healthwatch Norfolk

Family involvement in caring for older people in Norfolk

July 2026

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Registered office: Suite 6, The Old Dairy, Elm Farm, Norwich Common, Wymondham, Norfolk NR18 0SW

Registered company limited by guarantee: 8366440 | Registered charity: 1153506

Email: enquiries@healthwatchnorfolk.co.uk | Telephone: 0808 168 9669

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Who we are and what we do

Healthwatch Norfolk is the independent voice for patients and service users in the county. We gather people's views of health and social care services in the county and make sure they are heard by the people in charge.

The people who fund and provide services have to listen to you, through us. So, whether you share a good or bad experience with us, your views can help make changes to how services are designed and delivered in Norfolk.

Our work covers all areas of health and social care. This includes GP surgeries, hospitals, dentists, care homes, pharmacies, opticians and more.

We also give out information about the health and care services available in Norfolk and direct people to someone who can help.

At Healthwatch Norfolk we have five main objectives:

1. Gather your views and experiences (good and bad)
2. Pay particular attention to underrepresented groups
3. Show how we contribute to making services better
4. Contribute to better signposting of services
5. Work with national organisations to help create better services

We make sure we have lots of ways to collect feedback from people who use Norfolk's health and social care services. This means that everyone has the same chance to be heard.

Summary

This project explored how families and friends are involved in supporting older people in Norfolk, and what would help them play a bigger role. It is part of wider work by local health and social care organisations to support carers and help people stay independent for longer.

We wanted to understand what helps and what makes it harder for family members to get involved in caring, and what could be done to support them better.

To do this, we spoke with carers through focus groups and a county-wide survey, receiving 144 responses. Most people who took part were women over the age of 55. Many were caring for a partner or spouse, others for parents. Most carers were providing very high levels of support – often more than 50 hours a week – and many lived with the person they cared for.

People told us they take on a wide range of tasks, from shopping, paperwork and giving medication, through to emotional and social support. The most difficult tasks were those involving emotional and social care, as well as personal care. Even when family members helped, carers often felt the support was not enough.

A large number of carers said they received no help at all from other relatives. When help was given, it was more often daughters and sisters who stepped in, rather than sons or brothers. This reflects long-standing gendered patterns in family care.

Several factors made it more likely that family members got involved – such as living nearby, feeling a sense of duty, and having good

relationships. But there were also major barriers, especially family members living too far away, being too busy with work or childcare, or difficult family relationships. Many carers felt they had little say in how caring roles were shared, and that responsibility often "just fell" onto one person.

Carers said they needed better support. The most common request was for more respite services – giving them regular breaks. Many also wanted clearer, easier-to-find information about services and support available. Some said it was hard for relatives who lived elsewhere to know how to help, and wanted advice on caring from a distance. Others thought that better communication between services and wider family members would make a difference.

The findings point to important issues. Caring responsibilities often fall heavily on one person, mostly women, and many carers feel isolated and unsupported. While family circumstances cannot always be changed, there are things services could do to make a real difference.

Our recommendations are:

- Make respite care more widely available, so carers can take essential breaks.
- Provide simple, clear and centralised information for carers about services and support.
- Make it easier for relatives who are not the main carer to communicate with health and social care services.
- Expand peer support groups, befriending schemes, and counselling for carers, especially to help with emotional and social support.
- Offer guidance on how family members can contribute to care from a distance, such as managing paperwork or staying in touch with services.

Why we did this

The question of how to better involve and support informal carers in the future is a priority for both the Norfolk and Waveney Integrated Care Board's (NWICB's) 'Ageing Well Strategic Framework' and Adult Social Care's five-year strategic plan 'Promoting Independence'. Within the NWICB's framework, there is a focus on the second stage of ageing: the "active ageing phase", to prepare an individual's social and family network to be better equipped to support them in later life. Similarly, within the 'Promoting Independence' strategy, there is a focus on identifying carers and ensuring that they are supported accordingly. Within the research theme of family involvement in caring, the question of how families can be better prepared to look after their relatives for longer rather than formal social care being the starting point for an individual's care is therefore of particular interest.

Previous research on this topic is surprisingly sparse, meaning that we refer below to some international research, and some older research. Authors have highlighted that there has been a focus on care dyads (one carer looking after one person) as opposed to care networks (where a larger number of people look after one person). In Western Europe, more studies of care networks have been called for (Keating, Otfinowski, Wenger, Fast, & Derksen, 2004). Instead of family care networks, the role of primary caregiver often falls unequally to one family member as stated by the U.S. based Family Caregiver Alliance (2025). Numerous bodies of research have identified a variety of situational and demographic factors, both barriers and facilitators to greater family engagement in the care of older people.

The gradual changes in recent years to family structures and social norms are, as argued by Keating et al., reasons why some family networks are unable to take on the responsibility of caring for elderly family members. Changes such as "fewer children, high divorce rates, geographical mobility, and the competing demands of employment" (2004, p. 116) have all contributed to barriers in wider family engagement. Geographic closeness to an elderly family member is also cited by Chanfreau and Goisis (in a more recent study based in Britain) as affecting the likelihood of involvement in caregiving: "adult children with more contact with their parent and those living nearest to the parent, especially if their sibling(s) live a considerable distance away, have been found most likely to provide care"

(Chanfreau & Goisis, 2022, p. 203). Similarly, a study in Boston (U.S.) stated that proximity to the parent in need is one of the "strongest predictors of intergenerational support" (Pillemer & Suitor, 2013, p. 591).

In a broader sense, adult children's availability affects the extent to which they participate in their parents' care (Pavlalko, 2011). 'Availability' here relates not only to the proximity to the parent but also the consideration of competing roles and responsibilities, including the employment of the caregiver and whether they have children to look after. Research undertaken by Age UK suggested that there was "an estimated number of 5.7 million people aged 40-60 who are considering caring for or supporting an older parent in the future who would say that they would find it hard to care for or support their parent(s) whilst juggling their own life, such as their job and children" (Age UK, 2025). The same research contained an estimate that 6.6 million people aged 40-60 would not know how to support an older parent in the future (Age UK, 2025), suggesting that knowledge around caregiving could also be an issue.

Bianchi et al. (in a study in the US) advance the concept of exchange theory within family care networks, suggesting that "adult children bargain within sibling groups over care-giving according to relative opportunity costs" ((Bianchi, Hotz, McGarry, & Seltzer, 2006) referenced in (Chanfreau & Goisis, 2022, p. 202)). This means that, those who "encounter the fewest costs in terms of availability, competing time demands, and forgone income are expected to assume the role of a caregiver" as stated by Leopold, Raab, & Engelhardt in a US based study (2014, p. 302). There is also an element of give and take within exchange theory, with care for the elderly relative sometimes being given in return for care previously received by the caregiver either for themselves or their own children. This is echoed by other US American studies which concluded that these long-term exchanges were almost as important as gender in deciding which siblings gave care to their parents ((Henretta, Hill, Li, Soldo, & Wolf, 1997) referenced in (Leopold, Raab, & Engelhardt, 2014, p. 304)).

Another situational factor that affects the likelihood of a family member getting involved in the care of an elderly relative, is parental expectations of who will become their primary caregiver. When parents, particularly mothers, identified who their desired caregiver was to be, this had an important influence on who the caregiver did end up being (Pillemer & Suitor, 2006, p. 439). Another study found that children whose mothers identified them as expected future carers, were much more likely to provide care in the case of serious illness (and the adult

children were also more likely to live in proximity, share values, and be female (Pillemer & Suitor, 2013)).

As well as situational factors, family demographics also contribute to barriers and facilitators to family members becoming caregivers. Firstly, the characteristics of elderly people can impact on who makes up their support network. In a study based in the Netherlands for example: "Those who are older, unmarried, childless and in poor health are least likely to have robust support networks." (Tijhuis, Flap, Foets, & Groenewegen, 1998) referenced in (Keating, Otfinowski, Wenger, Fast, & Derksen, 2004, p. 119). Research shows age is a prominent factor and that the older someone is (85+), the smaller their family support network will be, owing to the loss of "same generation relatives and friends, and a tendency to maintain only the closest relationships" (Keating, Otfinowski, Wenger, Fast, & Derksen, 2004, p. 119). Elderly people requiring care have been found in some settings to prefer to receive care from their marital spouse, especially "for emotional and physical tasks" in Canada (Campbell, Connidis, & Davies, 1999) and the US (Ajrouch, Antonucci, & Janevic, 2001).

Gender is also an important factor in determining family care networks and primary caregivers. The 2021 UK Census showed that women are more likely to provide care than men, with 59 per cent of unpaid carers being female. When siblings are tasked with providing care for an elderly parent, it is daughters that are more likely to take on this role especially when caring for a mother (Leopold, Raab, & Engelhardt, 2014). This is attributed by several researchers to women being stereotypically perceived as having a socioemotional role: "It's easy for families to fall into common traps… that the son will handle finances while the daughter will take care of emotional or physical care needs." (Russo, 2025). Interestingly, when multiple sisters are present in a family they are likely to each take a share of caregiving responsibilities, whereas brothers tend to care for their parents individually ((U.S. based study by (Matthews & Heidorn, 1998) referenced in (Keating, Otfinowski, Wenger, Fast, & Derksen, 2004)). Linking to the previously mentioned issue of the availability of a caregiver, it was found in Singapore that female carers were more likely to be unemployed than non-caregivers "due to the role strain of balancing work and caregiving responsibilities" (Edwards, Zarit, Stephens, & Townsend, 2002) referenced in (Lim-Soh, Sung, Quach, & Malhotra, 2024).

Based on this previous research, we can see that both demographic and situational factors contribute to barriers and facilitators of broader family involvement in caring for older people. If services aim to effectively encourage

more relatives and friends in Norfolk to provide care for the over 65s, we need to find out how these aspects affect people in the county, and what kind of support would help more people to get involved. This research therefore aimed to answer two main questions:

1. What helps a wider group of family and friends to get involved in an older person's care, and what can stop them from doing this?
2. What can health and social care services in Norfolk do to help wider networks of family and friends get involved in the care of older people?

How we did this

The objective of this research theme was to understand what help carers are currently receiving from their broader circle of family and friends, and what support services might be able to provide that would help family and friends become more involved. This research required us to understand some of the complex web of relationships that develop around caring for an older person, as well as to understand general trends in how caring work is shared, across the county. We therefore used a mix of qualitative and quantitative research methods, to achieve both depth and breadth of insight.

We commissioned Carers Voice Norfolk and Waveney to do the qualitative part of the research for us, given their well-developed network of carers across Norfolk. They used a combination of focus groups and inviting written submissions, to gather feedback from 20 carers. The list of questions and prompts for the focus group was based on the overall research questions agreed with NCC, and questions arising from the review of existing research carried out on similar themes in other places.

A preliminary thematic analysis of the focus group transcripts was carried out, and used to produce a questionnaire which reflected the concerns that people expressed in focus groups, and aimed to find out which concerns were more broadly shared across the county. This was distributed across Norfolk, and remained open for six weeks. We promoted the survey through the following channels:

- The Healthwatch Norfolk website, newsletters and social media
- GP Footfall websites and other primary care IT platforms
- Targeted Facebook adverts for people in the appropriate age groups
- Patient Participation Groups in GP surgeries
- Health and Wellbeing Partnerships across the county
- Various voluntary sector organisations' email lists, social media and websites
- The NCC website and providers email list
- A 'Care for Carers' event held at the forum in Norwich on 9th June
- A Salvation Army coffee morning in Sheringham
- A Carer's coffee morning at Cromer Hospital

Respondents were entered into a prize draw to win £10 shopping vouchers as an incentive to take part.

Once all data was received, the qualitative data was analysed using the NVivo qualitative analysis software, to identify the principal themes of people's feedback on their experiences. The survey data was analysed using Smart Survey's own analysis functions, along with Microsoft Excel. The data was analysed both to uncover overall trends, but also to look at the results according to different geographical areas and demographic characteristics (such as age, gender, ethnicity and so on). We also checked the data against our qualitative findings to understand to what extent these were representative of the broader population of Norfolk.

Ethical considerations

This project was not put before an ethical scrutiny committee, because according to the Health Research Authority (HRA), it does not constitute formal research, and therefore does not require ethical scrutiny (see the HRA decision tool here: https://www.hra-decisiontools.org.uk/research/).

Care was taken to secure informed consent from all people participating in this research. Participants were told what the information would be used for, how long it would be kept before it was deleted, and that they would be able to withdraw their consent to participate at any time before publication of the report. People were made aware that all responses would be anonymised, and any identifying information removed before it was mentioned in the report. The data was stored in password-protected hard drives, and hard copy survey responses were stored in a locked drawer at the Healthwatch Norfolk offices. The data collected will be deleted at the end of the project, and participants were made aware of this. People participating in the focus groups were signposted to appropriate services after the interview ended, to help them to find support with any issues they raised during the session.

Who we heard from

We received 144 completed responses to the Family involvement in care: Experiences of Carers of people over 65 Survey. Please note that only two questions were compulsory so the number of responses will vary by question.

The heatmap on the following page displays where survey participants live based on the first half of their postcode. As shown on the map, we heard from people across a broad area of the county, but most respondents were located in and around Norwich, there was also a significant number of respondents to the South-East of Norwich (NR14 postcode) as well as to the South-West in the IP25 area.

Based on answers to each individual demography question, we found that:

- The majority were female, with 67% (80) of participants identifying as such.
- 94% (112) described their ethnicity as 'White: English, Welsh, Scottish, Northern Irish or British'. For comparison, 94.7 per cent of Norfolk's population were recorded as 'White' in the 2021 UK census (Norfolk Insight, 2024).
- Of 117 respondents who answered the question, 50 people had a long-term condition and 32 had a disability. 14 people also identified themselves as having Dementia.
- Most respondents were split fairly evenly between the age ranges of 56-65 (31, 26%) 66-75 (33, 28%), and 76-85 (33, 28%).
- Most respondents were heterosexual with 99 people (85%) identifying as such, with another 8% of participants preferring to not disclose their sexual orientation.

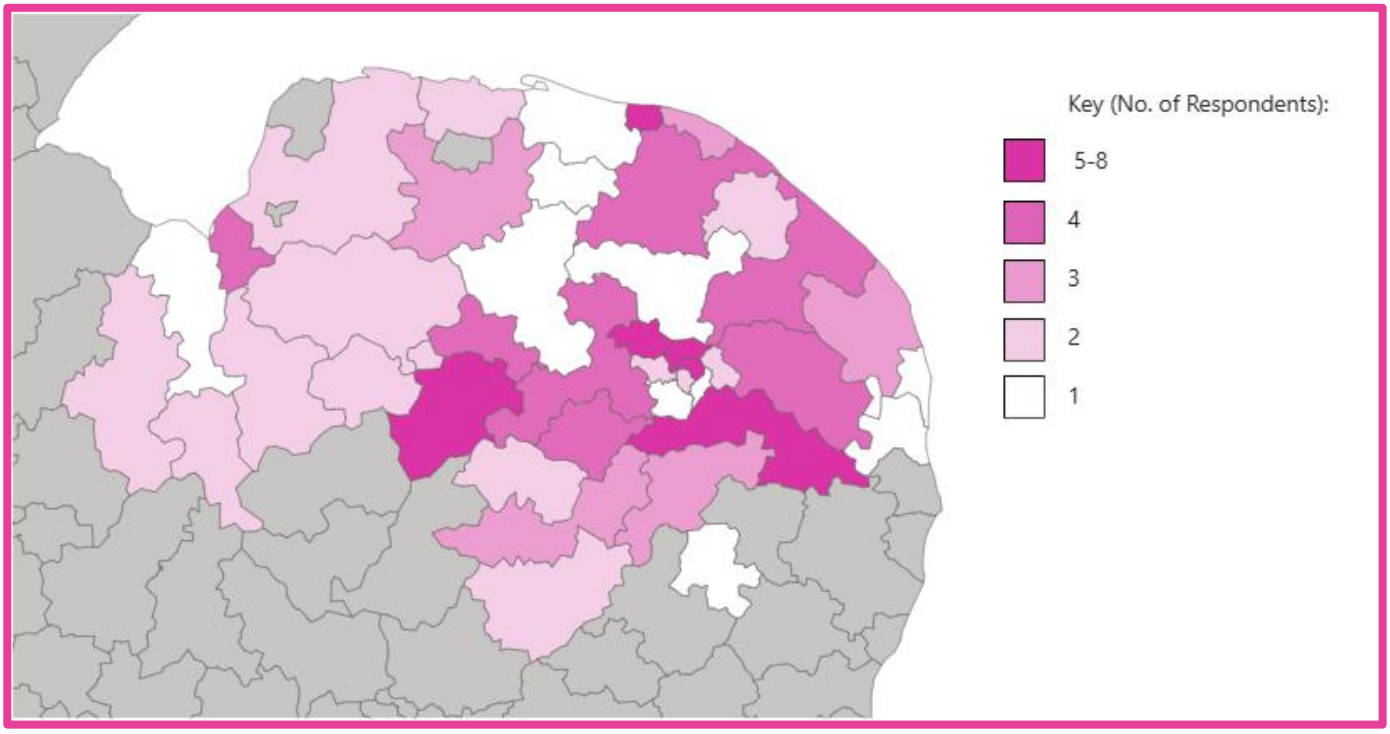

Figure 1 - A heatmap displaying the location of respondents. Total responses for this question numbered 115.

Below are a series of graphs and charts that depict the demographic data, outlined above in further detail:

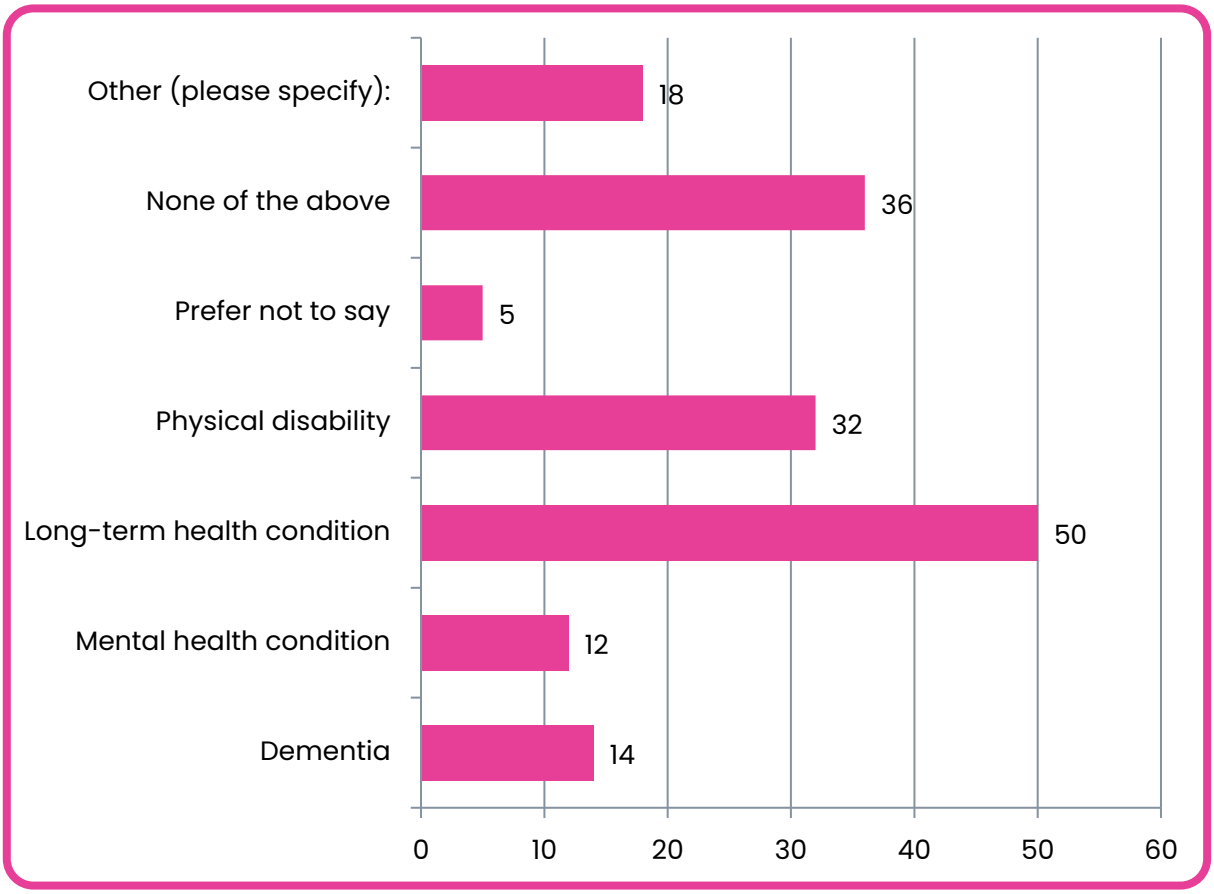

Figure 2 - Bar chart depicting the number of respondents who identified as having a disability or long-term health condition etc. Total responses for this question numbered 117.

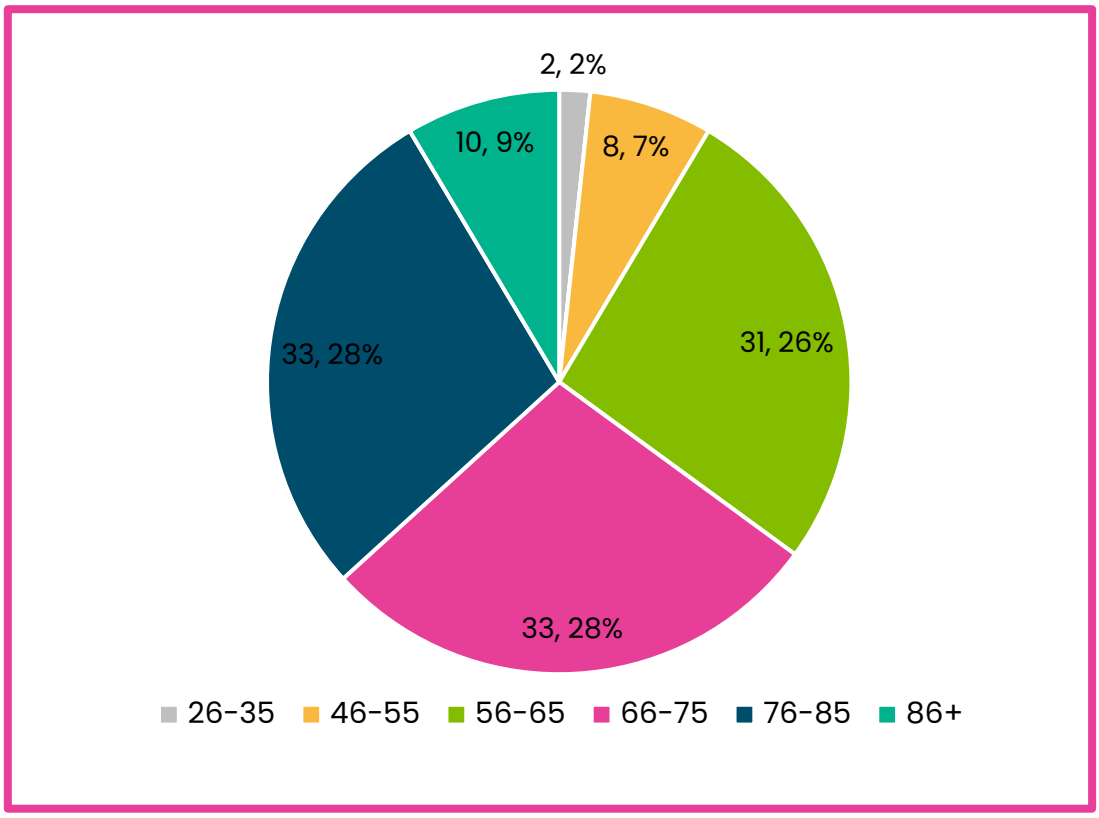

Figure 3 - Pie chart displaying the distribution of age ranges within the survey population. Total responses for this question numbered 117.

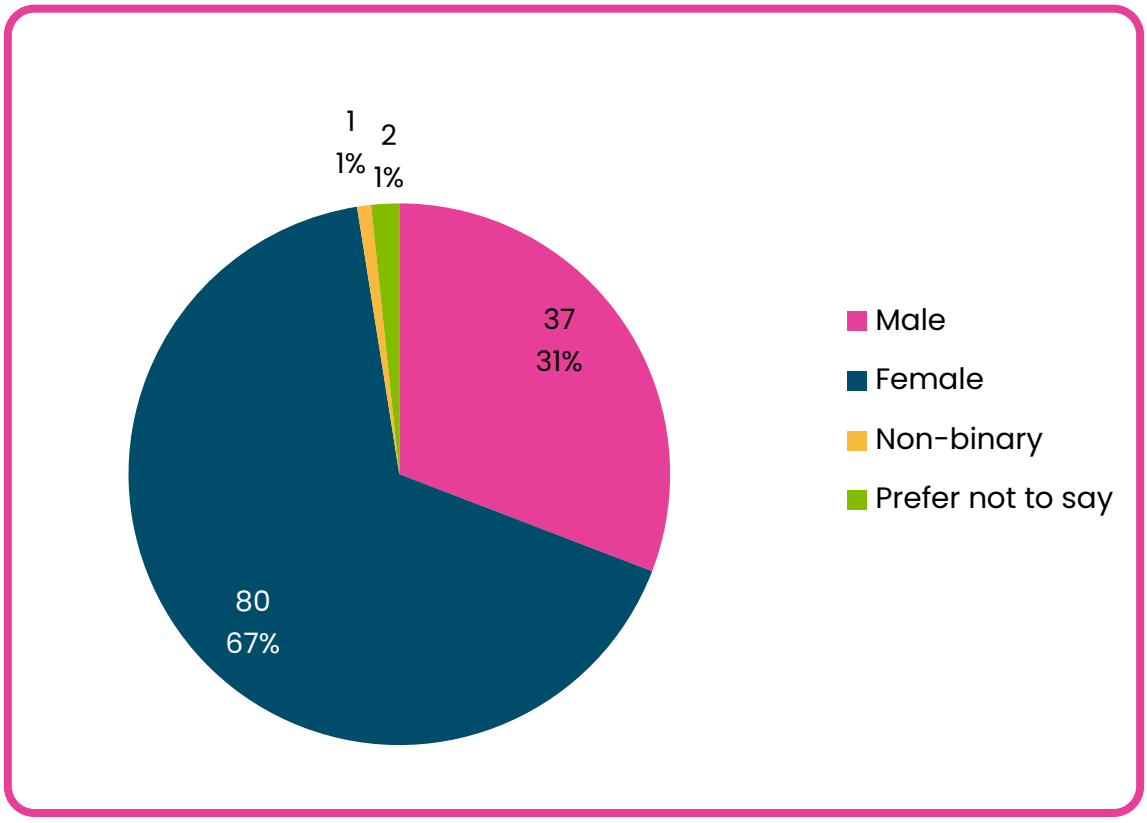

Figure 4 - Pie chart displaying the distribution of gender statistics within the survey population. Total responses for this question numbered 120.

What we found out

This section outlines what people told us about their experiences of trying to involve more family and friends in the care of older people.

The Carers and Care Recipients

The first part of the survey focused on finding out more about the respondents, and the people that they provided care for. Just over half of respondents (51%, 74) cared for a partner or spouse, while another 32% (46 people) cared for their mother or father. 12% (17) of respondents selected 'Other'. The below chart provides a visual representation of this distribution. The fact that 51% of respondents care for a partner/spouse supports the research carried out by academics that elderly people in need of care, where possible, prefer to receive it from their spouse or partner ((Campbell, Connidis, & Davies, 1999) (Ajrouch, Antonucci, & Janevic, 2001))

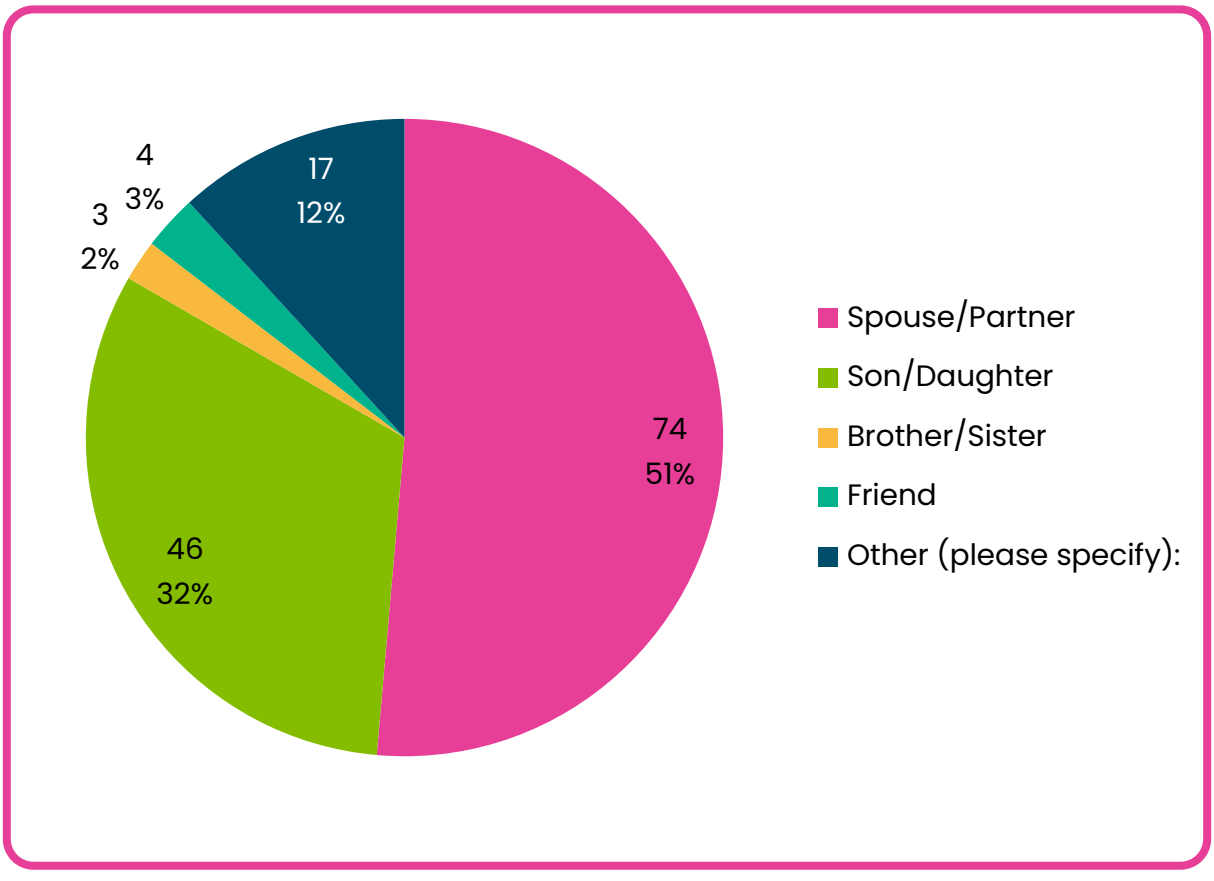

Figure 5 - Pie chart depicting respondents' relationship to the person they care for. Total responses for this question numbered 144.

As mentioned in the 'Who we heard from' section, most respondents were female (67%). A pie chart showing the breakdown of respondents by gender can be found in the previous section. Interestingly, only seven sons of care recipients participated in the survey, again supporting the idea that women and specifically daughters are more likely to become care givers (Leopold, Raab, & Engelhardt, 2014, Russo, 2025)

The most common conditions among care recipients were age-related, affecting just over half of individuals (75 people, 52%). Dementia, long-term health conditions, and physical disabilities were also prevalent, with 67, 61, and 70 recipients respectively experiencing these conditions. Many respondents' relatives having multiple conditions highlights the often complex and multi-faceted health needs faced by those who are elderly.

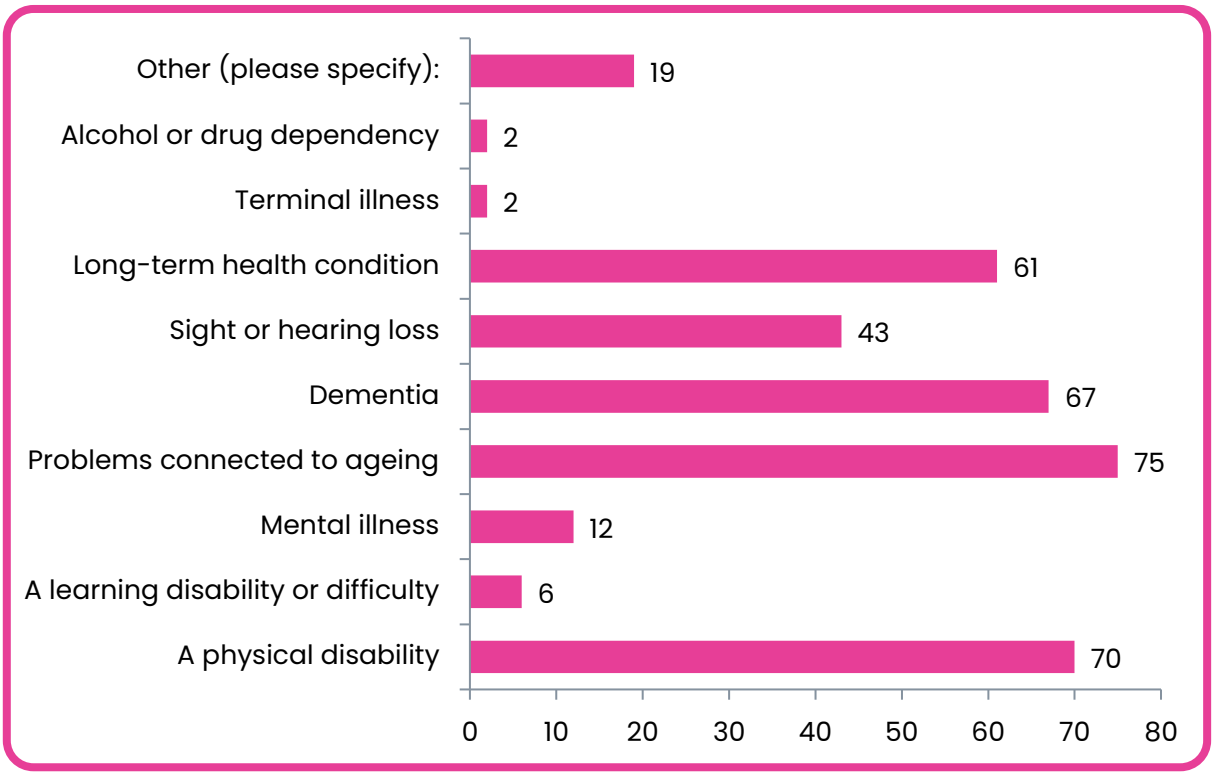

Figure 6 - Bar chart depicting what conditions the people that respondents were looking after had. Total responses numbered 144.

The largest age group of family members that respondents cared for was those who were 85+, 43% or 61 people cared for a family member in this group. The second largest group were those 75-84, with 58 people (40%). This might suggest

that those relatives who were older were more likely to be a care recipient, due to the health complications that can come with ageing.

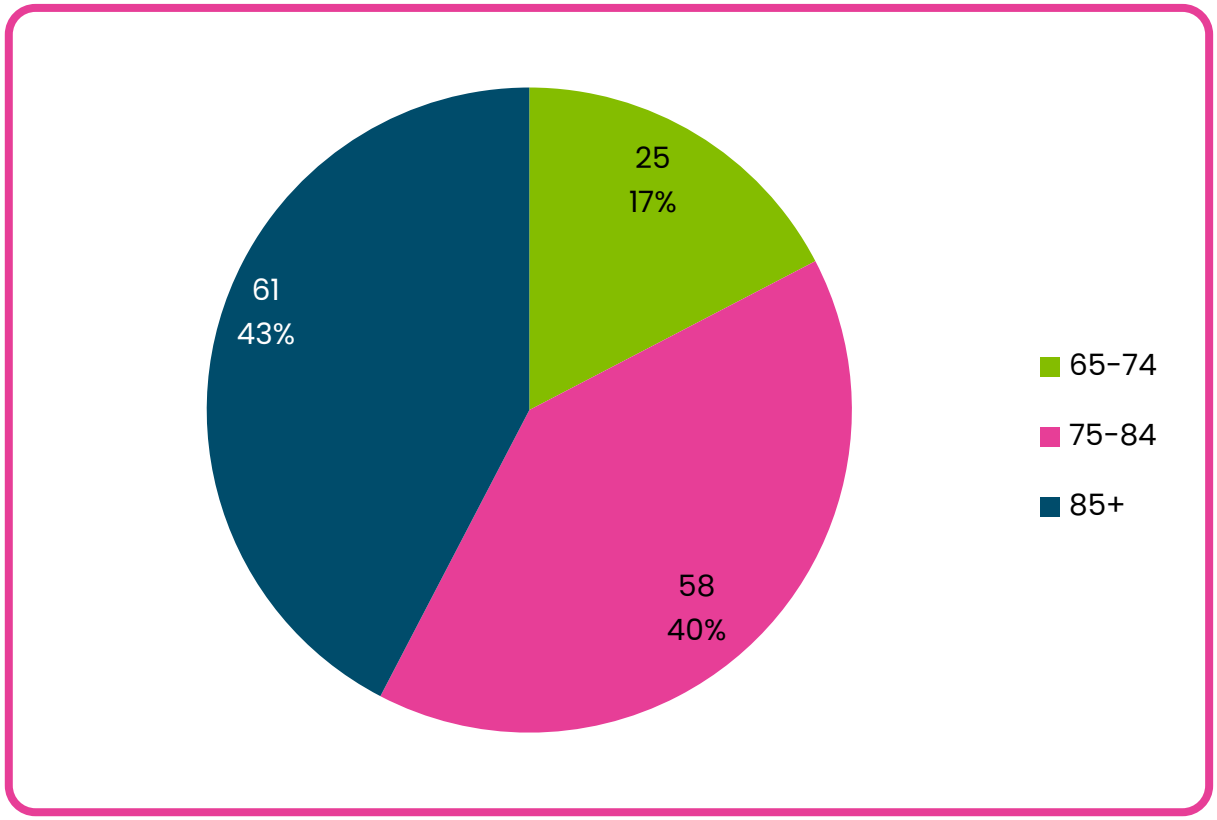

Figure 7 - A pie chart depicting the age of persons cared for by respondents. Total responses for this question numbered 144.

The duration that respondents had been caring for their relative was varied, with 55 people (38%) having provided care for 1-3 years, just over a quarter (26% or 37 people) had been caring for a loved one for 4-6 years, while 44 people (31%) had been caregivers for seven years or more. Just over two-thirds of respondents (68%, or 97 people) lived with the person they cared for. Most of these were caring for a spouse or partner (71 people), while another 19 were adult children living with a parent who required care.

More than half of respondents (52%, or 73 people) provided 50 or more hours of care each week. Among those living with the care recipient, this figure was higher, around three-quarters (76%, or 72 people) reported providing 50+ hours of care per week. Among participants who provided fewer than 50 hours of care weekly (68 people), nearly half (44%, or 30 people) were adult sons or daughters of the care recipients. This owed to the fact that they were less likely to live with the

parent that they cared for, and therefore also less likely to commit as much time to that care.

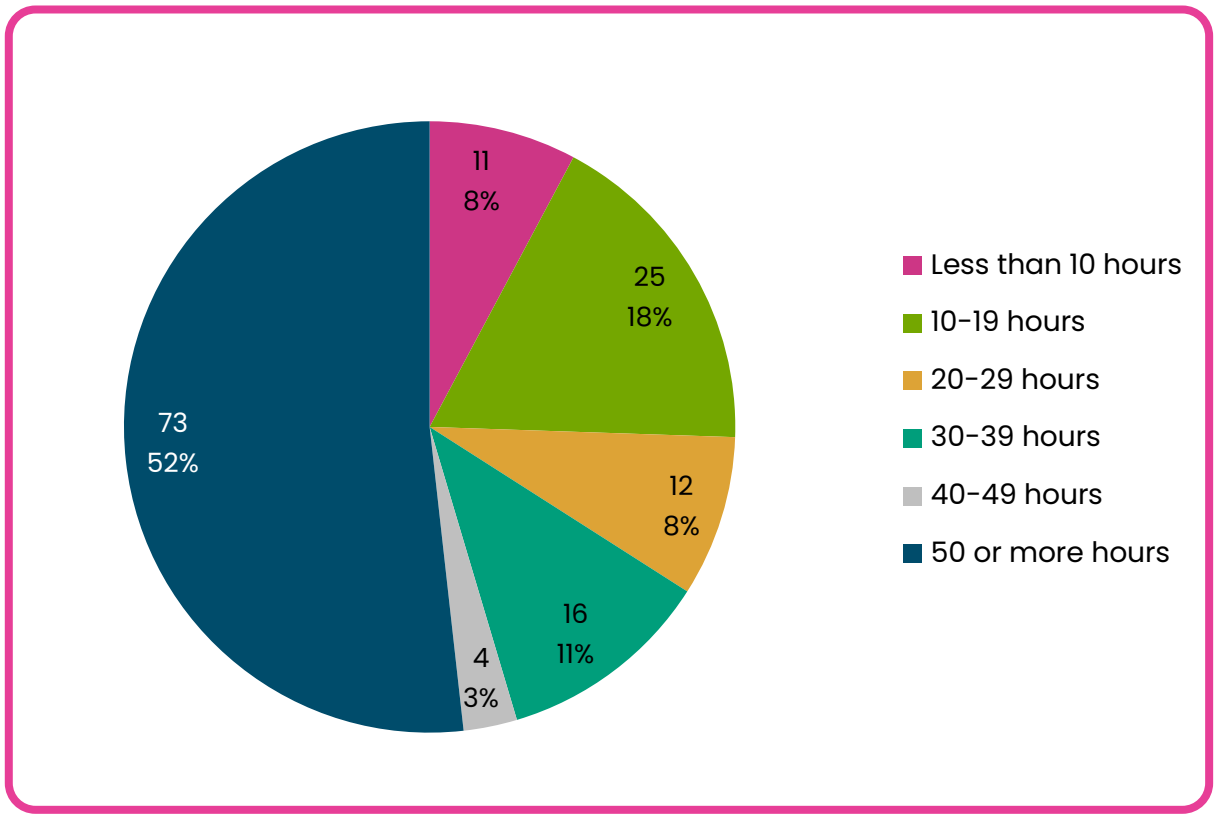

Figure 8 - Pie chart depicting the amount of time that respondents spent caring for an individual per week. Total responses for this question numbered 141.

When asked what tasks respondents carried out for relatives, the results highlighted the large and varied number of jobs that a caregiver could be involved in on a regular basis. Of the thirteen tasks presented as options, ten of them were carried out by at least two-thirds of participants. The most prominent task was 'Shopping' with 129 out of 144 participants (90%) engaging in this activity, followed by 'Emotional support' and 'Assisting with paperwork and legal matters' with 123 participants each. Interestingly, the tasks done by adult children who care for a parent differed from the whole sample of respondents. Adult children were less likely to be involved in 'Personal care' with only 50% of respondents (23 out of 43 people) doing so, compared to 60% of respondents in the wider sample. This could be attributed to personal boundaries as well as the fact that over half of adult children did not live with their parent. Similarly, a smaller percentage of adult children engaged in 'Administering medication'. There was however a higher proportion 'Assisting with paperwork and legal matters' with 94% of adult children

(43 out of 46) carrying out this task. This could potentially be attributed to the declining cognitive abilities of some older people, who therefore need support in this area. It could also be that these tasks can be carried out by family members who do not live with the care recipient, but want to contribute from afar.

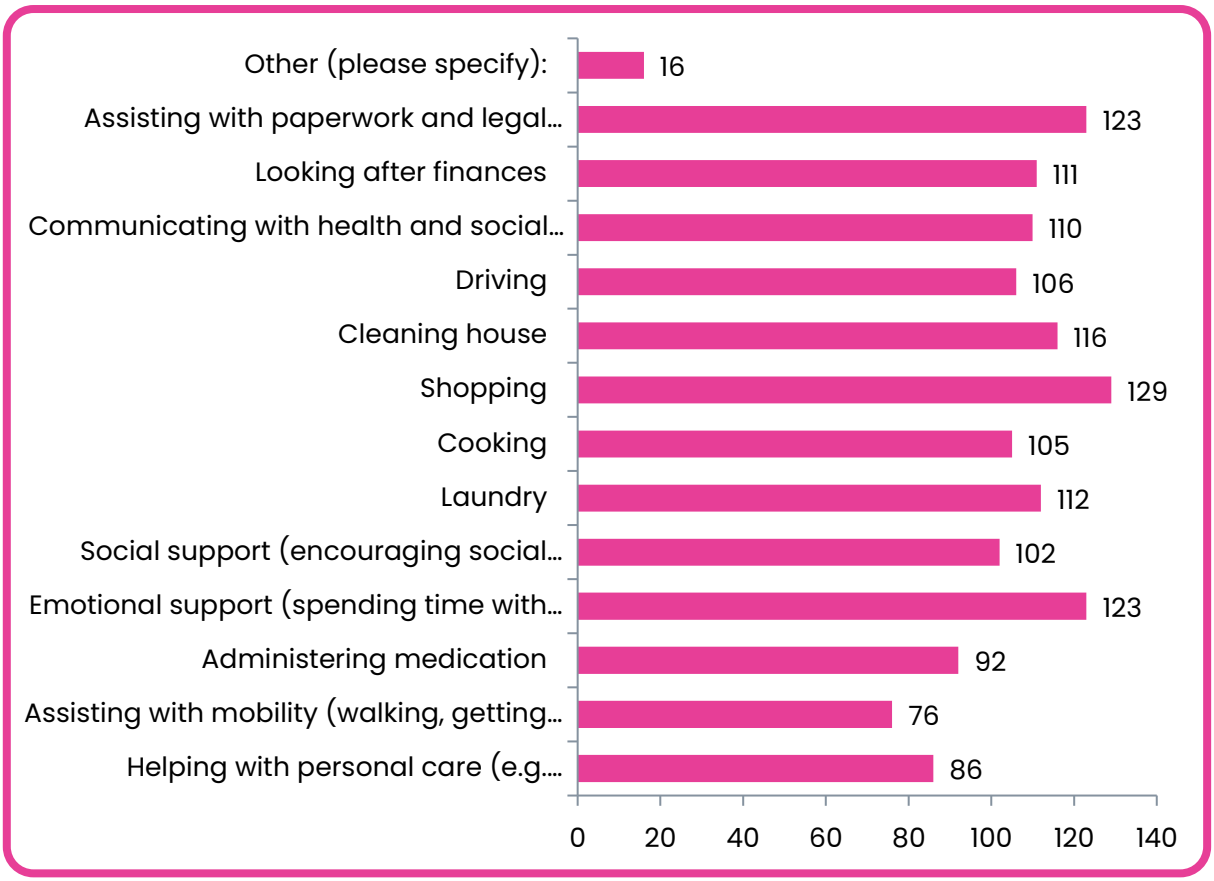

Figure 9 - Bar chart depicting the tasks that respondents carry out for the person they care for. Respondents could select any that were applicable. Total responses numbered 143.

Of those respondents who did not live with the person that they cared for (45 people), more personal and 'hands on' tasks such as 'Administering medication' and 'Cooking' were carried out far less - just 14 of 45 respondents (29%) in this subcategory cooked for an elderly person. It is, of course, harder to regularly engage in these tasks when not constantly present in the home.

Participants were then asked which of these tasks that they carried out did they find the most difficult and would like support on. People responded that 'Emotional support' (58 people) and 'Social support' (54 people) were the most challenging tasks. This is also even though most respondents actively engaged in these tasks - this suggests that while possible to carry out, having to be constantly

emotionally and socially supportive towards a care recipient can be taxing on a care giver's own emotional wellbeing. It may also be the case that to provide adequate social support, the care recipient will need to socialise with a wider group of people than just the primary caregiver.

The third highest selected task that participants felt was challenging and that they needed support on was 'Helping with personal care'. This fits with the results of the previous question, in which the same task was identified as being one that the least people engaged in (86 of 143 people, third lowest only to 'Assisting with mobility' and 'Other').

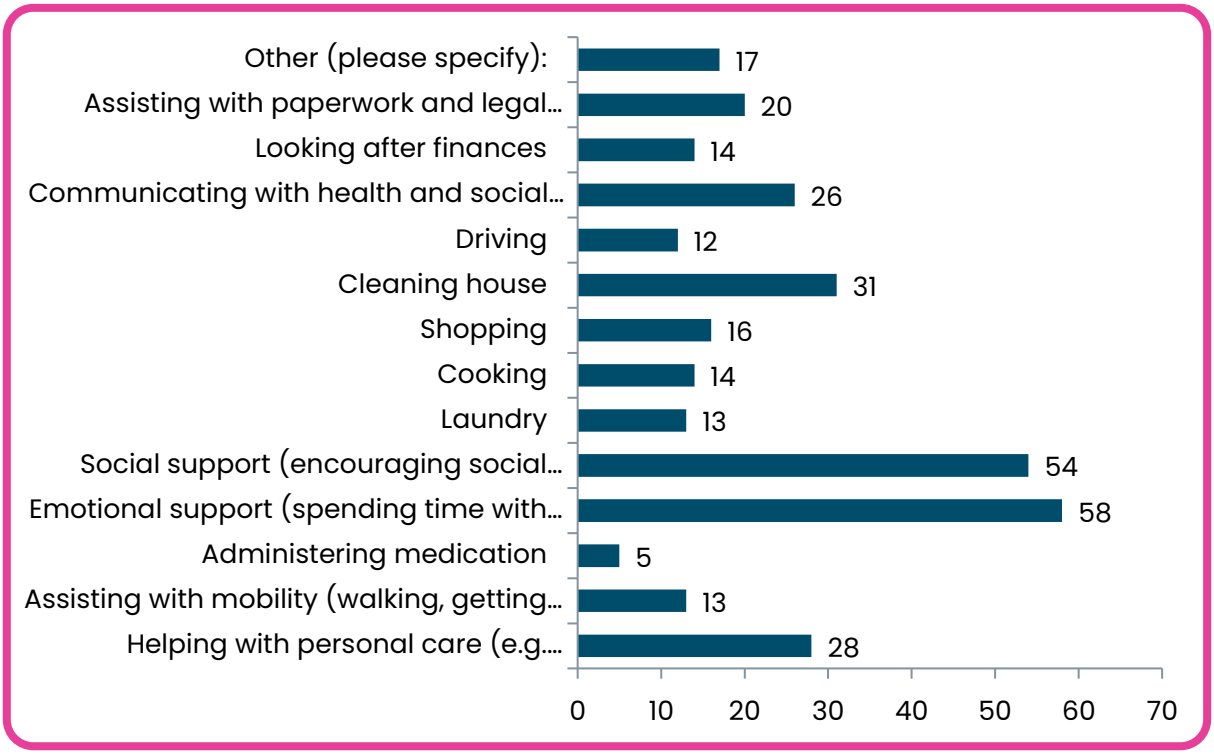

Figure 10 - Bar chart depicting which tasks respondents found particularly difficult and would like support on. Participants could select any that applied. Total responses for this question numbered 112.

'Communicating with health and social care services' was identified by a larger percentage of those who did not reside with the person they cared for, with 49% (18 people) selecting this option. By comparison, only 23% of the total sample population identified this as a task they found challenging. It could be assumed that more or different issues arise in communicating with health and social care services, when the carer is not living at the same address as the person they are caring for.

Adult sons who cared for a parent identified different tasks that they found challenging compared to the wider survey population. The most common task within this subgroup being 'Assisting with mobility' (60%) followed by 'Cleaning' (40%). Interestingly, no sons selected 'Personal care' as a task they found challenging. This, coupled with the fact that only two of seven possible respondents identified it as a task they engaged with highlights the potential of gender to impact which tasks caregivers do (Russo, 2025). It is worth noting that only five sons (of a possible seven) answered the question and therefore the reliability of the finding is questionable. On the other hand, and as previously mentioned, the lack of responses from adult sons chimes with the idea that male children are less likely to become primary carers (Leopold, Raab, & Engelhardt, 2014).

"They have nothing to do with him and that makes me very cross. He was in hospital last summer for about three weeks and I frustratingly wrote to them and said, look, I need some help... and since then they still haven't even called."

Despite most respondents having multiple family members, 53 out of 128 people (41%) stated that no relatives helped them in the care of a family member. This option was selected by the largest number of respondents and supports the idea that the role of a primary care giver often falls unequally onto one person (Family Caregiver Alliance, 2025). The most prominent family member to help respondents provide care were adult daughters, (30 people), reinforcing existing research findings that women are more likely to take on the role of caregivers for family members (Leopold, Raab, & Engelhardt, 2014). Despite respondents having a total of 92 adult sons, and 95 adult daughters shared across all respondents, only 18 sons were involved in helping with the care of a relative - just over half the number of adult daughters who were involved. Similarly, despite there being more brothers than sisters identified in the sample (103 and 97) more sisters were involved than brothers in providing care (16 compared to 11).

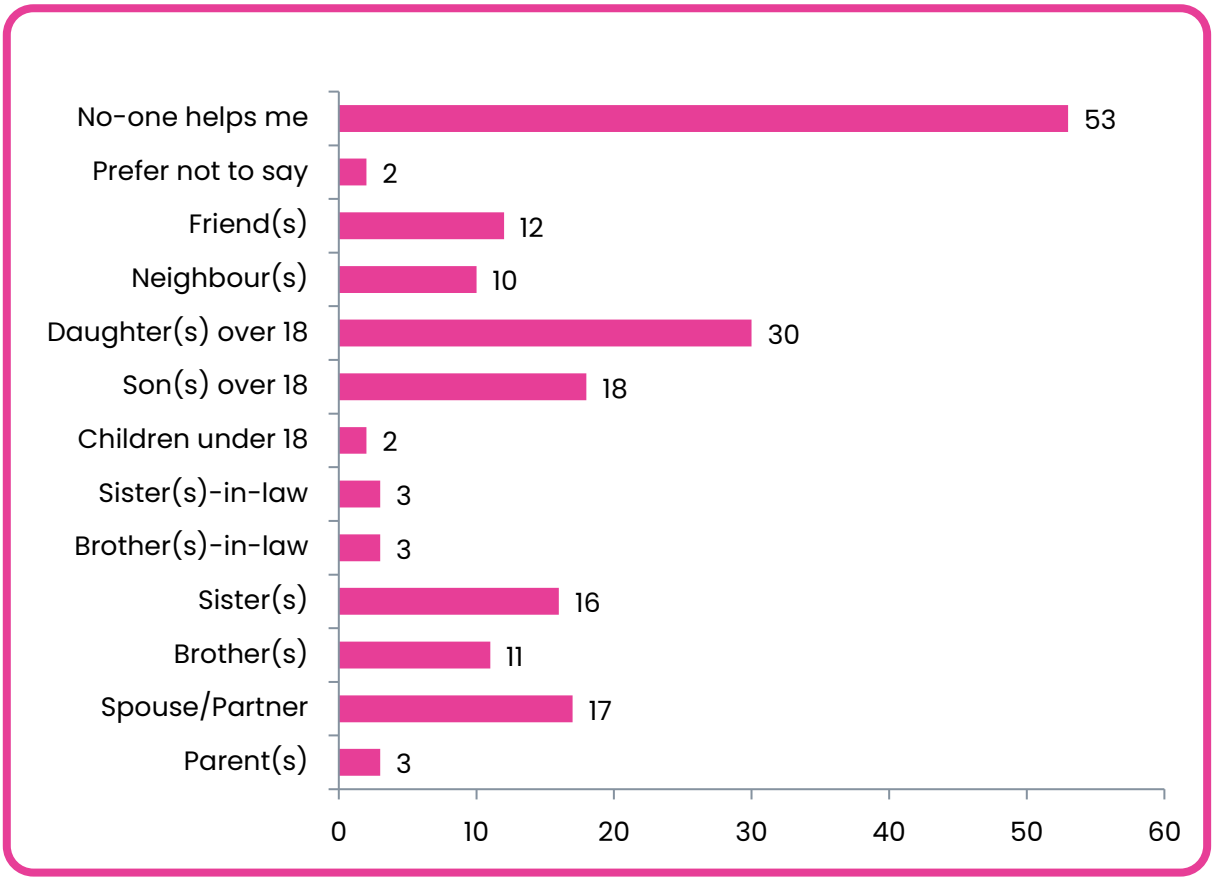

Figure 11 - Bar chart depicting which people (if any) help respondents care for a relative. Participants could select multiple options. Total responses for this question numbered 128.

The most prominent tasks that these relatives would carry out in assistance of the primary care giver were both 'Emotional' (43 people, 47%) and 'Social' support (31 people, 34%). This is interesting considering that these two categories of tasks were identified as those that people found most difficult and would like to receive help with. This could suggest that whilst respondents were provided support by relatives with these care tasks, this support was not considered enough to solve the issue entirely. Of those respondents that received both social and emotional support from a relative (22 people) over 60% still maintained that they needed support in both of these areas. The results were similar when each task was looked at individually: 65% for those who received emotional support, and 57% of people who received help with providing social support said that they still found it challenging and needed extra support. From the focus groups, family members providing emotional support for a relative was the most common subtheme within types of caring tasks mentioned. One focus group member expressed how, through a relative providing emotional support for her father, it also provided support for them as a primary carer:

My younger sister, she lives away couple of hours away in Peterborough and she does get involved by contacting my dad on like a Skype call daily so that I feel has really helped. That he just has that extra person to call and chat to.

I think it's a benefit for all of us. I think it's a benefit for Dad, so that he has got that extra somebody to talk to and I think it's a good support for me as well.

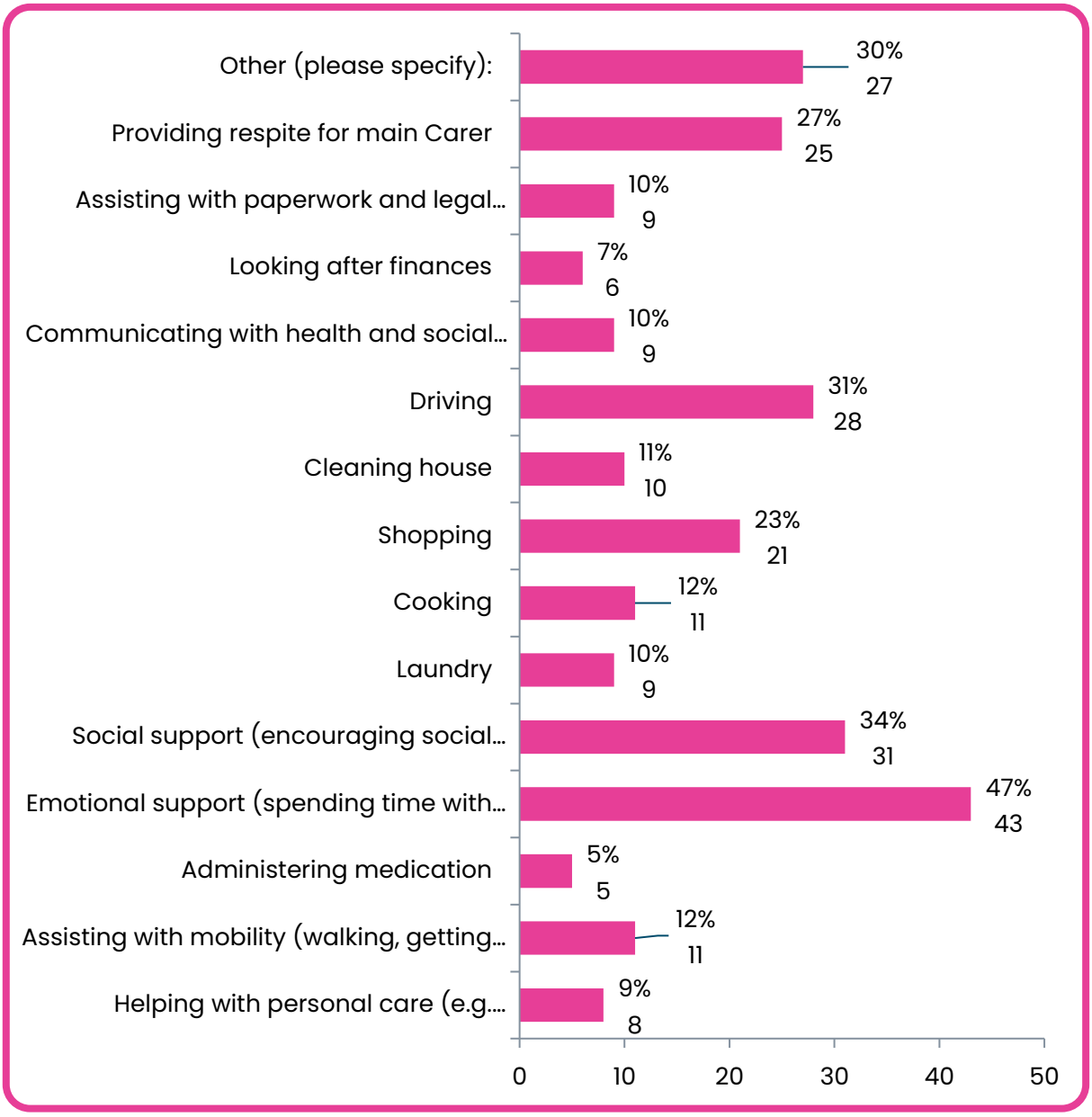

Figure 12 - Bar chart depicting what kind of care those people provide for respondent's relatives. Participants could tick any option that applied. Total responses for this question numbered 91.

'Driving' (31%, 28 people) and 'Providing respite for the main Carer' (27%, 25 people) were also prominent tasks within this question. Respite care also featured heavily within the focus group discussions:

> My daughters have been involved, but in giving respite care for me, rather than care for my husband, but that's involved at the same time, if you see what I mean.

> The benefits of having the family involved have been to give me some respite time and I have been away already for one weekend to stay with a friend.

> My family and I are going on holiday, and I've arranged that I'm going to take my dad to my sister's for the week that we go on holiday. Just to have a complete break.

A notable number of participants (27) selected 'Other' when asked about the types of tasks their relatives contributed to. Respondents mentioned tasks such as household maintenance as well as emotional support for the carer. Other people expressed that there was in fact no one to assist them with these tasks.

Barriers and Facilitators to Family Involvement in Care

Four main factors that help family members get involved in the care of a relative were highlighted by respondents. These were:

1. Sense of family responsibility/ duty (53 people)
2. Positive relationship with respondent (49 people)
3. Positive relationship with care recipient (46 people)
4. Geographical closeness (46 people)

These factors can also be found within the literature, with academics citing geographic proximity as one of the strongest facilitators of a family member's involvement in care (Chanfreau & Goisis, 2022, p. 203) (Pillemer & Suitor, 2013, p. 591). Those family members who live near a care recipient are far more likely to engage in caring for that person. Respondents also identified family members' sense of duty and good relationship with care recipients as a factor in why they contribute to the care of that person. This could be linked to exchange theory, in that the care for an elderly person can often be given in exchange for care previously received by the caregiver either for themselves or their children. It could be that the results of this question reflects family members feeling the sense of duty or responsibility to give back to their relatives (Leopold, Raab, & Engelhardt, 2014, p. 302). A positive relationship with one another would contribute towards long-term reciprocity, which is "almost as influential as gender in the process of caregiver selection" (Henretta, Hill, Li, Soldo, & Wolf, 1997 referenced in Leopold, Raab, & Engelhardt, 2014, p. 304).

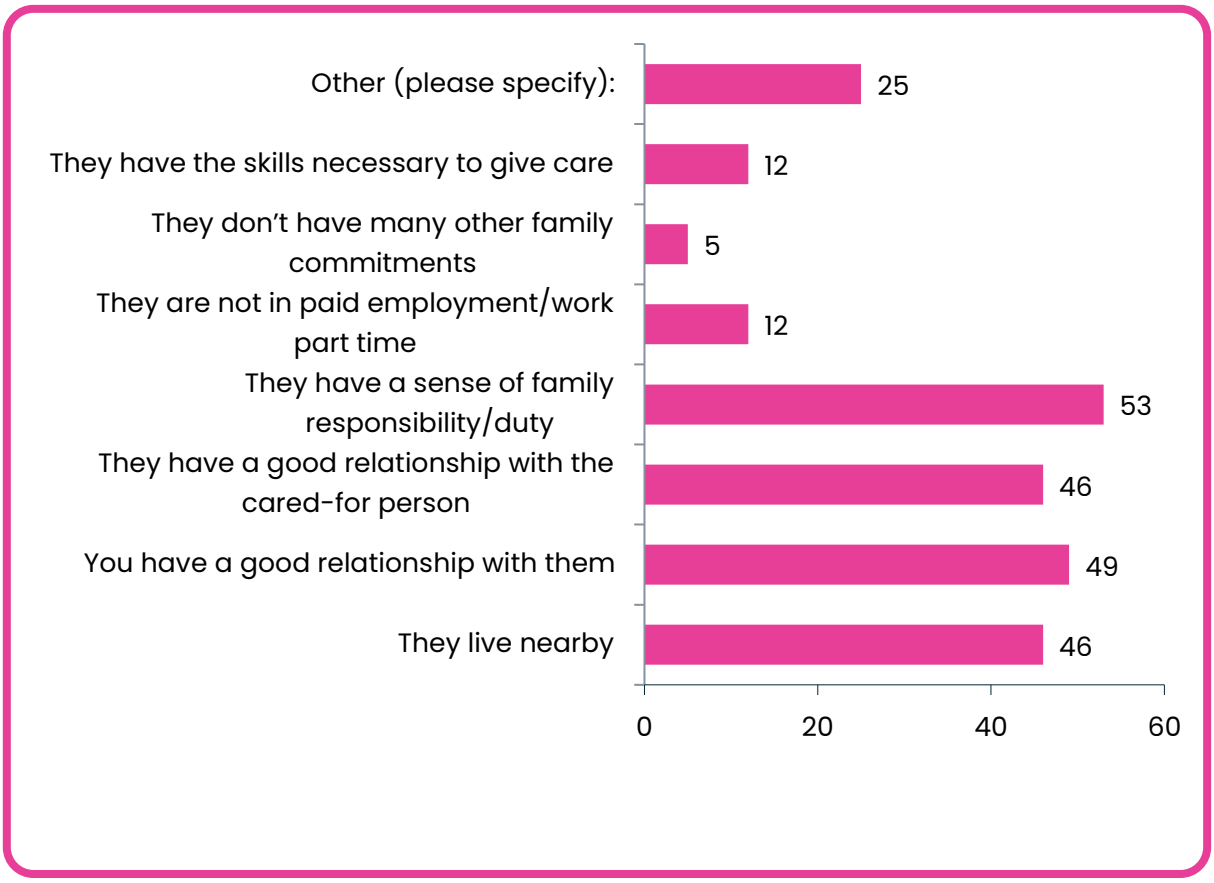

Figure 13 - Bar chart depicting factors contributing to someone getting involved in a person's care. Participants could tick any option that applied. Total responses for this question numbered 88.

When questioned about potential barriers to a family member becoming involved in the care of an elderly relative, respondents highlighted some key factors. These are shown in a list of the most prominent, below. Please note that other options included within these categories are not displayed in the list below due to a lack of respondents selecting them.

1. Geographical distance (79 people, 61%)
2. Availability
    a. Relatives being busy with work (63 people, 49%)
    b. Relatives being busy with childcare or other family responsibilities, including caring (40 people, 31%)
3. Family relationships and conflict
    a. Relatives uninterested (33 people, 26%)
    b. Unwillingness to take on specific caring tasks (25 people, 19%)
    c. Unwillingness to accept the nature of the condition the person that you look after has (20 people, 16%)
    d. Breakdown in family relationships (14 people, 10%)

Noticeably, geographic proximity was very prominent in the results of both the facilitators and barriers to getting involved in caring for a relative. Again, this supports previous findings by academics that where a family member lives will affect the likelihood of them becoming involved in the care of an elderly relative. With the exception of family conflicts, geographical distance was also the most mentioned barrier within the preliminary focus groups:

> I mean, we do have a son, but he's in Australia and has been there for a long time, so the geographical issue is significant for us.

> I think for, personally, my family. It's just that we're just quite spread out. So, it makes that day-to-day help harder.

> I have a brother who lives on the Suffolk coast. I don't really have very much help at all from him, but he does ring up on a Sunday regularly.

Availability of family members was identified as the second largest barrier to family members becoming caregivers, with work commitments (63 people) as

well as caring for children and other loved ones (40 people) having an impact on care involvement.

We've been married 33 years, but I have two children from my first marriage who are in their 50s now, and they're both in full time work. I have a daughter who runs a business out of Great Yarmouth who works all the hours under the sun. She has a family of three children to look after as well, and she's often worked till about midnight some nights getting all the products online and doing her online work.

Interviews from the focus groups also revealed that barriers often intersect with one another. Geographic distance and availability, for example, can come together to inhibit family involvement.

> We don't have that geographic closeness. I don't have any siblings. My husband has one brother who lives in Newport Pagnell, which is again as far away as Oxford is, and he's caring for his wife, who has terminal cancer. So, you know, there's nothing from any of the rest of the family. There's no input from anybody else other than myself, really.

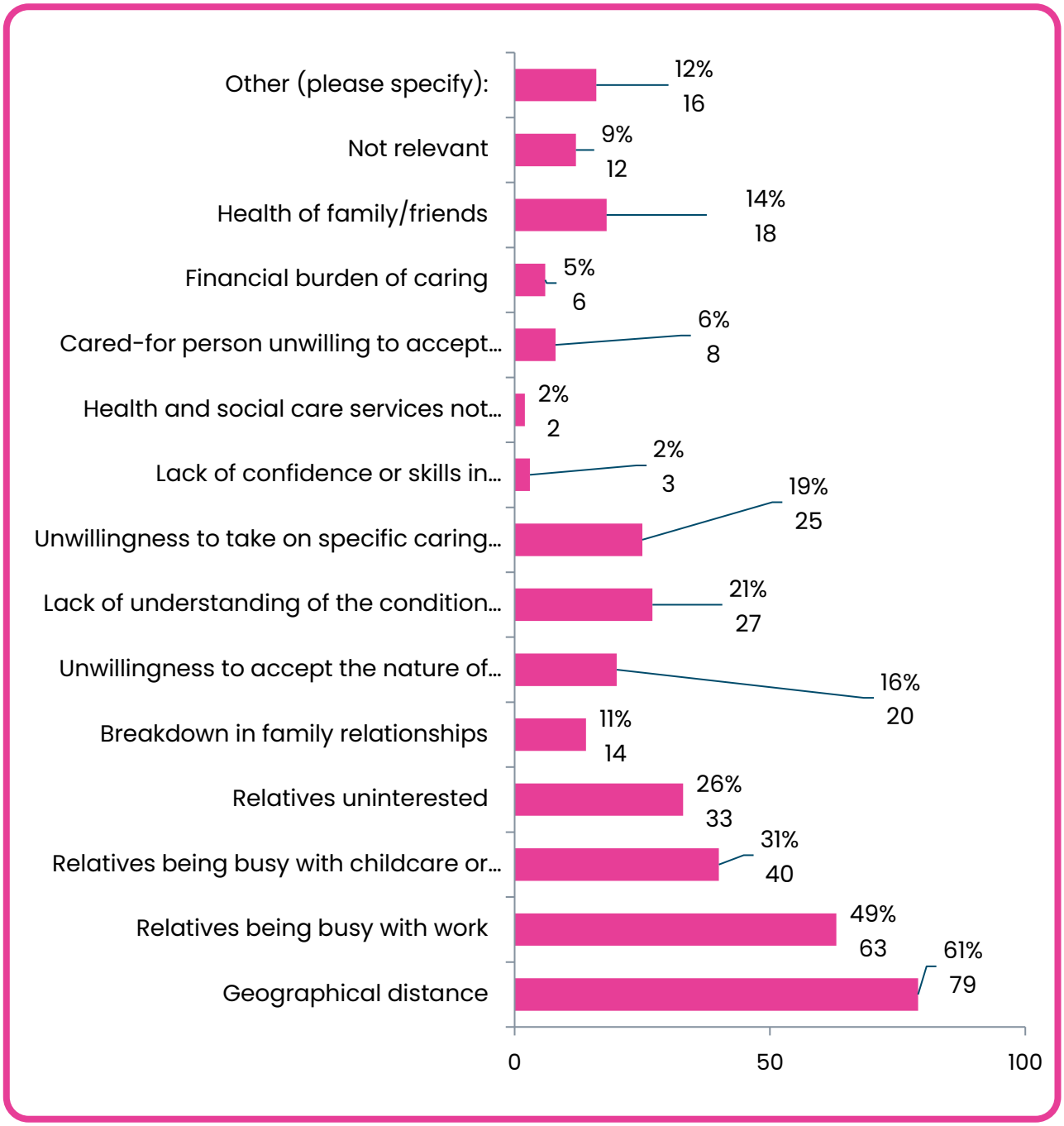

Figure 14 - Bar chart showing perceived barriers to a respondent's family members and friends becoming involved in caregiving. Participants could tick any option that applied. Total responses for this question numbered 129.

Family conflicts and relationships were also a popular category within the question of barriers to family member involvement in care, with respondents citing relatives being generally uninterested in the care of a loved one (33 people, 26%) as well as the unwillingness of relatives to accept both the nature of a family member's illness (20 people, 16%) and reluctance to take on specific care responsibilities (25 people, 19%), amongst other issues. Family conflicts were the most common theme within barriers to relatives' involvement in caregiving,

I think it's fair to say it's been very difficult because to start with it was a long time before my daughters could come to terms with what was happening to their dad, and there was a lot of resentment, particularly from one of them, directed at me, which was incredibly difficult.

I think the barrier is past history, as well as which is leading to reluctance now and lack of motivation to really get involved and do anything.

And my other sister? Well, she's just decided to cut all ties from all of us as a family. So, there's that element that she's just, I don't know, just decided that this isn't for her, um, and then that just then pulls on my shoulders and, you know, it is very difficult

While there is limited research into the effect that family conflict has on caregiving, one study from California found that of 100 adult caregivers, 40% were in conflict with another family member (often a sibling) due to them not providing sufficient help. As a direct result of such conflict, primary caregivers had "significantly higher perceived burden and poorer mental health" (Strawbridge & Wallhagen, 1991, p. 770) even when gender, age, and income were taken into account. The burden of being the primary caregiver was expressed by those in the focus groups.

> It's become obvious because my mental health has deteriorated and therefore I've had to say to them virtually, if you want me to go on looking after your dad, you have to step up to the mark.

When asked what caused friends or relatives who were previously involved in the care of an elderly family member to stop being involved, most respondents selected that it was 'Not relevant' (74 people). Of the other options, 'The relative moving away' was selected eight times, emphasising the importance of geographic proximity in people's ongoing involvement in care. Changes in family circumstances and work circumstances were also selected by some respondents, which can be linked to their availability. Within the 'Other' category, some people said that family members became less involved in caring for a relative when their own health declined.

Coordinating family care

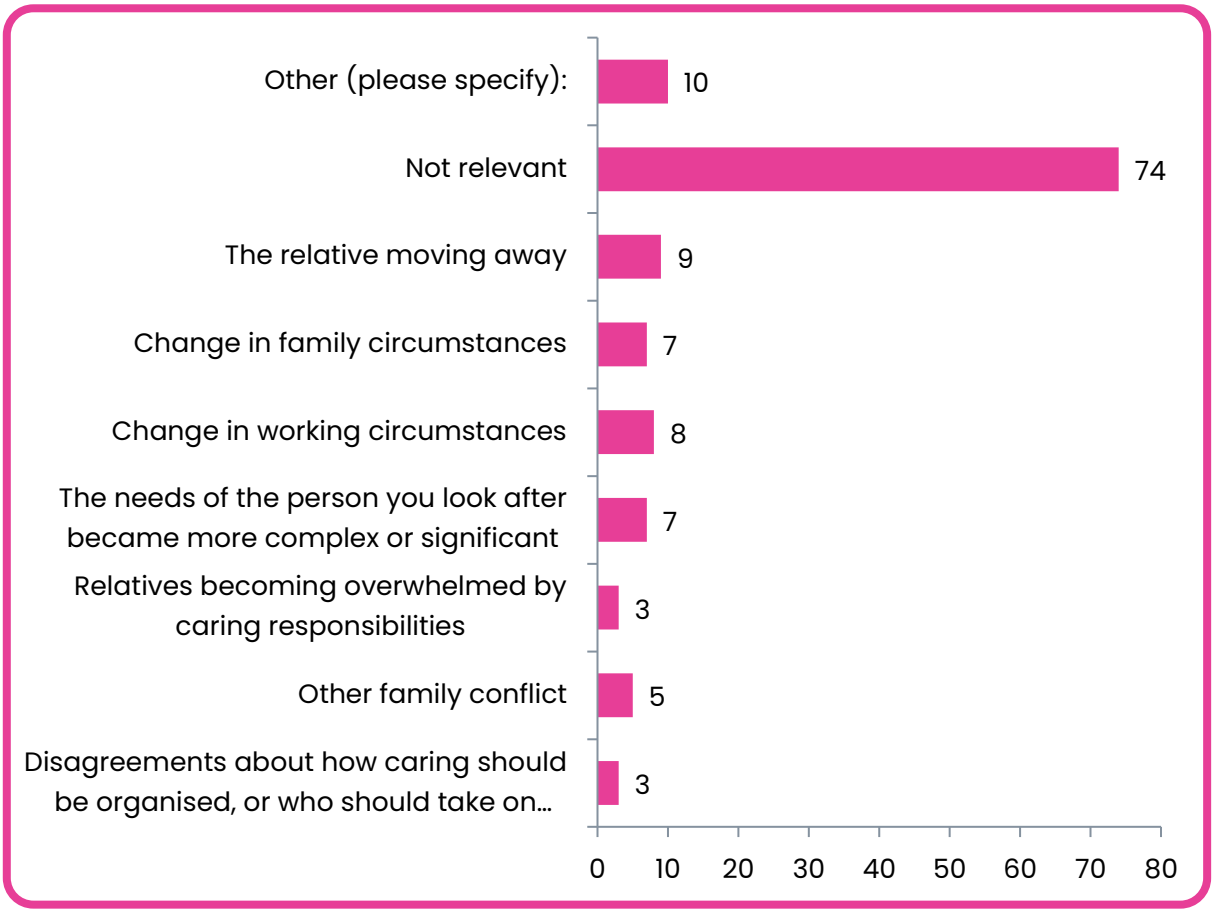

Figure 15 - Bar chart depicting reasons why people previously caring for a respondent's relative ceased to do so. Participants could tick any option that applied. Total responses for this question numbered 129.

We asked people about how they co-ordinated care between different members of the family, since easing the organisational challenges of caring could be a way that services could provide support to people. Most respondents used a mix of digital, phone and in-person communication to coordinate the care of an elderly

relative with other family members. Digital communications consisted of Text messages (50 people), Email (16 people), and using an App (2 people). 56 people also organised the care of a relative in person with family members, and 45 people did this on the phone. It is likely that a combination of these methods are used by respondents depending on the geographic proximity of family members.

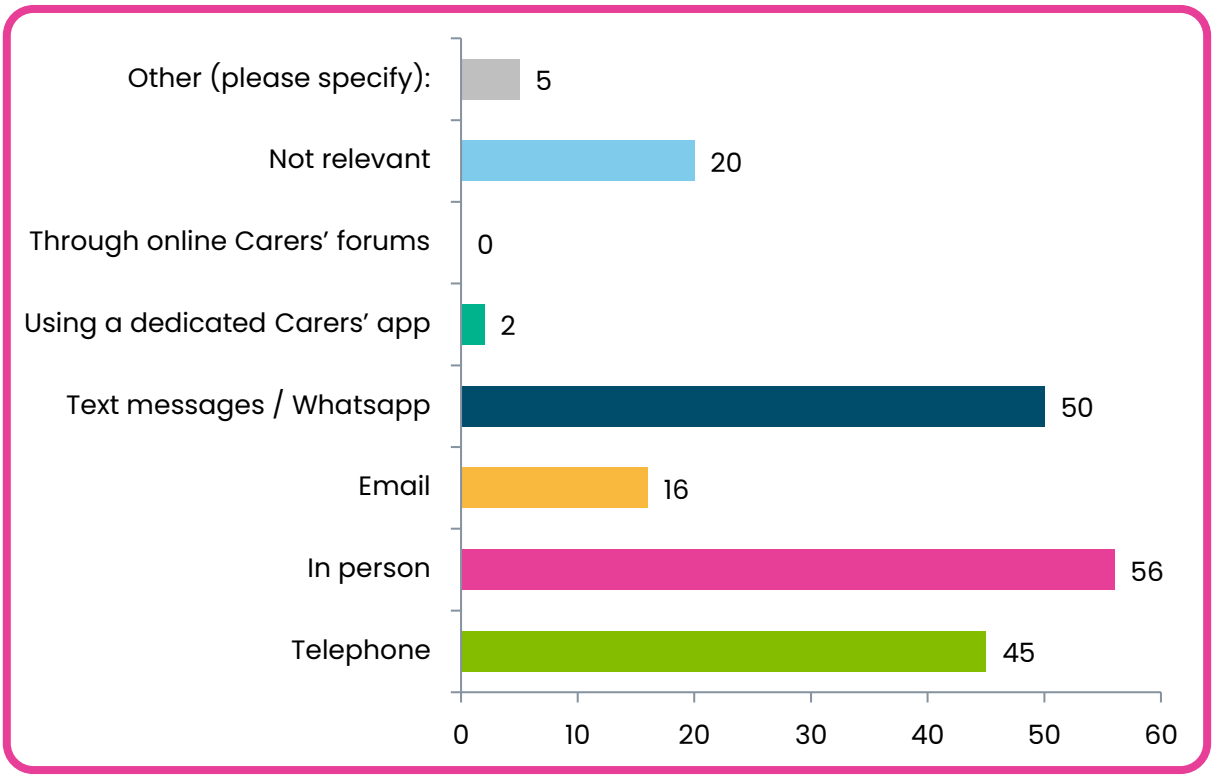

Figure 16 - Bar chart depicting how respondents coordinated care with others involved in the caregiving of a relative. Participants could tick any option that applied. Total responses for this question numbered 99.

When asked to explain how they came to decide who would carry out which caring task, respondents provided a wide range of responses. The most prominent theme being that there were "No actual decisions it all evolved naturally" about who would undertake which task, and that roles and responsibilities developed based on proximity and availability, "who lives close by" for example, as opposed to concrete discussions. Care was also often given on an ad hoc basis: "No decision - whatever needs to be done is done by whomever is present". Some other respondents said that tasks would be taken on depending on ability, skills and scheduling: "He drives & I don't. He will do the other tasks". Many people also used the question as an opportunity to express frustration that they were the primary caregiver and that they received little to no help, whether that was by choice, distance or lack of alternative: "If I hadn't stepped in to do everything dad would

probably be dead". Professional support was rarely mentioned, which underlines the reliance of primary caregivers on family members as well as themselves.

Potential support to help more family members become involved in care

The final question in the survey, asked respondents what support could be provided to help more of their relatives become involved in the care of a family member. The most prominent option selected by participants was for Respite Services which would allow the primary carer (the respondent) to take a break. 56 people (71%) selected this option. Within literature and echoed in the focus groups, it was expressed that for the primary carer, having to organise alternative care for

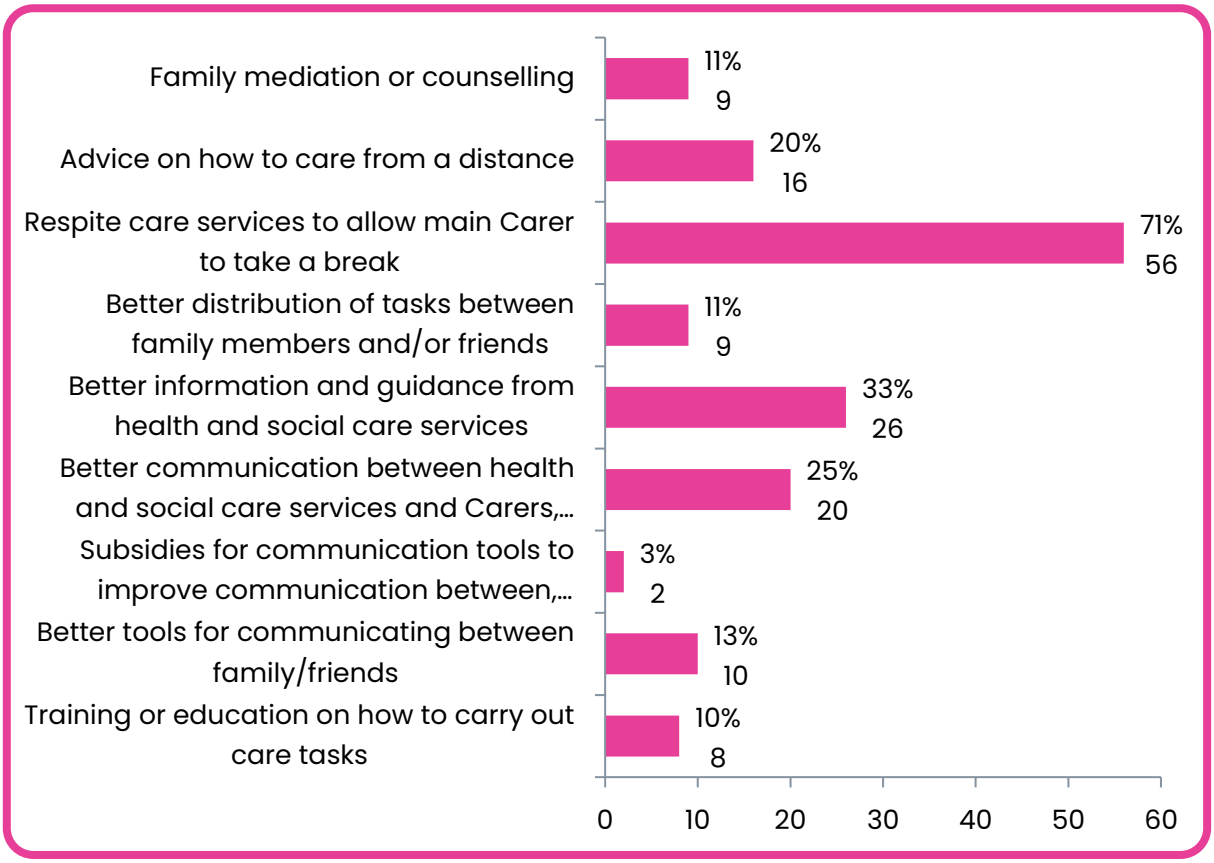

Figure 17 - Bar chart depicting what support respondents believed would help more of their relatives become involved in caring for a family member. Total responses for this question numbered 79.

their care recipient can be difficult whilst continuing to carry out the very demanding role of being the main carer. By giving the main carer an opportunity to have a break, they would then be able to better communicate and arrange for other family members to get involved in that care. The large number of people who selected the option of respite care for the primary caregiver would reflect

this, but it may also be reflective of the widespread desire for more respite care in Norfolk more generally (Healthwatch Norfolk, 2024), making it difficult to interpret.

> Everywhere you go it's a fight. Everything is a fight. There's nothing. You know, at the very least, we should all be having two weeks free respite care a year. I mean think of the money that the caregivers have even just saved the County Council and yet they just do not want to do anything to help us.

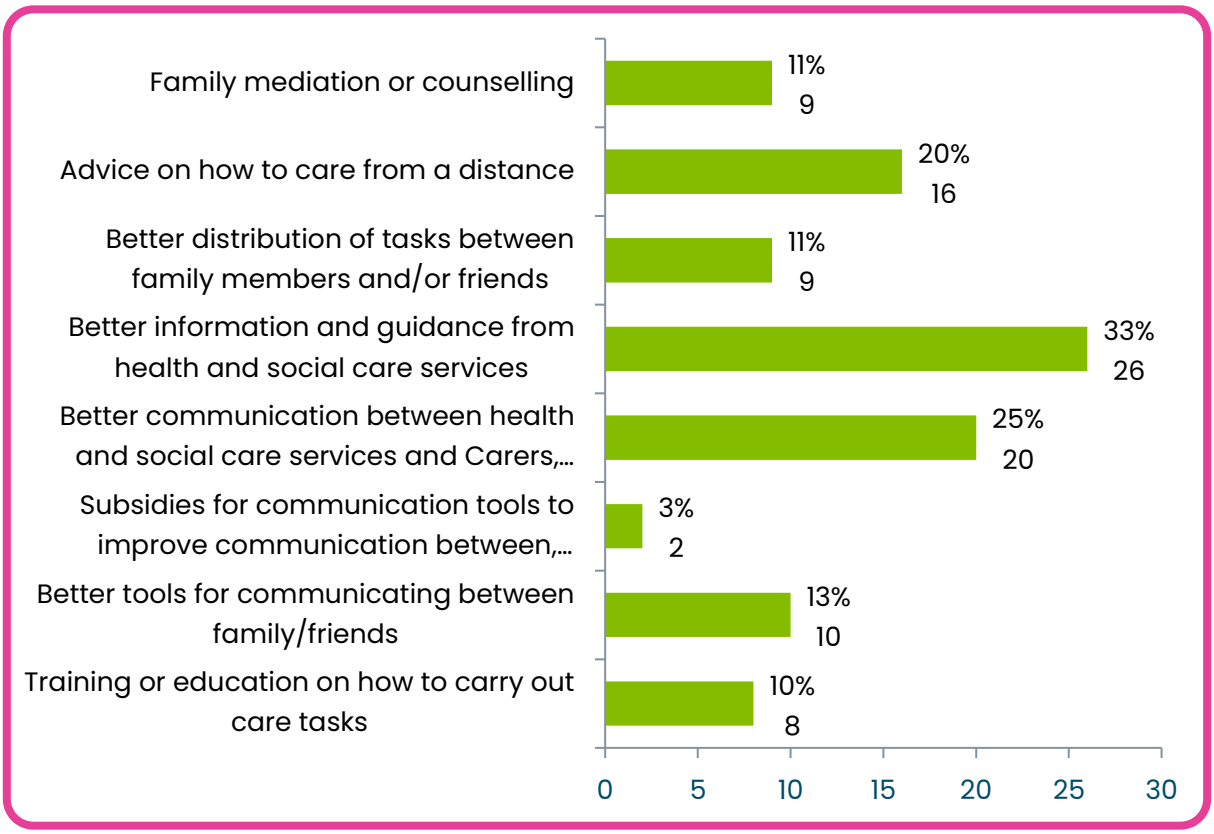

Figure 18 - Bar chart depicting what support respondents believed would help more of their relatives become involved in caring for a family member, with the option of 'respite care' removed.

The chart above, shows the data for responses to this question with the option of respite care removed. It highlights the enthusiasm for other support to involve family members in care that were less apparent in the original. This includes 'advice on how to care from a distance' as well as 'family mediation', supporting

the results of previous questions where geographic proximity and family conflict were identified as barriers to family involvement in care.

Respondents said that better communication and information/guidance from health and social care services would help them to get more people involved in the care of their looked-after person. A third of respondents (26 people) to this question selected that more information and guidance would be helpful. Similarly, 20 people identified 'Better communication between health and social care services and Carers, family and friends'. Members of the focus groups expressed similar thoughts, with people stating that they wanted more information from organisations about what support was available to those providing care to an elderly relative. Communication issues were mentioned previously in the report, where 49% of carers (18 people) that did not live with their care recipient identified that they found communication with health and social care services to be difficult, and that extra support would be welcomed.

> This is what the County Council say: 'All this stuff is out there for you to, you know, to have help', and actually has anyone ever negotiated the County Council website for adult social care help? They put everything in your way.

Related to participants wanting better communication and information from health and social care services, some focus group members expressed a desire for a centralised digital information 'hub' that can provide carers with material about the many support services, community groups, and general information for carers, that is otherwise spread across multiple websites and is hard to access.

> What social services could do to support greater family involvement is, maybe if there could be some sort of hub that pulls together all the, you know, all the various sort of Facebook [carers'] groups and other things, so that there's a one-stop space.

Similarly, another participant said that, having had to deal with multiple council departments on behalf of their mother, that it would be beneficial to not just the

primary carer but also to other family members involved, or wanting to get involved, to have a "centralised, you know, hub that says, 'These are the people [organisations] involved. This is what they do. These are the various sort of degrees of authority or impact that they have'".

Some members thought that support from services was not suitable to engage family members in caring for a relative, saying that family relationships and conflict can pose potentially insurmountable barriers to engagement in care:

> Though all the support in the world's available, actually, those family relationships, all those individuals themselves, means that whatever sort of [help] is put in place is not actually gonna lead to more support, because of that certain situation or the person themselves.

What this means

We received 144 completed responses to our survey, which is not enough to produce statistically significant findings. The proportion of women amongst respondents was 67%, which is a higher proportion of women compared to national figures for informal carers in the UK (in the 2021 census, 59% of unpaid carers were recorded as being women Carers UK, 2025). In addition, almost all respondents were over 55, which may over-represent older carers.

Nevertheless, there were some clear patterns in our findings, which may point to some broader trends amongst people caring for older people in Norfolk. A significant proportion of the carers we spoke to do not receive any help from their family or friends when supporting the person they care for.

These findings illustrate an important implication of our findings: what people told us about the most prominent barriers to greater family involvement suggests that services in Norfolk might struggle to improve this situation radically. More daughters and sisters were assisting in the care of a family member, than sons and brothers, reflecting the gendered patterns in caregiving that have been found in research on this topic in other settings. This suggests some ingrained cultural and social causes of family caring patterns, which would be difficult for services to shift.

The most common barriers carers mentioned were family and friends being too far away to help, or being too busy with work or family responsibilities. Difficult family relationships were also often mentioned as a problem, and focus group participants expressed scepticism about services' ability to help with these.

However, there are some barriers to caring that people mentioned, which services could more easily provide support with. Two of these were related to communications and information. The first was to provide better information and guidance from health and social care organisations. Particularly mentioned here were centralised information resources about support services, online and in-

person community groups and general information for carers. A guide for newcomers to the health and social care sector, describing the roles of different organisations, was also suggested.

The second was to make it easier for people who were not the primary carer, to communicate with health and social care services. This seemed to be a particular problem for people who did not live at the same address as the person they care for.

Some people also mentioned that they would like advice on how to provide care from a distance, and research on this topic suggests that there are useful ways that relatives and friends who live far away can contribute to easing some of the caring burden. These might include dealing with administrative, legal and financial tasks, and keeping in touch with health and social care services.

Most carers told us that they carry out a wide range of tasks in their caring role. The tasks that people most wanted support with were emotional support and social support. Even people who had support from relatives in these areas, still said that they would like more support, suggesting that these are areas of particular challenge. Peer-support groups and befriending services could be expanded, and those which exist could be better advertised, to help carers with these problems.

Finally, the most popular suggestion for how carers could be helped by services, was through increased opportunities for respite care, and we would hope that efforts to increase capacity in this area will continue.

Recommendations

1. Expand Respite Provision
    a. Increase access to regular and flexible respite services so that primary carers can take essential breaks.

2. Improve Information and Communication
    a. Create a centralised information resource for carers with clear, up-to-date information on local services, in-person and online carers groups, financial support, and legal guidance.
    b. Simplify Adult Social Care navigation by providing clear information for newcomers to the sector on the roles of different organisations.

3. Strengthen Support for Emotional & Social Care Tasks
    a. Develop more peer-support groups, befriending schemes, and carer counselling services to address emotional strain, and provide better signposting where these already exist.
    b. Offer training and resources to help carers manage the emotional and social support burden that many find most difficult.

4. Investigate why carers beyond the primary carer find it difficult to communicate with, and be recognised by, health and social care services
    a. This seems to be a particular problem for those not living with the person they care for, and should be rectified.

5. Provide information for people on how to provide care support from a distance
    a. An information resource should be developed for people who live far from the person they want to care for. This could include suggestions on what tasks they could help with (such as administrative, financial and legal jobs, and liaising with health and social care services), advice on how to stay in touch with formal and informal caregivers, and how to make the most of visits.

Response from Norfolk County Council

NCC replied that it is committed to the All-Age Carers Strategy for Norfolk and Waveney's Integrated Care System, which is coordinated by Carers' Voice and commissioned by NCC. The strategy focuses on eight priorities co-produced with carers, and NCC noted that these align well with the findings of the report. NCC also said that support for carers is being considered as part of wider work on commissioning, quality improvement, integrated working and governance, with an emphasis on more holistic and relational support.

In response to the recommendation to make respite care more widely available, NCC said that respite and short breaks are important priorities within the All-Age Carers Strategy. It said it is taking a strategic approach to developing a broader range of options, recognising that carers and families may need different types of support. NCC said it is exploring how community-based models, short breaks, technology and existing support mechanisms could help carers to take breaks in more flexible ways. It also noted that respite is being considered as part of wider work on day opportunities and support for carers.

In response to the recommendation for clearer and more centralised information, NCC said this is also an important aim of the All-Age Carers Strategy. It highlighted Carers Matter Norfolk as a countywide source of advice, carers' assessments and support planning. NCC acknowledged that carers still need easier ways to navigate complex systems. It said it is working with partners to strengthen community-based information and support, and is developing resources such as a carers' handbook and a hospital discharge booklet. NCC also said it has updated its website in response to carer feedback, and that neighbourhood working is intended to support better communication between professionals and make services easier for residents to navigate over time.

In response to the recommendation to expand peer support, befriending and counselling, NCC said that peer support has been identified as an important part of carer support. Through its work on day opportunities and respite provision, it is

encouraging providers to consider how they can support carers as well as the people they care for. NCC also referred to work with voluntary and community sector partners to develop local peer support and community-based support for carers. It said Carers Matter Norfolk can also support carers to access counselling where appropriate.

In response to the recommendation on supporting family members who contribute to care from a distance, NCC said that carers have been clear that they want to be involved in care and support, and that being heard and understood is important. NCC said it has been reviewing quality improvement measures to help teams better understand the experiences of people and their families. It also said its quality team is supporting operational teams to involve families and carers in people's support where appropriate. NCC also referred to work on assistive technology, which aims to help practitioners explain how technology can support carers, including those caring from a distance.

NCC said it is keen to understand whether changes being made are having the intended impact. Healthwatch Norfolk will review the position now and again in approximately one year's time, while NCC will also look at the impact of local changes, share learning and make adjustments where needed.

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healthwatch Norfolk

Healthwatch Norfolk
Suite 6 The Old Dairy Elm Farm
Norwich Common
Wymondham
Norfolk
NR18 0SW

www.healthwatchnorfolk.co.uk
t: 0808 168 9669
e: enquiries@healthwatchnorfolk.co.uk
@HWNorfolk
Facebook.com/healthwatch.norfolk