

Unpaid carer experiences in Edinburgh

June 2024



What is the Edinburgh Carers Survey 2023?

The Edinburgh Carers Survey 2023 was funded and commissioned by Edinburgh Health and Social Care Partnership (The Partnership) and coordinated by VOCAL (Voice of Carers Across Lothian), on behalf of organisations that support unpaid carers in Edinburgh. Building on the previous VOCAL surveys from 2015, 2017 (both funded by VOCAL) and 2021 (partially funded by EHSCP), it provides a vital snapshot into the lives of carers across Edinburgh at a time of significant change and pressure for unpaid carers and society more widely.

About this report

Being an unpaid carer is challenging at the best of times, but in the context of the COVID-19 pandemic, the level of services provided, the cost of living crisis and changing demographics – including an ageing population, it is more important than ever to understand how Edinburgh carers are coping with daily demands. For the 2023 survey, 1,169 carers across Edinburgh completed online and paper-based surveys, and three focus groups took place to understand carer experiences in more detail.

This report outlines the key findings, and highlights recommendations for consideration across the Edinburgh carer partnership.

Partners

The **Edinburgh Health and Social Care Partnership** is responsible for the planning and delivery of all community health and social care services for adults and older people, along with homelessness, mental health and disability services in Edinburgh. Additionally, the partnership¹ is responsible for the duties associated with the Carers (Scotland) Act 2016², and for managing and reporting on associated funds on behalf of the Edinburgh Integrated Joint Board.

The recent **Joint Strategic Needs Assessment for Edinburgh carers**³ aims to collate published data and research on unpaid carers to assist in strategic and service planning across the Partnership. Feedback from unpaid carers and those with lived experience has been key to developing the Joint Edinburgh Carers Strategy⁴ and this is a key mechanism to plan and deliver support required for unpaid carers.

The Edinburgh Carers Survey complements this suite of information to contribute to planning and delivery of key priorities for carers.

The Edinburgh Health and Social Care Partnership recognises the findings expressed by carers, which align with current knowledge and intelligence about what matters to unpaid carers.

Scotinform⁵ is a market research organisation which has developed and conducted the survey, in conjunction with VOCAL over a number of years.

VOCAL⁶ is a registered charity which supports unpaid carers in Edinburgh and Midlothian. The Edinburgh Carers Survey involved over 20 organisations which support unpaid carers⁷, and were commissioned by the partnership to co-ordinate the delivery of the survey and findings.

Wider Edinburgh carer organisations, like VOCAL, play a valuable role in delivering commitments in the Edinburgh Joint Carer Strategy, have had the survey extended to them this year, and they are members of the Edinburgh Carer Strategic Partnership Group, and highlighted in the Carer Strategy, appendix 10.

1 Edinburgh Health and Social Care Partnership, <https://www.edinburghhsc.scot/>

2 UK Government, Carers (Scotland) Act (2016), <https://www.legislation.gov.uk/asp/2016/9/contents/enacted>

3 Edinburgh Health and Social Care Partnership, Carers, <https://www.edinburghhsc.scot/the-ijb/joint-strategic-needs-assessment/carers/>

4 Edinburgh Health and Social Care Partnership, The Joint Edinburgh Carers Strategy 2023-2026, <https://www.edinburghhsc.scot/the-ijb/carersstrategy/>

5 Scotinform, <http://www.scotinform.co.uk/>

6 VOCAL, www.vocal.org.uk

7 VOCAL, Edinburgh Carers Survey 2023 - Partner Organisations, <https://www.vocal.org.uk/carers-support/information-resources/vocal-carer-surveys/edinburgh-carers-survey-2023-partner-organisations/>

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1 Introduction

This survey asked carers about their health, finances and ability to sustain employment and take time away from caring, to better understand the extent and impact of these increasing responsibilities. The survey also assessed the level of satisfaction with services and support currently offered to carers in Edinburgh, as well as the types of services and support carers accessed. The findings will help to inform the delivery and future development of the Edinburgh Carers Strategy.

Across Edinburgh, carer organisations report a growing number of carers who are finding it more challenging to arrange support or services for the person they care for. It is considered that more responsibility is being placed on carers and families to fill what they feel/tell us are gaps in statutory care provision. It is evident that this is coming at a cost, to their health, finances and personal lives.

Who are unpaid carers?

The Carers (Scotland) Act 2016 defines an unpaid carer as 'as an individual who provides or intends to provide care for another individual ('the cared-for person'). The person or people they care for might be affected by disability, physical or mental ill-health, frailty or substance use. A person 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 very elderly people – and the people they may care for can cover that same age span. In Edinburgh there are an estimated 70,000 carers.

Caring for or helping a family member or friend with a long-term health condition, disability or problems related to ageing is something that most of us will do in our lifetime. Providing care has many benefits, allowing people to remain at home and maintain a better quality of life whilst saving the overall health and social care budget in Scotland over £36 billion annually. However, caring can have negative impacts on carers themselves. This includes the impact on their physical and mental health, their employment, pressures on their personal finances, family life and relationships and their time for other activities including leisure. Employers, businesses and the wider economy may

also be impacted by pressures on carers, notably because of absenteeism, lost productivity and reduced tax revenues.

Carers in Edinburgh provide an essential service, and they have recorded – and continue to record – many achievements despite the daily pressures and struggles they face. It is important to recognise these achievements which include everything from setting up a bank account for an elderly parent, going on holiday with a disabled child, taking a family member to a care unit for physiotherapy for 6 weeks, or assisting in educating a child with learning difficulties.

These are essential services provided by family members or friends out of love, commitment or responsibility – and they help to improve the lives of those with care requirements. But the impact of such activities on the health, wellbeing and finances of the carer should not be underestimated. Those in a paid caring role can access support, training and resources, and as equal partners in care we must have similar investment for unpaid carers.

2

Key findings

Health and wellbeing



Money and work



Breaks from caring



Carers' rights



3 Recommendations

Infrastructure of care and support services for supported people

For the carers participating in the survey, it is clear that the care and support infrastructure for supported people is placing an unsustainable pressure on some unpaid carers, causing them to leave employment, preventing them from taking short breaks or having a life outside of caring.

Recommendation 1

Edinburgh Health and Social Care Partnership should work with carers, supported people and delivery partners to offer more consistent and regular care and support to supported people.

Recommendation 2

Reviews and changes to care packages for supported people should involve consultation with the cared-for person and their unpaid carers and families. An Adult Carer Support Plan should be proactively offered or where there is already one in place, this needs to be reviewed in light of any changes in the support package to ensure the carer is supported to continue their caring role.

Recommendation 3

The commitment in the Edinburgh Joint Carer Strategy to ensuring carers' health, employment and wellbeing should not be compromised or negatively impacted as a result of taking on a caring role, should be upheld.

Economic impact of caring

The additional pressures experienced by some carers are having a detrimental impact on their finances, employment and ability to manage daily expenses.

Recommendation 4

Continued efforts should be made through proactive information, advice and income maximisation routes to enable carers to access universal financial supports and carer benefits to optimise their income.

Breaks from caring

There are many reasons and contributing factors for why some carers struggle to take a break from caring. These can include the stress of organising a break, the expense of taking a break, lack of replacement care and feelings of guilt and worry. These are compounded by the fact that the person they care for may not accept care from others. The Edinburgh Carers Strategy should be read in conjunction with the following recommendations.

Recommendation 5

Through information, advice, income maximisation and commissioned short breaks services, investment should be optimised which addresses the financial challenges of taking a break.

Recommendation 6

Continued investment in replacement care, ensuring that any replacement care that is put in place enables the carer to take a break from caring (which may alleviate stress and distress for carers). The new social work database system should be developed to more clearly demonstrate the impact and carer benefit of carer-led replacement care.

Recommendation 7

Continued investment to ensure carers are supported to plan and organise breaks from caring that meet their needs and outcomes. This should include ensuring appropriate residential respite and opportunities which provide carers with the choice to take a break either by themselves or with the person they care for.

Lifelong carers

The changing profile and demographic of unpaid carers in the Edinburgh Carers Survey, most of whom are of working age, underlines that caring is often not a temporary situation but a lifelong commitment. Parent carers, predominantly women, can find themselves caring for younger or adult children and older relatives in multiple caring roles which increase the risk of health and economic issues and relationship breakdowns.

Recommendation 8

Ensure professionals working with carers early in their caring role and at key transition points (e.g. moving from children to adult services, discharge home from hospital, taking on an additional caring role, carer's own health issues) are offering support to complete an Adult Carer Support Plan. Professionals should also refer carers to appropriate supports to ensure support is in place to enable carers to attend their own health appointments, to receive treatment to aid recovery.

Support for carer organisations

The survey evidences the positive impact of early intervention from a carer organisation.

Recommendation 9

Based on this evidence, optimise available funding to local carer organisations to continue to provide support for those most in need, and meet as a priority, the duties within the Carers Act.

Carers' rights

The survey highlights that many carers are unaware of their right to an Adult Carer Support Plan.

Recommendation 10

Work with the Edinburgh Health and Social Care Partnership and carer organisations to raise public awareness of a carer's right to an Adult Carer Support Plan, alongside their rights under the Carers Act and self-directed support legislation, and the supports available to them to enable them to exercise these rights.

4

Findings in more detail

4.1 Carer identification

The survey evidences the positive impact of early carer identification and referral to carer support agencies and the difference that this can make to carers. Carers who are supported by a carer organisation are more likely to agree with the following statements:

- 'I feel supported to continue caring' (30% compared with 16%)
- 'I know what financial support I can access' (35% compared with 25%)
- 'I am confident in applying for financial support' (30% compared with 25%)

Comments from carers

"They stepped up when I was completely drained financially emotionally and physically. They helped me in every way to put my life back together and still help me to keep it that way. I am eternally grateful to them."

"The advisor was just very friendly and approachable, and worth her weight in gold - I cannot praise her highly enough! She really helped me to navigate that first year, when everything was new and scary and uncertain."

"Lots of help with finance, spend time with other people / let you feel you are not alone with your problem."

89% of respondents had engaged with one of the survey partners or with another organisation. VOCAL was the organisation most engaged with, with 78% of respondents having used its services. 20% of respondents had engaged with Care4Carers and 12% with Alzheimer Scotland.

11% of respondents had not engaged with any organisations. This figure decreased as caring duration increased. 28% of those who had been caring for less than a year have not engaged, compared with 14% of those who have been caring for 3-5 years and only 5% of those who have been caring for 20+ years. Respondents in employment (15%) or who are studying (21%) (note small sample size) are also less likely to have engaged with a support organisation.

Many barriers still exist at practice, health system and policy level in relation to identifying and supporting carers. This includes factors such as "...lack of time and reimbursement; failure to self-identify as a carer; focusing on the care recipient to the exclusion of the carer (by both the carer and the health service provider); disjointed health and community systems; inadequate services; and a lack of policy and ethical guidance".

Carers expressed mixed feelings and experiences about being identified as a carer. Some carers felt it led to recognition of their role, whilst others had feelings of sadness, confusion, pressure, responsibility and being overwhelmed, and found it hard to identify the distinction between being a loving family member and being a carer. Carers also reported negative experiences of their role being minimised, not acknowledged or denied by other family members or friends. Some carers felt that they were not 'seen or heard' in relation to their caring role or legal rights and this extended to medical services and agencies working with the cared for person through to employers.

There was universal acknowledgement by carers that most people do not understand the impacts of caring on day-to-day life. Some stated that this was because they did not feel able to share the reality of their situation with others, either because it underlined the extent of the situation, because it required a great deal of emotional effort, or because it seemed to make people feel uncomfortable. Carers in similar positions are often the only people who understand the issues - without the carer having to spell it out - highlighting the importance of peer support services and opportunities.

In addition to these challenges, many carers highlighted the inability to separate themselves from their caring roles, highlighting the all-consuming nature of caring.

The importance of early identification as a carer is significant, to enable timely assessment and support - as is the need to respond in a timely fashion to avoid crises. A significant challenge is that carers often experience isolation and loneliness, which can limit opportunities for support.

In Scotland, we know that carers are often not identified, leading to increased risk of crisis and burnout, if their diverse needs are not met. In the qualitative research as part of this survey, it was found that carers were mainly identified by external agencies such as general practices, schools, occupational therapists or somebody helping them apply for support. A minority identified as a carer through their own observations.

4.2 Carers' rights

The Carers (Scotland) Act 2016 came into effect on 1 April 2018 and it aims to ensure better and more consistent support for carers and young carers so that they can care in better health and have a life alongside caring. The Act is designed to support carers' health and wellbeing and to help make caring more sustainable, given the multiple pressures on many carers. This includes:

- a duty for local authorities to provide support to carers, based on the carer's identified needs which meet the local eligibility criteria;
- a duty to offer an Adult Carer Support Plan (ACSP) and Young Carer Statement (YCS) to identify carers' needs and personal outcomes;
- a requirement for local authorities to have an information and advice service for carers providing, amongst other things, emergency and future care planning, advocacy, income maximisation and carers' rights;
- a requirement for local authorities to consider whether support should be in the form of a break from caring and the desirability of breaks from caring provided on a planned basis.

Implementation of the Act by local authorities is an important mechanism for providing services and support to carers. Edinburgh carer organisations VOCAL, The Action Group, Care4Carers and Edinburgh Young Carer Collaborative, along with a number of partner organisations, are commissioned to support Edinburgh Health and Social Care Partnership to implement the Act.

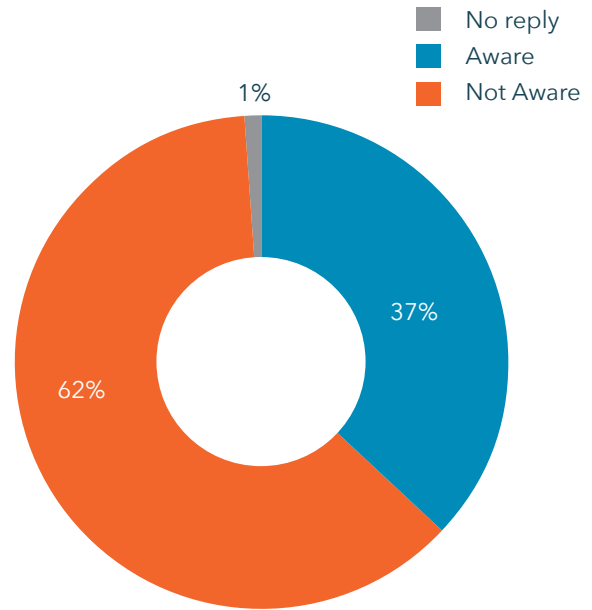
The Edinburgh Carers Survey highlights a concerning lack of awareness by carers of their legal right under the Carers (Scotland) Act 2016 to request an Adult Carer Support Plan.

Awareness of Carers' Rights

Respondents were told:

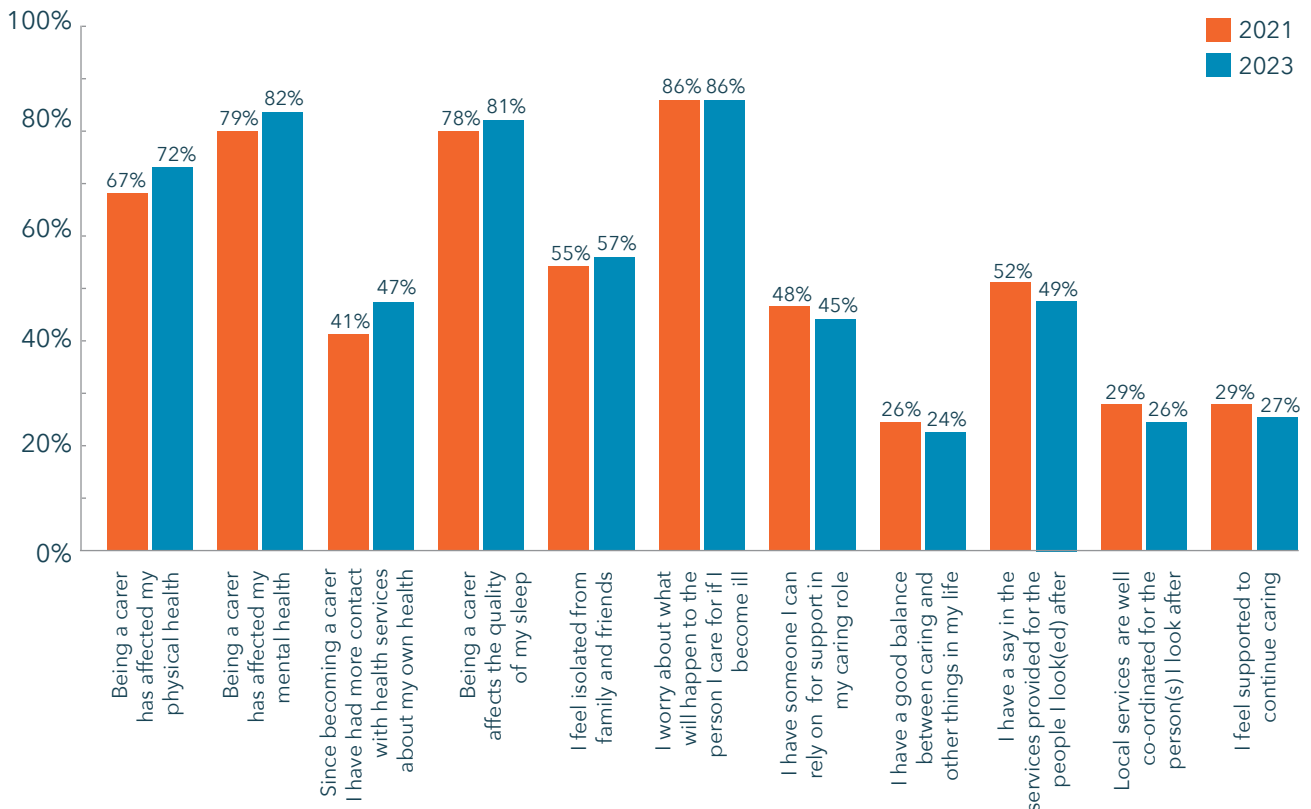
'Since 2018, under the Carers (Scotland) Act 2016, every carer has a legal right to request support, known as an Adult Carer Support Plan or Young Carers Statement (for carers under 18). This captures information on your caring role and sets out how you wish to be supported as a carer.'

Only 37% of respondents were aware of this right, a decline from 42% in 2021. 63% of those who have been caring for more than 20 years reported that they have no awareness or experience of an Adult Carer Support Plan. It is vital that this is addressed, as carers in Edinburgh are missing out on support that they are legally entitled to.



4.3 Health and wellbeing

The survey reveals a concerning decline in carers' physical and mental health and wellbeing (compared to 2021 carers survey), highlighting the significant impact of caring as more responsibilities have shifted onto carers to provide care. It is also more likely a carer will be suffering from ill health if they have been caring for longer; if they are a multi-carer; or if they are caring for a child, someone who is neurodivergent, using substances, or who has a palliative and terminal condition.



Compared to 2021, more carers have been in contact with health services about their own health. An increasing number of carers are reporting lower quality of sleep and feeling isolated from family and friends.

It is unsurprising then that fewer carers said that they had a good balance between caring and other things in their life (26% in 2021 vs 24% in 2023). Carers also continue to have a high degree of concern for those they care for should they, themselves, become ill (86%).

The impact of the COVID-19 pandemic on carers is significant in terms of increased caring responsibilities and isolation, likely exacerbating the situation for carers. A recent report by Carers Trust Scotland⁸ highlighted that high levels of distress or mental health problems can result from isolation combined with a lack of support.

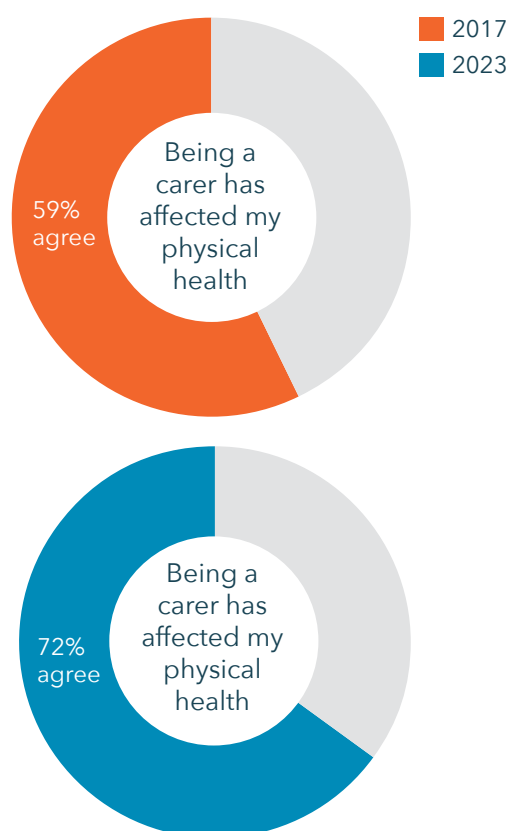
Fear of infecting the person they care for with COVID-19 meant that carers restricted their activity and social interaction well beyond the lockdown periods and some are continuing to do so. This has had implications for their own health and wellbeing – resulting in increased isolation and stress.

Furthermore, carers often felt abandoned during the pandemic when normal services closed – many carers, almost overnight, became solely responsible for providing care for those they looked after. In some cases, such as school at home for children with significant additional needs, the expectations were beyond the capacity of both the carer and the person they were caring for.

Many support services have not resumed – despite the last remaining COVID-19 restrictions being lifted in March 2022, with exception of the wearing of face coverings. This has placed significant pressure on many carers and those who they care for.

Physical health – the key data

- 30% agreed strongly and 42% agreed that being a carer affected their physical health, representing a total of 72% of carers who feel that their caring responsibilities are impacting their physical health. This is higher than the 67% figure in 2021 and the 59% figure in 2017.
- As in 2021 there appears to be a relationship between the duration of care provided and the impact on physical health. 50% of those who have been caring for less than a year said that their physical health is being affected, compared with 81% of those who have been caring for 20 years.
- Agreement is also higher for multi-carers (83%), respondents caring for somebody aged 16-25 (83%), respondents caring for 50+ hours per week (81%), and those aged 36-45 (81%).



⁸ Carers Trust Scotland, Experiences of Older and Adult Unpaid Carers in Scotland (2023), <https://carers.org/downloads/older-adult-unpaid-carers-in-scotland-report.pdf>

Physical health - comments from carers

"Over a previous caring situation, I ended up very ill indeed and was at collapse point as there wasn't enough support for palliative care at home as I was an isolated person with no family support."

"My Aortic valve burst in my room. So had to have major open heart surgery. My son took a bad turn, I got to him, and collapsed in my mums. I fractured my pelvic bone, and clean break on my collar bone, and 3 broken ribs. My son and mum will always come before me."

"I generally try to exercise regularly including at the gym but that is getting harder and harder. I find looking after my own nutrition is becoming harder, I have lost weight recently through stress."

"I am myself recovering from cancer treatment but have had little chance to deal with this [due to my caring responsibilities]."

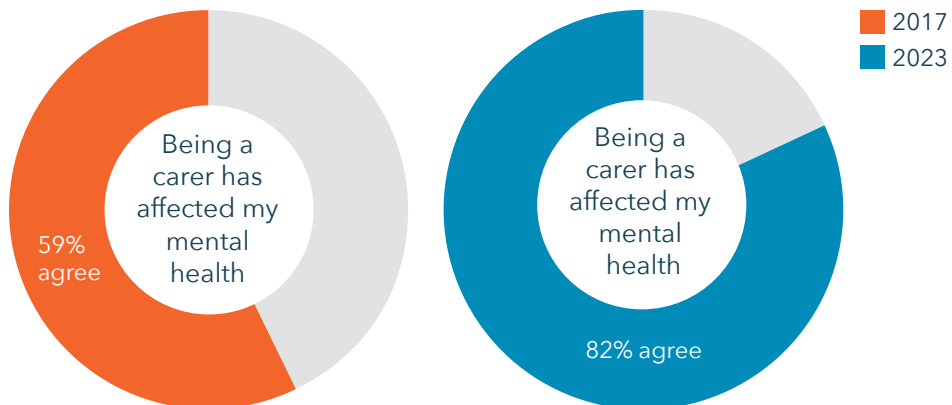
"Had a miscarriage and couldn't tell those in my care. Was gravely unwell for 4 weeks and was in and out of hospital. Every time on the way home I'd need to jump back into the role with shopping, cooking, cleaning etc."

"Since my husband's diagnosis of Alzheimer's I have had pneumonia once and bronchitis six times."

Mental health - the key data

- 44% agreed strongly and 38% agreed that being a carer affected their mental health - an overall agreement level of 82%. This is slightly higher than the 79% agreement in 2021 and much higher than the 59% in 2017 who felt that being a carer made their mental health worse.
- Agreement with this statement is particularly high for respondents caring for their child (89%), respondents who care for more than one person (89%), respondents caring for someone who is neurodivergent (94%) or using substances (92%), or somebody who has a palliative/terminal condition (92%), or is looking after somebody aged under 25 (92%).

- Respondents aged 36-55 are more likely to agree with this statement than respondents aged over 75 (91% vs 62%).



Mental health - comments from carers

"My quality of life has greatly reduced, I feel like I live in an open prison on a desert island."

"I have no one else to turn to which has led to me feeling very isolated. I currently do not leave the house unless I am with someone and suffer with social anxiety."

"Caring for my dad has at times left me depressed and even suicidal. I have had times that I have cried every day thinking about the weight of my caring role and dealing with challenging behaviour that comes along side this."

"It pretty much overrides everything else. I have only recently begun to look after myself a little more. It is not so much the caring role as such but the emotional impact (stress, fatigue, etc) that prevents looking after one's own needs."

"It causes me anxiety as I am not in control of my life. My child's needs come first and I have to put everything [else] off."

"I find the care I provide very demanding and as a result I feel physically and mentally drained...I have already battled with my mental health all through lockdown and I cannot handle stress or pressure at all."

4.4 Money and work

*"...one in seven workers in the UK juggle paid work while caring for an older, disabled or ill person... and many carers will have to give up paid employment altogether in order to provide care."*⁹

The role of an unpaid carer often comes with a financial burden, and for those in work, there are significant impacts on employment. Furthermore, increased caregiving during and after the peak of COVID-19, due to the closure of support services or withdrawal of other support - coupled with the need to socially isolate - has resulted in many carers reducing or leaving their paid employment. This has exacerbated an already challenging financial situation for many carers, who now face debt or are unable to provide for the basic needs of their household during the current economic instability and cost-of-living crisis. These trends are reflected in the data collected from the Edinburgh Carers Survey, the highlights of which are outlined below and clearly indicate that the financial circumstances of carers has generally worsened since 2021 and 2017 respectively.

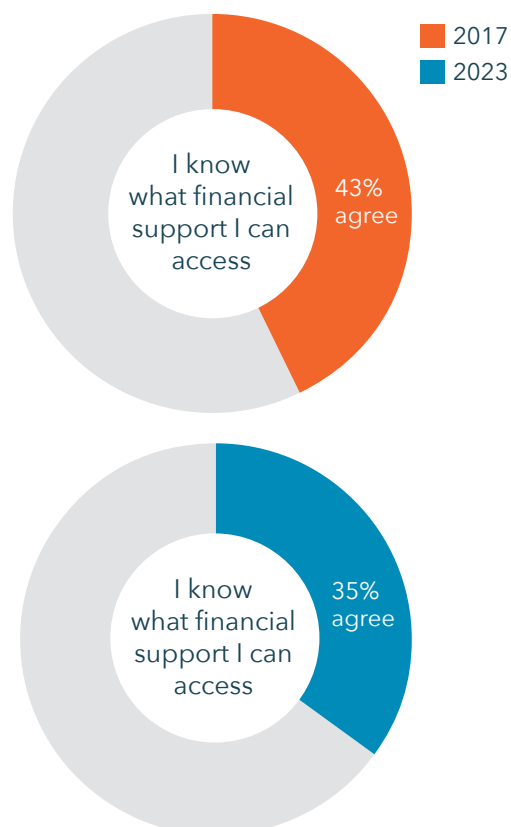
Household finances are tighter in 2023

The Edinburgh Carers Survey highlights the significant financial pressures on carers across the city. Many carers face the same financial pressures as people who do not provide informal care, however given that many carers are not in work, or have reduced their working hours, they are likely to be disproportionately affected by the costs associated with support services closing during the COVID-19 pandemic, and then by the rise in the cost of basic commodities during the cost-of-living crisis, such as fuel, food and clothing.

On top of that, many carers indicated higher costs that other households are unlikely to face, including paying for care (including care home fees) and additional supplies and equipment associated with caring for someone.

Money and work - the key data

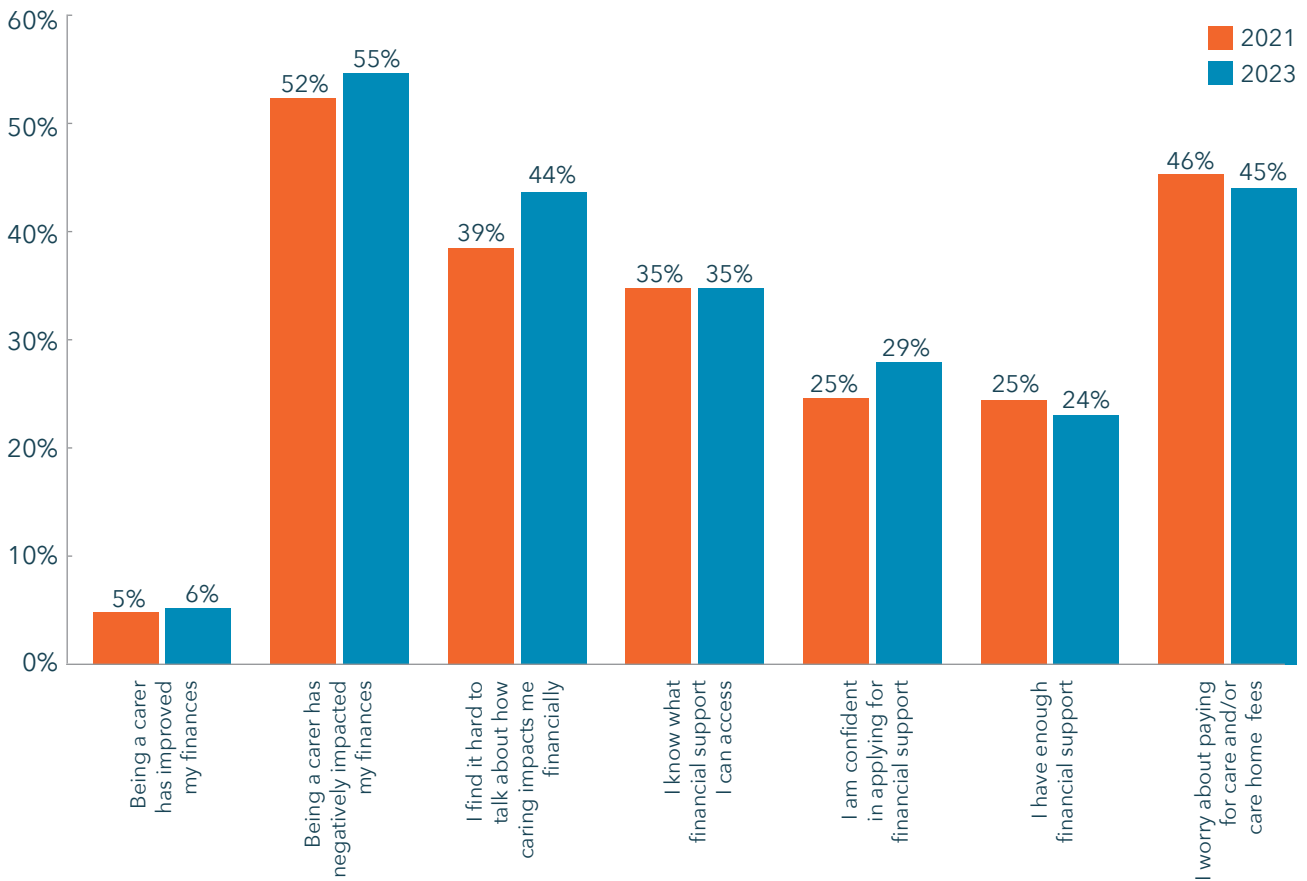
- In response to the statement "being a carer has improved my finances", 41% strongly disagreed and 31% disagreed - leading to an overall 72% negative response. Just 5% of respondents agreed with the statement, while 1% strongly agreed. This highlights the significant negative impact that caring has on the finances of unpaid carers in Edinburgh.
- 13% of respondents agreed strongly and 31% agreed that they find it hard to talk about how caring affects them. This represents an overall agreement level of 44%.
- 3% of respondents agreed strongly and 32% agreed with the statement "I know what financial support I can access" - an overall agreement level of 35%. This is consistent with the 2021 figure but lower than the 2017 figure of 43%. 33% of respondents felt that they did not know what financial support they could access. Interestingly, 35% of respondents who are supported

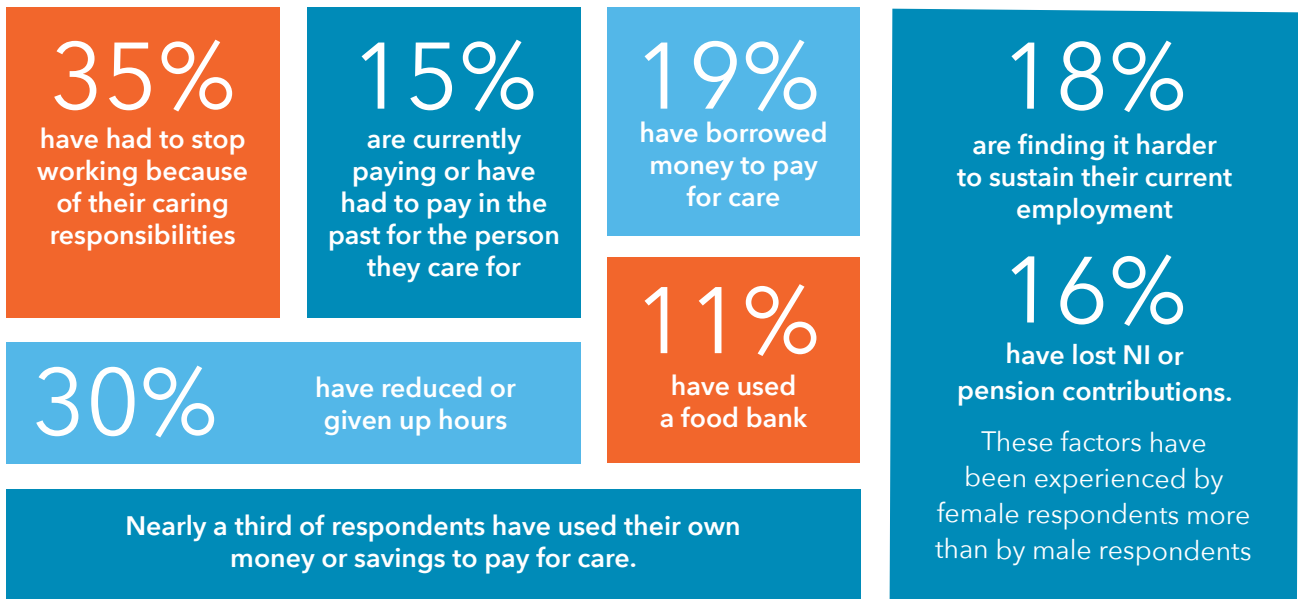


⁹ Carers UK (2019), Juggling work and unpaid care, <https://www.carersuk.org/media/no2lwyl/juggling-work-and-unpaid-care-report-final-web.pdf>

by a carers organisation did know what financial support they can access, compared with 25% of respondents who are not supported - highlighting the positive impact that carers organisations can have on unpaid carers.

- In response to the statement "I am confident in applying for financial support", 3% of respondents agreed strongly and 21% agreed, representing less than a quarter of respondents. This is a small decline from the 25% reported in 2021, and a greater decline from the 32% reported in 2017. Agreement varies by economic status. 36% of those who are retired and receiving a pension agree with this statement, compared with 21% of those who are in paid employment, 18% of those in education and 17% of those not in paid employment, education or in receipt of a pension.
- 19% of respondents agreed strongly and 26% agreed with the statement "I worry about paying for care and/or care home fees" - an overall agreement level of 45%. This is slightly below the 46% reported in 2021 and indicate the difficulties for many carers in affording suitable care.





Levels of financial support available - comments from carers

"I have had to live very simply for a long time so I manage but I constantly go without, it's been the norm since 2007."

"We have lost his salary, I have dropped 2 days a week, we are not entitled to benefit and am roughly £1500 less a month in income since he became ill."

"Always feels like I'm robbing Peter to pay Paul."

"My household income is reduced by £600 by per month giving up work to care for my father. As far as I am aware I am receiving all benefits available. I am concerned that when I retire in 8 months that carers allowance will stop and I will be worse off. I only have a very small amount in a private pension."

"Edinburgh Council will not help with wheelchair adaptations to my house unless I pay a percentage, I have no money so can't. Their reason is only universal credit recipients qualify and we haven't been moved from the old tax credit DLA system onto the new universal credit system yet."

"I have to live payday to payday...I've used food banks or [have] just gone without food, clothes, gas and electricity just to try make ends meet."

The cost-of-living crisis - impact on carers

As noted above, the COVID-19 pandemic has had a significant impact on the finances of carers, and the survey finds that the cost-of-living crisis, caused by a period of economic instability, has had a significant impact on their finances, too. The biggest areas of increased expenditure during the cost-of-living crisis for carers in Edinburgh were energy (88%), food and drink (86%), consumer goods (e.g. clothes) (64%), cleaning products (54%) and transport (49%).

While these increases are likely to have been experienced across society, there are some circumstances where carers have had higher demand for amenities like energy, food and drink. For example to ensure that a house is adequately heated for the person being cared for who is more susceptible to colder temperatures, to accommodate specific dietary requirements, oxygen needs or to travel to health appointments.

Some respondents also reported increased prices on items that are not likely to affect the wider population, such as supplies for caring (e.g. incontinence pads) (29%), equipment (e.g. medical devices) (16%) and safety mitigations (e.g. PPE, COVID tests) (16%). 30% indicated rising costs in rent or mortgage.

Half of carers (49%) felt confident about managing their monthly finances, while just 37% felt confident about managing their monthly finances in 6 months' time. The respondents who are the least confident at the moment about managing their finances are those who are not in employment, full-time education or are in receipt of a pension (34% not confident). In six months' time, the figure for this cohort is 38% not confident - indicating that some people expect their financial situation to worsen in the coming months.

It is also worth noting that 28% of those in paid employment are not confident that they will be able to manage their monthly finances in six months' time. This includes those on reduced incomes, such as people who are working part-time. While those on fixed incomes, including those who rely on pension income, may be impacted more than those in work - the Edinburgh Carers Survey reflects the financial challenges faced by many people in work across society, including carers in part-time employment.

The cost-of-living crisis - comments from carers

"Cost of living is continuously going up. Income is not. By default this has a significant impact."

"The rising cost...[of living]...is impacting on everything in my life that needs paid: transport, energy costs, rent, food, clothing etc. It is a great concern that if the rise keeps going up without an increase on my income. I have [the] fear that we won't be able to afford to live or afford basic essentials."

"I can't earn more to help my situation with being on carer allowance so it has impacted my finances as bills have shot up."

"I've lost out on over 20 years of working. Currently worried about rising interest rates as fixed mortgage comes to an end in January."

"Heating in the colder months was an issue and I am concerned about winter fuel bills."

"I use my car more, constantly running errands. Fuel has increased."

4.5 Breaks from caring

In comparison with previous surveys, carers demonstrated an increased recognition of the importance of taking a break from caring.

48%

would prefer a mix of breaks with and without the person they care for

55%

find taking a break stressful, worrying or they feel guilty

Nearly all of the barriers to taking a break from caring appear to have increased since 2021, with a notable increase in the proportion of carers (now 34%) who say that it is too expensive.

31%

preferred to take a break on their own or with other friends or family members

41%

find it difficult to relax during a break

When asked to describe a good break, there was a strong preference for a longer break of several days. There was a lot of variety in the responses but common themes included: the person they look after being cared for properly (whether they are on the trip or not); spending time with friends or family; health and wellbeing activities; being able to relax; and being free from caring responsibilities.

17%

preferred to take a break with the person they care for

39%

say that there is nobody else to provide care when they take a break

Breaks from caring - Comments from carers

"My wife is unable to go anywhere for respite care & I have to rely on my daughters to take over my role as a carer. This is difficult due to their own work & family commitments."

"Would love even a day/night away but years of asking for help for some more respite is more stressful, it's taken 15 years to get 6 hrs a week. We asked for overnight and got refused."

"I am so tired, I don't have the energy to go on a break."

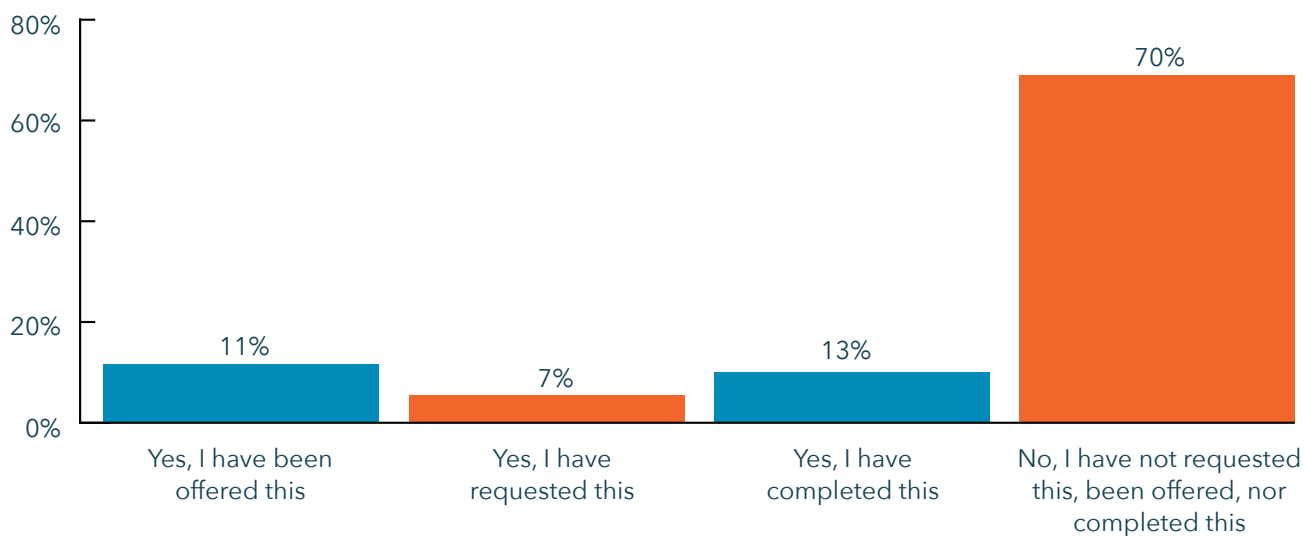
"My son receives services from Breakaway but breaks offered greatly reduced since Covid due to lack of carers, lack of funds. Personal budget not increased for years, while cost of services have rocketed. Seems to be being withdrawn by back door and expecting it to fizzle out completely."

"I have found, particularly in my first year of caring, that I used the vast majority of my annual leave from work to take time off to care for my mum, which left very little annual leave left to actually have a proper break from both work and caring."

4.6 Services and support for the person being cared for

The number of carers who felt that services for the person they care for were well coordinated dropped (29% in 2021 vs 26% in 2023) as did the number of carers who felt that they were supported to continue caring (29% in 2021 vs 27% in 2023).

Experience of Support Plan/Statement



- 11% of respondents have been offered an Adult Carer Support Plan or Young Carers Statement. This is down from 14% in 2021. 7% have requested it themselves - up from 4% in 2021.
- 13% of respondents have completed this plan/statement, down from 16% in 2021.
- 70% of respondents - up from 65% in 2021- have not requested, been offered nor completed a statement or plan. This is not due to recently becoming a carer; 63% of those who have been caring for more than 20 years report that they have no awareness or experience of a support plan.
- 90% of respondents who have not been supported by a carers organisation have no awareness or experience of a support plan.

Contributors to the qualitative research all reported very different packages of care and support based on the nature of the conditions of the people they were caring for. For example, carers of children often relied on their school and associated services involved in their school to support and signpost them to accessing support. There was mixed success reported in this regard. Carers of adult children did not appear to have an equivalent support system. Some carers of children in Edinburgh reported not being "believed" or "trusted" by agencies or organisations and a feeling that they were being judged in some way.

In the case of parents and spouses, there was often a medical crisis that led to a hospital admission and then the introduction of a package of care. The assessment process was regarded as necessary by carers but in some cases they felt that they were not fully engaged with it. Some carers stated that they were explicitly denied a role by care providers, in contravention of their legal rights. Participants in all groups reported long delays in arranging the package of care.

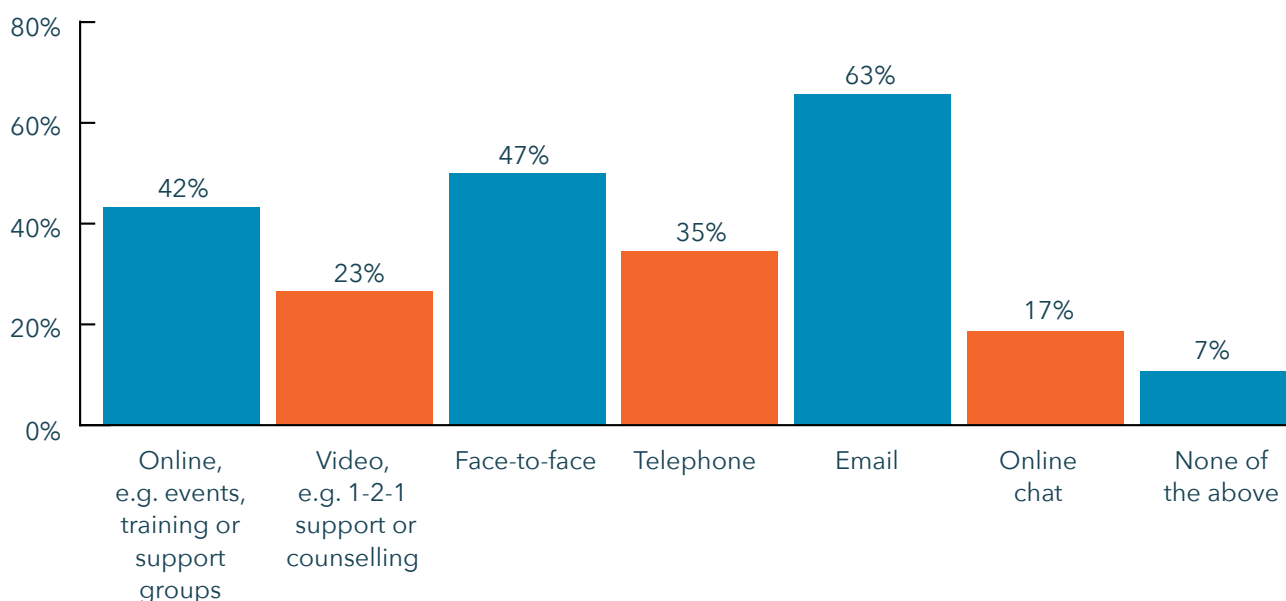
Finally, those caring for people with mental health conditions felt that the assessment process carried risks for people in their situation, due to the emphasis placed on gathering information from people who may not be well enough to respond accurately.

Self-directed support legislation came into effect in 2014 to provide individuals with greater choice and control over their care and support. Across Scotland, the implementation of self-directed support has been slow, and hampered by lack of awareness, excessive bureaucracy, inequalities in access and growing waiting times. These challenges are reflected in Edinburgh where the survey finds variable awareness of self-directed support amongst carers. And while the principle of having control and choice

was well received by carers taking part in the survey focus groups, some carers raised concerns about the additional responsibilities and work involved in being an employer as well as a carer. Others expressed concerns about the burden of finding the right services and support as there is little or no choice available to them.

One parent carer had been dissuaded by the stories they had heard from other carers about the paperwork and administration involved in self-directed support. The complexity of the idea, with the various options, was considered overwhelming for some carers.

4.7 Shaping future services



In order for organisations and agencies to successfully shape future services, it is important to ask carers themselves about their preferences and needs. The Edinburgh Carers Survey asked people about digital technology and communication preferences, as these are important in designing local support services and information for carers

74% of respondents said that they were very or quite confident in using digital technology like apps, internet and video calling. The corresponding figure for 2021 was 71% and for 2017 it was 62%. Respondents who are in paid employment or education are generally more confident than those who are retired, highlighting the additional technological support that some older carers may require.

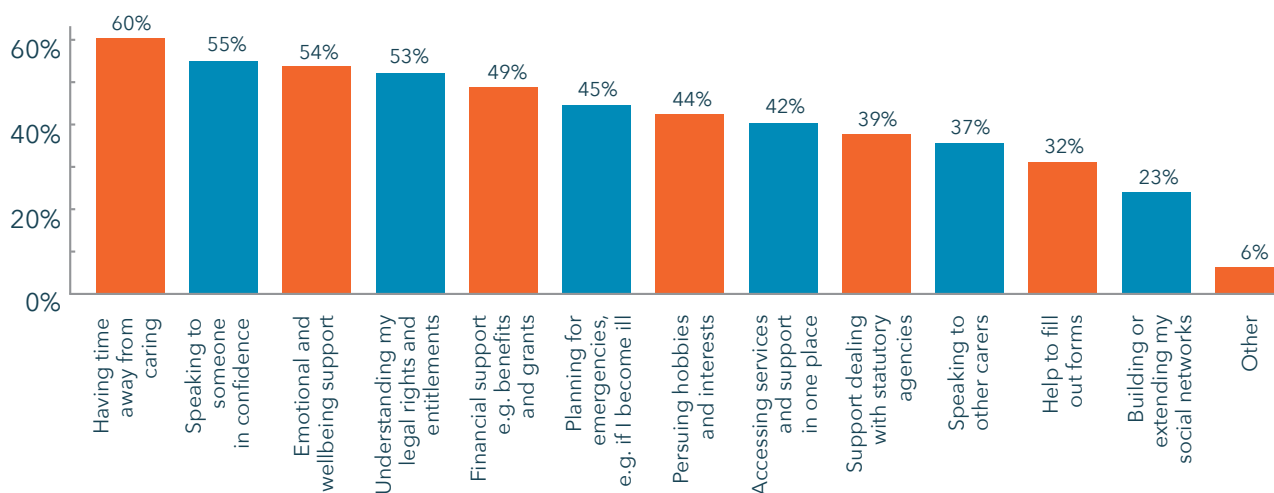
59% of respondents said that they are broadly comfortable with the general trend towards using more technology in everyday life and doing things digitally or online. 22% said that they are broadly uncomfortable; 11% are indifferent and 7% don't know. The proportion of people who said that they are comfortable declines with older age.

Email is the most popular communication channel across the sample, with 63% of carers selecting this as the way in which they would like to receive support and information from support agencies. 42% would like online support, 23% would like video support and 17% would like an online chat service.

Alongside online or digital support, there is still strong preference for face-to-face communication (47%) and telephone support (35%). 39% of respondents aged 16-25 would like to receive face-to-face support, increasing with age to 53% of those aged 56-65 and then declining to 38% of those aged 85+.

Interest in potential services and local service provision

The Edinburgh Carers Survey also asked carers about the type of services they would like in the future, including the importance of local services and service location.



The proportion of respondents who would like support in order to have time away from caring has jumped significantly since 2021. At that point, the figure was 45% and it was the fourth most requested type of support. In 2023, it is the most common type of support requested, by three in five carers (60%). The figure is even higher for respondents who are caring for a child (68%) or a grandchild (70%).

Similarly, demand for support to pursue hobbies and interests has increased from 36% to 44%. The other most requested types of support are very similar to those requested in 2021: speaking to someone in confidence, emotional and wellbeing support, and understanding legal rights and entitlements.

However, many carers in Edinburgh find taking a break challenging. Over half of respondents (55%) found taking a break hard, citing feelings of stress, guilt and worry. Planning and organising a break is difficult for many carers, too. 32% said that planning a break is so stressful that it is not worth it. Just under half (39%) said that there was no-one else to provide care and 23% said that there are no services available for them to take a break. 26% said that the person they care for won't accept care from others in any case, while 34% said that it is too expensive to take a break from caring (up from 24% in 2021, and likely reflecting the rise in the cost of living).

Just over half of respondents (54%) are interested in accessing support and services in their GP practice. This figure is the same as in 2021. 45% of respondents are interested in accessing support in a carer centre, 42% in a library and 41% in a community centre (50%, 38% and 38% respectively in 2021).

In a new development uncovered during the 2023 Edinburgh Carers Survey, 44% of respondents said that they would like to access support in their own homes, likely a lasting legacy of COVID-19 and the apprehension that some carers may have about contracting COVID-19 due to their own ill health, or because the person they care for is vulnerable to infectious diseases. 30% would be interested in accessing support in a local café (26% in 2021) and 20% in a local hospital (16% in 2021). 19% of respondents are interested in accessing support in a mobile location; the 2021 figure was 21%.

Finally, 80% of respondents said it was important that they had access to support services locally, the same figure as in 2021. Nearly half (49%) said that it was "very important" to have local support services. As in 2021, the proportion of respondents saying that local support services are very important is higher for those looking after a child (55%) and those looking after somebody who is neurodivergent (62%). This may reflect the greater level of support required due to the complex and all-encompassing nature of caring for these vulnerable groups of people.

Supporting carers in future - comments from carers

"Being able to claim carers allowance without the person I care for's benefits being affected. I did claim carers allowance but cancelled it when they took the same amount off the person I care for's benefit."

"Right at the beginning when dad was diagnosed it would have been helpful for the GP/Consultant to have passed on contact details for organisations that could help either then or in the future when required."

"Having a named person in the caring organisation, having check-ins. Letting you know what is available and making it easy to understand, most carers are limited for time away from caring duties or lack the energy when they do."

"Follow ups, community services with compassion who drop in daily. Who you can raise concerns with and get advice."

Support in securing time off from caring

"Prior to COVID-19 our son had a great package involving 5 days a week at a purpose built unit and 42 nights a year overnight respite in the same facility. This stopped when COVID-19 struck and has only been restored to 3.5 days a week with no overnight respite. We have been given a self-directed budget but carers are hard to source and it would massively help us, and many others like us, if the previous service was restored."

"Respite as some kind of home help where it is needed to lighten the load, a carer assistance team or better yet funding to pay trades so some of the domestic chores are reduced and quality of life at home is improved."

More activities for the person they care for

"I need my husband to have an equivalent of Care4Carers. Something social where he can choose from a range of activities with regular meet-ups. Something like a drop-in session where he could turn up for a game of badminton, snooker, petanque or similar activity would be wonderful."

"There are no groups for my son in our area. He has a disability social worker and even she cannot find any groups for him. He will not travel so it needs to be within Leith but there is just nothing at all that he can go to to interact with peers similar to himself. The closest things we have found are the Yard and Branching out together which both have waiting lists that are completely full and have been, potentially for years."

"There is not really much educational support for neurodiverse children outside school e.g reduced or free extra tuition, guides to good online resources, targeted learning clubs outwith school."

More support in understanding legal rights and entitlements

"Help filling in financial forms & being aware of what entitlements are available."

"I just feel a wee bit lost as to who I may contact if a problem suddenly arises with my wife. It would be helpful if there was a comprehensive list of all the various things that could happen or develop, accompanied by names and telephone numbers of the respective people to contact."

"Very overwhelmed with the whole system as I'm also neurodivergent and found it extremely confusing, overwhelming and end up with no productivity coming of any meetings about my son."

Other support requested by carers

It should be noted that many other carers requested support such as enhanced legal rights and entitlements or support for carers; (more) mental health support for the person they care for; help with transport, closer support services, help securing the support to which the person they care for is entitled (e.g. form filling support); the opportunity to speak to other carers in similar positions; support to encourage the person they care for to live independently for as long as possible; support with planning for the longer-term and training or therapy for the person they care for.

Carers' requirements of services have shifted in 2023

The Edinburgh Carers Survey highlights the shifting requirements for carers after successive lockdowns during the COVID-19 pandemic and the changing profile of carers. For example, the qualitative feedback reflected demand for support on day-to-day activities, such as house maintenance, housework, shopping and chores (such as "life admin") that are sometimes difficult to keep on top of while caring for someone. This is a new theme for 2023 and may reflect the changing profile of carers and a recognition that this is not a temporary situation but a lifelong commitment.

The type of support required by carers reflects earlier observations of increased recognition of the importance of taking a break. The requirement for support to take a break is now the most requested type of support, up from fourth in 2021, requested by 60% of all carers in 2023. This indicates that many carers are feeling burnt out, and unable to find time away from caring due to the intensive nature of the role, combined with relative isolation and a lack of support network.

Other types of support requested by carers included a focus on better support for the person being cared for. This includes more activities suitable for their needs (particularly for children) and in some cases support for people to accept that they require caring and to accept the needs of the carer.

There is no doubt that digital and online technology has created more opportunities to support more carers. However, the responses to the Edinburgh Carers Survey suggest that more traditional face-to-face and telephone support is still required for a lot of carers. General comfort with new technology and online activity decreases with age, and it is unlikely that the requirement for more personal and direct engagement will ever disappear altogether.

5 Demographics and identification

Methodology

A total of 1,169 responses were received to the Edinburgh Carers Survey. This is higher than the 826 responses received in 2021. In a change from previous years, the data set includes those who are caring for someone living outside Edinburgh, but who live in Edinburgh themselves and/or who are accessing support from Edinburgh-based services.

Carer characteristics

The majority of carers (4 in 5) responding to the survey are women, which reflects national carer demographics. Compared with previous surveys, the number of younger carers has increased – 71% are of working age and 8% are aged 35 and under. One third of respondents are not in employment at all, nor are they in full-time education, nor do they receive a pension. This indicates that many carers, and those they care for, will rely on social security support, including Carer’s Allowance or Adult Disability Payment. In an increase from 2021, nearly a quarter of respondents considered themselves to be in ‘poor’ or ‘very poor’ health – highlighting the strain of caring on the physical and mental wellbeing of unpaid carers.

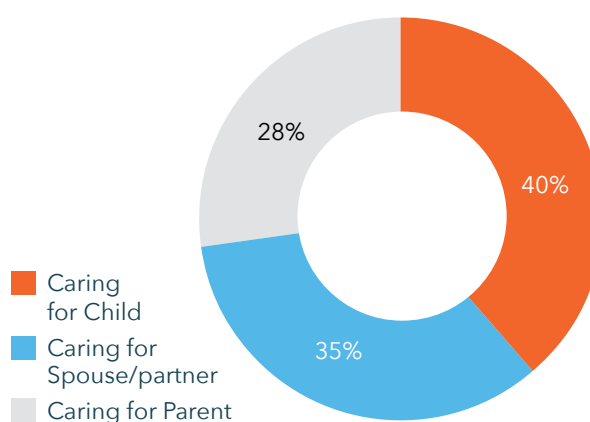
Caring responsibilities

The survey highlights the wide variety of caring responsibilities and circumstances of carers in Edinburgh.

The majority of respondents (66%) have been caring for more than five years. This is in line with the 2021 figure of 65%. 19% of respondents have been caring for more than 20 years (20% in 2021).

40% of respondents are caring for their child, 35% for their spouse/partner and 28% for their parent.

Carers are most likely to be caring for someone with a physical health condition, for someone with a mental health condition, for somebody who is neurodivergent or for someone with Alzheimer’s Disease or dementia.



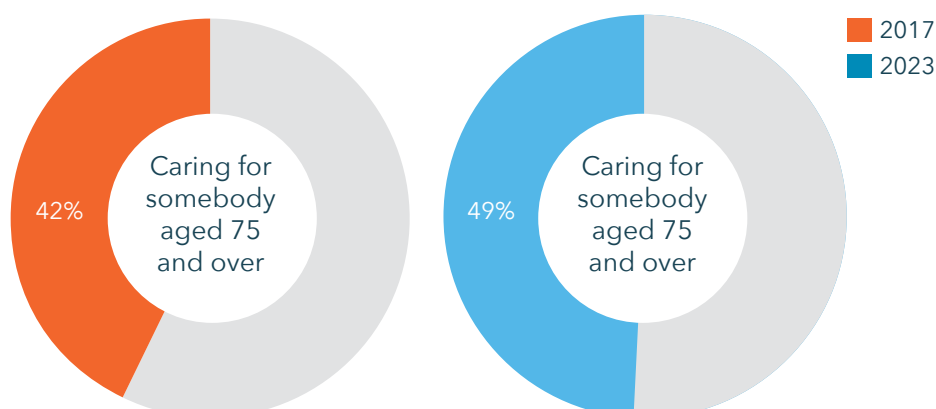
New carers (who have been caring for up to 2 years) account for 11% of the sample overall. The figure is higher for respondents caring for a grandparent or neighbour (15%), caring for somebody with Alzheimer’s or dementia (17%), and who are aged 26-35 (22%) or 75+ (17%) and caring for somebody aged over 75 (14%).

71% of carers always live with the person they care for. Nearly two thirds of respondents have been caring for more than five years; a fifth have been caring for more than 20 years.

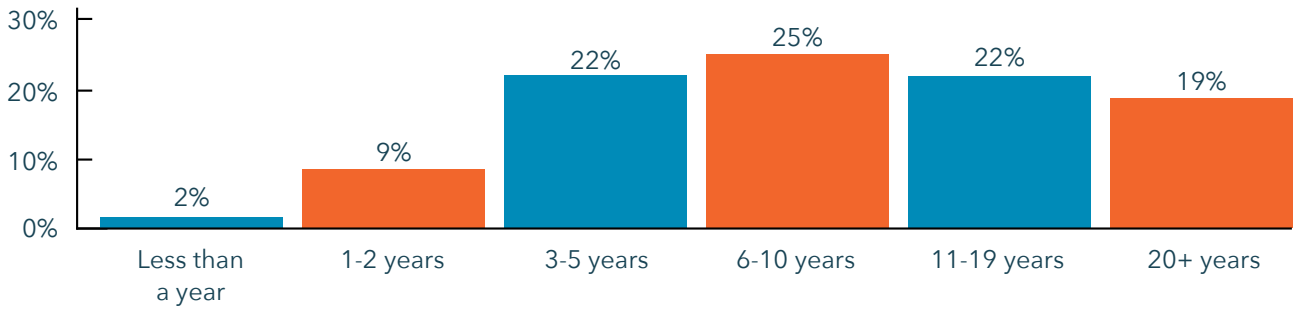
More than half of respondents provide more than 50 hours of care per week. This figure is up from 2021.

30% of respondents are caring for more than one person. This figure is also higher than in 2021.

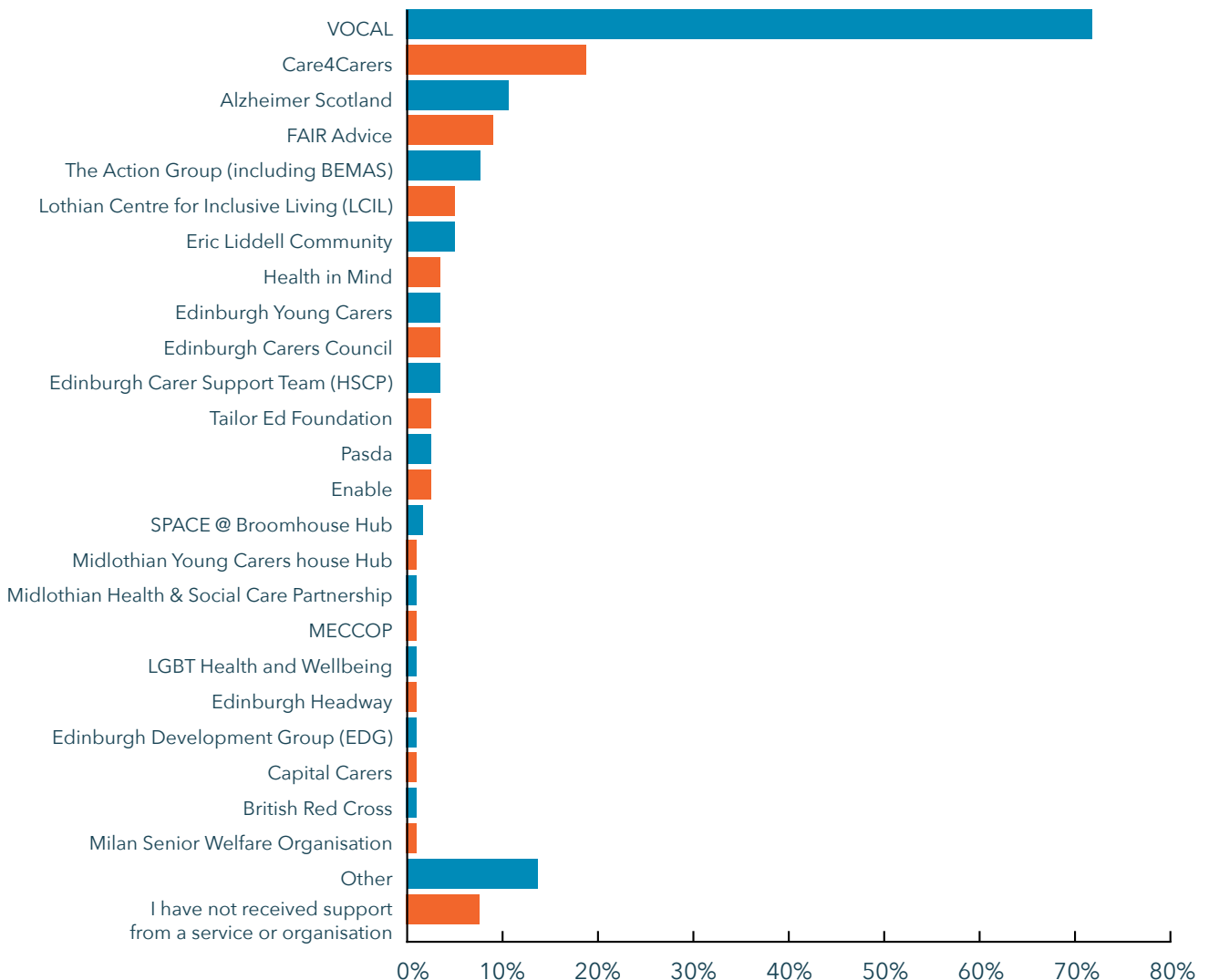
42% of respondents are caring for somebody aged 75 and over, down from the 49% reported in 2017. Meanwhile, the proportion of respondents caring for somebody aged 25 and under has increased from 19% to 36% over the same period.



Duration of care



There are differences in caring experiences depending on the age of the person being cared for. In general, respondents looking after someone aged 25 and younger are 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 are also more likely to be caring for people with conditions that will require long-term support: learning disabilities, neurodivergence, or substance use. The support required for this set of carers is likely quite different from the support required by carers of older people, who may have been doing it for a relatively shorter period of time, may not be living with the cared-for person, and who are caring for a terminal or degenerative condition. 87% of respondents received support from one or more carers' organisations.



Conclusion

The findings from the Edinburgh Carers Survey are clear: they suggest that the health and economic wellbeing of unpaid carers has got worse. There are fewer services and support for the person they care for which requires unpaid carers to shoulder more caring responsibilities. There is less time, support and money available to take time away from caring, which is now the most requested form of support.

More carers in Edinburgh are experiencing ill health, poorer personal finances and employment circumstances, and greater difficulty in accessing support services. While these have been factors for carers for a long time, they have been exacerbated during the double blow of COVID-19 - and the resultant closure or suspension of services - and the current challenging economic circumstances, which have placed greater financial pressures on caring households.

This report sets out a range of recommendations which could help enhance the implementation of The Carers (Scotland) Act 2016 in Edinburgh, based on what carers have said they need to be able to continue caring. Because the health and care system is so reliant on unpaid carers, it is essential that they are supported in line with the aims of The Carers (Scotland) Act 2016. Failure in this regard will only result in an ever-growing number of carers facing ill health and financial crisis.

The data from the Edinburgh Carers Survey is evidence of that trajectory. More services are required - supported by greater resource, not less. Cuts to services will increase the burden on unpaid carers. The Scottish Government's National Carer Strategy states that 'no-one should need to put their aspirations and ambitions on hold because they are providing care to a loved one'. The Edinburgh Health and Social Care Partnership, together with partner carer organisations, has the opportunity to ensure this is the case for Edinburgh carers.

6

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