engagement with carers organisations and agencies leads to increased understanding and exercising of these rights.

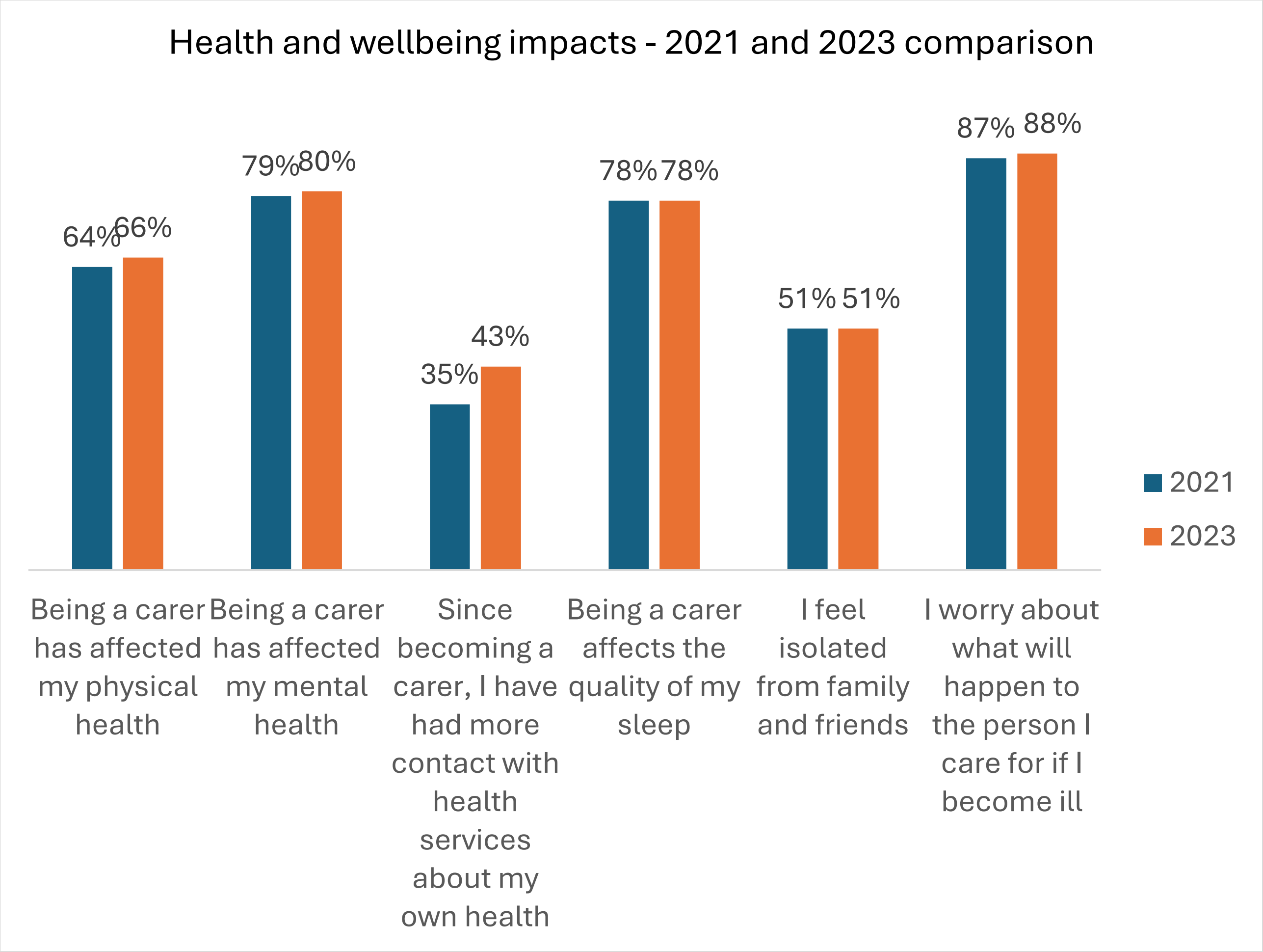


5.3. Health and wellbeing

Nearly all measures of the impact of caring on the health and wellbeing of carers have worsened since 2021.

80% of carers reported effects on their mental health, while 66% cite impacts on their physical health. These challenges have led 43% to seek increased contact with health services for their own health issues. Additionally, 58% indicated that caring responsibilities reduce their ability to see health professionals, suggesting that the need for healthcare among carers may be underestimated.

Sleep quality is also affected, with 78% of respondents reporting poor sleep. Many felt isolated, with 51% expressing a sense of disconnection from family and friends. Only 27% believed they maintain a good balance between caring and other aspects of their life. Support structures for carers are lacking, with less than half (45%) stating that they have someone they can rely on for assistance in their caring role.

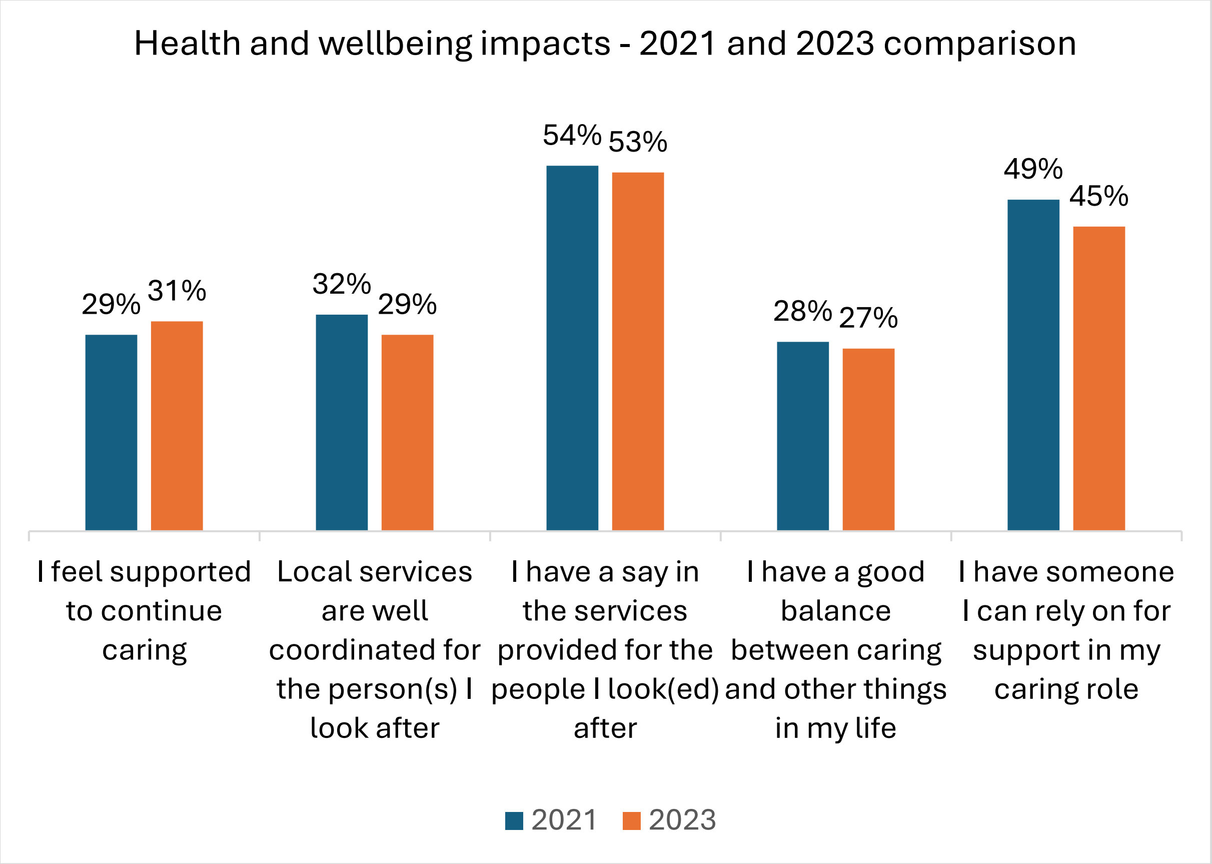


Only 53% felt they have a say, and 29% believed local services are well-coordinated. Furthermore, 31% felt supported to continue in their caring role, raising concerns about the sustainability of the current caring model. A striking 88% worried about the future of the person they care for should they become unwell, a scenario that seems increasingly likely given that many carers are presenting in crisis.

Carer quotes

- "Due to focusing on my two children's complex additional needs I was not able to look after myself that has resulted in hearing and inner ear problems that have now caused me to lose permanent hearing and now have two hearing aids, I have infections through my body and require treatment most months as I'm unable to rest or fight the infection by myself."
- "I had a heart attack which they put down to stress."
- "Get about an hour a day after work before I take over caring for my son. Weekends 24/7 with no support. Exhausting."

87% of respondents received support from one or more carers' organisations, indicating a need for support from external resources.

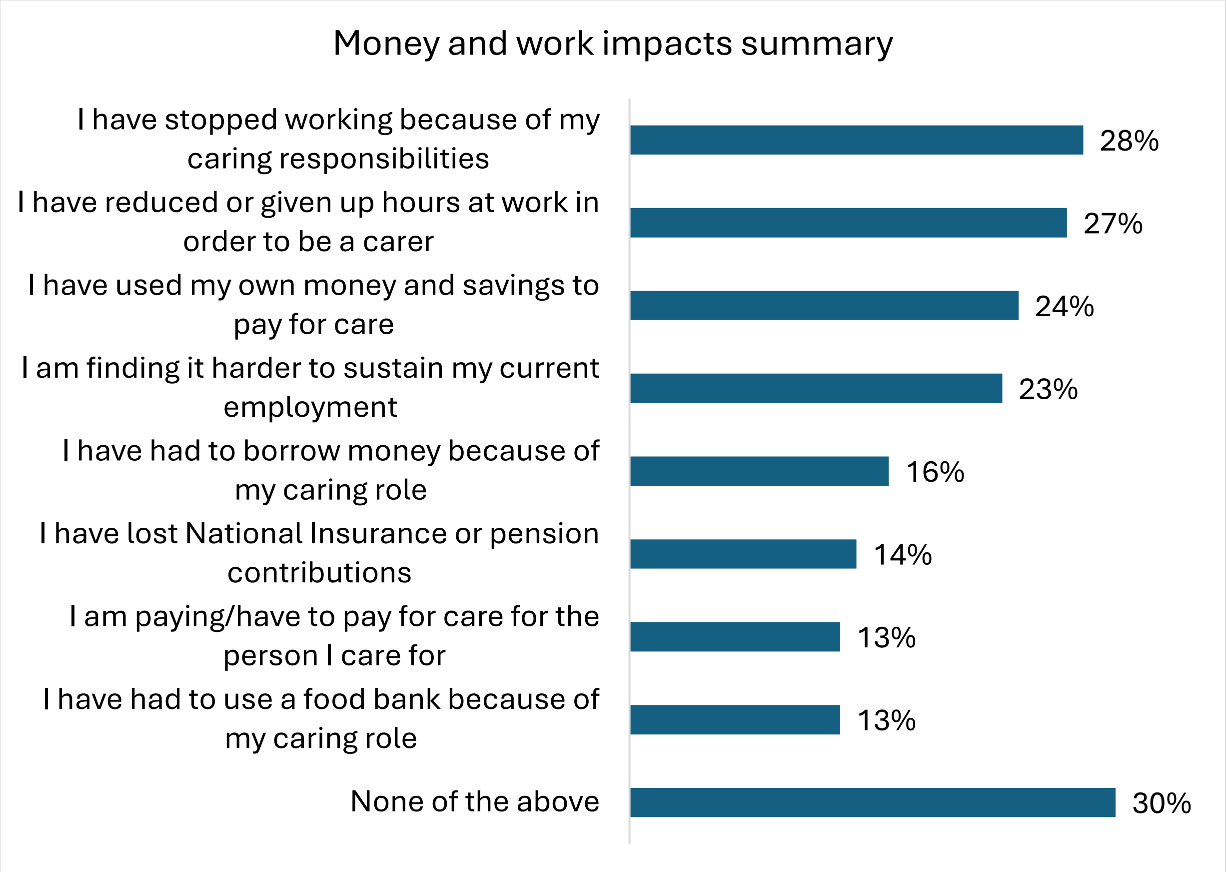


Qualitative feedback from the survey underscores the severe strain on carers, revealing that many lack the time or energy for self-care. Unhealthy coping mechanisms are common, and in extreme cases, some carers report missing treatment for serious conditions, experiencing self-harm, or having suicidal thoughts.

The physical and mental health challenges faced by carers, coupled with insufficient support and services for both carers and those they care for, creates a significant risk. If carers become unable to continue in their role - a scenario that appears increasingly likely given the health and wellbeing crises seen in the survey findings - the health and social care system may struggle to manage the resulting strain.

5.4. Money and work

The financial situation of carers has seen little improvement since 2021, with significant challenges still impacting carers’ economic wellbeing. A notable 49% of respondents reported that caring negatively affects their finances, yet 41% find it difficult to discuss their financial situation, reflecting a reluctance to seek support.



Concerns about the future are widespread. 44% of respondents expressed anxiety about affording care or care home fees. Awareness of available support is low, with only 38% reporting that they felt knowledgeable about resources. Confidence in navigating this support is even lower - just 32% felt confident in applying for assistance, and only 26% considered the financial support available adequate. Although there have been slight improvements since 2021, many carers still face instability.

The impact on employment is stark. 28% of respondents have left the workforce entirely, 27% have reduced their hours, and 23% were struggling to maintain their jobs. Some respondents reported difficulty finding employment, and 14% had lost pension and National Insurance contributions. Female carers were disproportionately affected by these impacts.

Financial strain is evident as 24% of carers have used personal savings for care, 16% have borrowed money, and 13% have relied on food banks. This is worsened by rising living costs, making it difficult for carers to reduce spending on essentials. At the time of the survey, only 53% felt confident covering monthly expenses. This figure dropped to 40% for the winter.

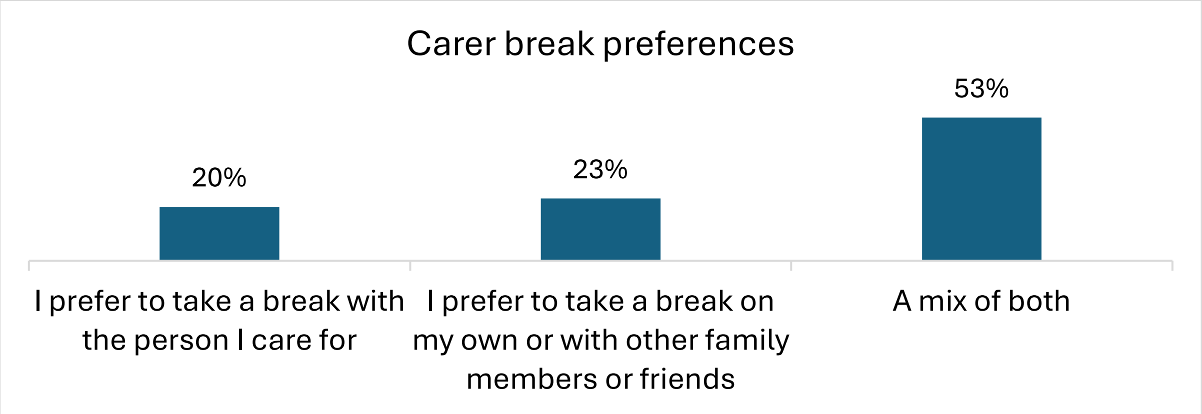
Overall, many carers continue to struggle with financial insecurity, limited awareness of support and resources, and significant employment challenges.

Carer quotes

- “There isn’t adequate information on what financial help you can get and the process of getting it is long and difficult.”
- “With the price of everything going up I try my best to provide but it's getting more difficult. The energy price increases has hit me hardest as there have been days we have to go without gas (as it's a choice between food or gas).”
- “Due to working part time for years I haven't got a good pension ahead of me, I feel that I will never be able to retire.”

5.5. Breaks from caring

20% of respondents prefer taking a break with the person they care for, 23% prefer breaks alone or with family and friends, while 53% prefer a combination. However, the survey found that carers are facing significant barriers to taking breaks.



52% of respondents found taking a break to be stressful, worrying, or guilt-inducing, and 38% struggled to relax during their time off. Additionally, 39% reported a lack of available replacement care or respite options to enable them to take a break.

When asked to describe an ideal break, many expressed a strong preference for longer breaks of several days. Common themes included ensuring the person they care for is well-cared for, spending quality time with friends or family, engaging in health and wellbeing activities, and having the freedom to relax without caring responsibilities.

Compared to previous surveys, there is a growing recognition among carers of the importance of taking breaks, but the ability to take a break appears to be more limited. This finding highlights the need for better resources and support to facilitate breaks for carers, enabling them to recharge and maintain their wellbeing.

Carer quotes

- “Because of no respite anywhere it’s not viable to take a break.”

- “I have made concentrated efforts to find respite/companion care so that I can take a break with my husband, who shares my caring role, but there doesn't seem to be anyone available in Midlothian just now.”
- “Because my husband is so dependent on me I think he would worry I had abandoned him if I was to take a break. It is the personal and hygiene part of the caring too. The thought of a worry free break sounds lovely though.”

5.6. Carer identification and perceptions of caring

The following findings were gathered through focus group discussions. These insights reflect the personal experiences and perspectives of carers, providing valuable qualitative data to complement the broader survey results.

Respondents were primarily identified as carers by external agencies such as GPs, schools, and occupational therapists, with a few recognising their role independently or through the Carers Survey advert. Emotions surrounding this identification were mixed. While many felt a sense of recognition and achievement in their caring role, others experienced sadness, confusion, and overwhelm.

Many struggled to distinguish between being a loving family member or friend and a carer, particularly those caring for their child, where caring overlaps with parental duties. Carers reported varying experiences with the "carer" label and how this affected how others perceived them. Some respondents explained how being identified as a carer resulted in additional support from GPs, social services and their employer, while others encountered minimisation or denial of their situation from friends and family.

There was a universal acknowledgment that most people do not understand the day-to-day realities of being a carer. Many respondents felt unable to share their experiences, fearing it would highlight the negative extent of the situation, or because it required a great deal of emotional effort, or it would risk making others uncomfortable.

There was a sense, particularly amongst those who had been supported by carers organisations, that other carers in similar positions were the only people who fully understood their caring role and the challenges it brought. This was echoed in a discussion around feeling heard as a carer. Carers did not feel that their role or legal rights were acknowledged by friends, family members, health and social care professionals or their employers.

These diverse and shared experiences illustrate the complexities of caring and the need for greater awareness not only by health and social care professionals, but in our wider society. Carers should not feel ashamed or worried about sharing the challenges of caring or accessing support.

Carer quotes

- "I didn't really consider myself a carer, as it just felt like I was looking after my partner like you normally do, but since seeing the carer survey advertised on a Lothian bus earlier this year I realised I do count as one after doing the survey and some research."
- "I think [identifying as a carer] made me more compassionate towards myself, before that I just thought I was a rubbish parent struggling."
- "My work are fantastic. They let me work from home so long as I go into the office if I need to have a face to face meeting. I normally try to go in one day every 2 weeks. I also have 5 care days from the firm. They really are very supportive."
- "Family and friends know how challenging things can be at times but don't really understand as it doesn't affect them directly."
- "I am so sick of fighting I haven't got the energy to tell somebody else how bad it is. The thought of finding someone and saying it all again – I'd rather not. It's too much effort."

5.7. Accessing care packages and support

The following findings were gathered as part of the focus group discussions.

Participants reported diverse experience of arranging packages of care and support for the person they care for. Carers of children often relied on their child's school for support, experiencing mixed success, while parent carers of adults lacked similar systems.

Many carers of children felt disbelieved or judged by agencies and professionals. In cases involving those caring for their parent or partner/spouse, care packages were typically organised following a medical crisis and hospitalisation. In these situations, some carers felt excluded from the assessment process, contrary to their rights.

All groups faced significant delays in arranging care, and carers of children found assessments repetitive, especially in cases where conditions were lifelong. Discussions also highlighted issues surrounding benefits assessments, particularly Personal Independence Payment (PIP).

Carer quotes

- "My son had a S23 assessment by social work, this was a positive experience, I really wasn't expecting very much and was pleasantly surprised. The social work assistant / practitioner who visited us spent time with my son and also observed him at school. She met me separately and really took a lot of time to listen how I felt. She also made sure she got his views on life and what was good and not so good."
- "You feel like a criminal, you've got to prove everything."

- “Every time I tell them about a change I am worried that they will find something I have done wrong and I will have to pay back thousands of pounds.”

5.7.1. Support at home

Participants expressed a desire for increased support with household tasks, social opportunities for themselves, and activities for those they care for. Those living with those they care for particularly valued help with household tasks. Additionally, many requested more respite care and highlighted the need for counselling and information as vital support.

5.7.2. Self-directed Support

Of the 15 participants in the qualitative research, six were aware of Self-directed Support, though some lacked confidence in the details. Interest in the concept of Self-directed Support was high, but participants expressed concerns about the need for additional administration and the challenges of becoming an employer or finding suitable services.

6.0. COVID-19 pandemic

The pandemic had a profound impact on carers and those they cared for, leaving many carers feeling abandoned and solely responsible for care. For instance, expectations for homeschooling children with additional needs often exceeded carers’ capabilities.

Many support services, especially those focused on social and wellbeing activities, halted during the pandemic. These services have yet to resume, creating significant gaps in support for both carers and those they care for.

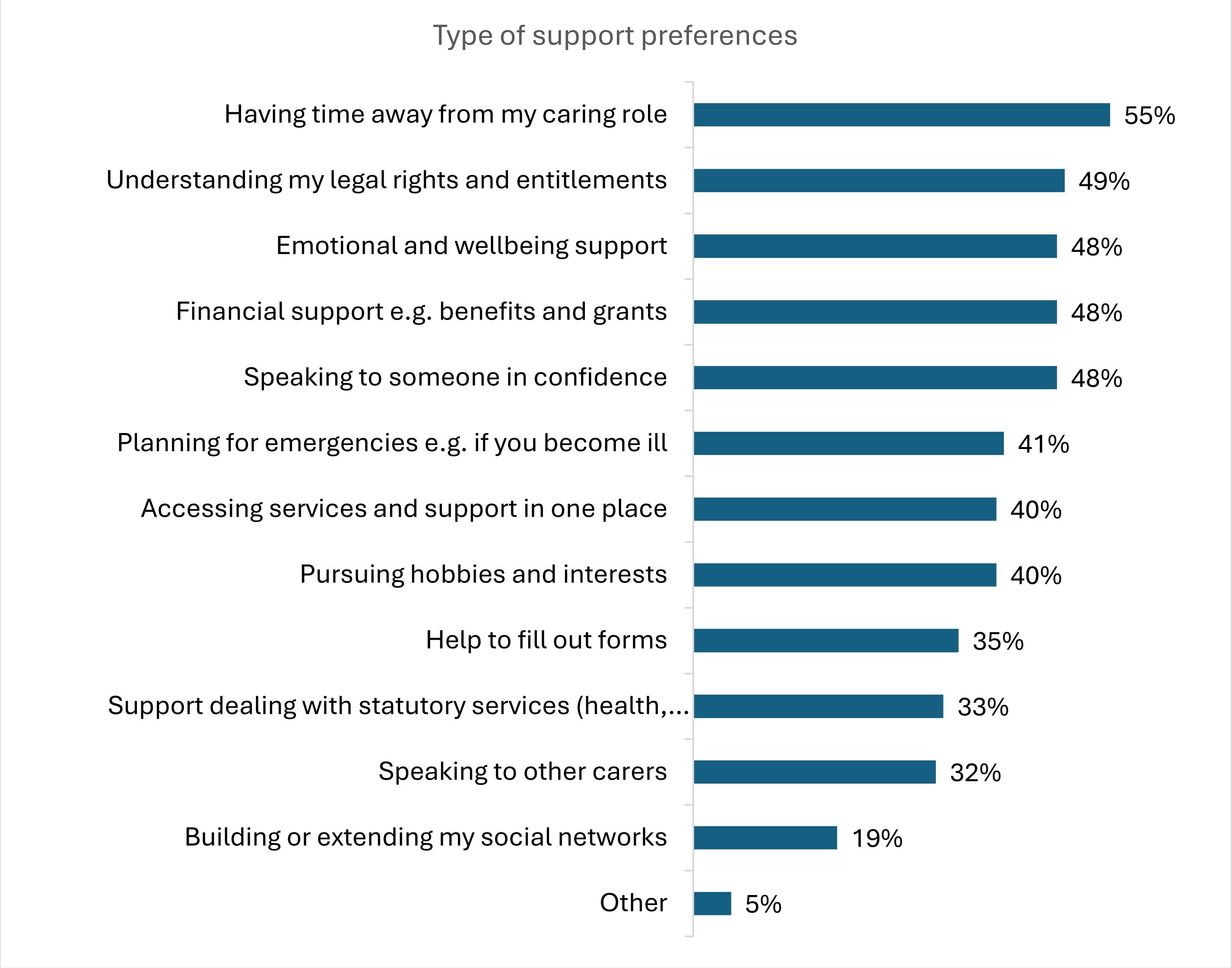
Carer quotes

- “They cancelled everything. And they never brought it back.”
- “My child used to go to a quiet space at lunchtime. Then after lockdown we were told they couldn’t staff it. So he already had his struggles, we went through this pandemic and then he was going back into school without the support that he used to have. He would call at lunchtime all upset.”

7.0. Future support needs

Digital and online technology has undoubtedly expanded support options and increased flexibility for carers, yet survey responses indicate a strong ongoing need for traditional face-to-face and telephone support. While confidence with new technology generally declines with age, the demand for personal engagement is likely to continue to be required.

The support needs of carers reflect an increasing awareness of the importance of taking breaks; 55% of respondents identified this as the most important type of support. Additionally, there is significant demand for understanding legal rights and entitlements, financial and emotional support, and confidential discussions. An overwhelming 81% of participants consider access to local services important or very important.



In terms of preferred locations for support, 51% expressed interest in accessing services through their GP surgeries, 49% in their own homes, and 43% at dedicated carers' centres. This highlights a desire for accessible and convenient support options tailored to carer needs.

When asked for suggestions on additional support, respondents prioritised the availability of respite care, which includes both overnight stays and shorter activities.

Overall, while digital solutions play a valuable role in supporting carers, traditional support methods remain essential. Enhancing access to local services and respite care will be crucial in addressing the diverse needs of carers and ensuring they receive the comprehensive support necessary for their wellbeing.

Methodology

The Midlothian Carers Survey, designed by Scotinform in collaboration with VOCAL and partner agencies, employed a mixed-methods approach. The quantitative phase included an online survey distributed via email and social media by VOCAL and its partners. A paper version was provided for individuals without email access, with copies available at partner locations. VOCAL staff assisted respondents in completing the survey in person or over the phone. Paper responses were submitted using a prepaid envelope to eliminate costs for participants.

A total of 525 responses were received, marking an increase from 392 in 2021. The qualitative phase, introduced in 2023, aimed to explore areas better suited to open-ended questions and to address insights from the quantitative findings.

Focus groups were organised based on respondents' caring situations. The research included Group 1 (carers of children), Group 2 (carers of spouses/parents), and Group 3 (carers not currently receiving support), ensuring diverse representation and insights. There were 15 participants in total.