healthwatch
in Devon, Plymouth and Torbay

The impact of providing unpaid care at home

A Phase 2 survey report of Carers' experiences

May
2024

About Us

Healthwatch in Devon, Plymouth, and Torbay are the three local independent consumer champions for people using health and social care services across Devon.

The role of Healthwatch is to listen to what people say about their experiences of local health and social care services, to identify what works well and what could be improved, and to make those views and experiences known to those involved in the commissioning, provision and scrutiny of health and social care services; ensuring the voice of the community is used to influence and improve services for local people.

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Introduction

According to the Office for National Statistics (ONS) update, released 19 January 2023, Unpaid care, England and Wales: Census 2021 Census 2021, "an estimated 5.0 million usual residents aged 5 years and over provided unpaid care in 2021, this is an ASP of 9.0%, a decrease from 11.4% in 2011." With "the proportion of people who provided 20 to 49 hours of unpaid care a week increasing from 1.5% in 2011 to 1.9% in 2021" and "The proportion of people who provided 50 or more hours of unpaid care a week increased slightly from 2.7% in 2011 to 2.8% in 2021."

In November 2023, Carers UK published their findings on The impact of caring on: health which highlighted "a widespread lack of support and recognition from health and care services is severely damaging unpaid carers' mental health. It highlights how people caring round the clock for older, disabled or seriously ill relatives do not have adequate support from statutory services that are in place to help them – leaving many steeped in thoughts of hopelessness, fear, and dread, and urgently in need of support."

Around the same time, Healthwatch England published The Public's Perspective Report, which highlighted Carers' struggles with social isolation and the cost of living, with more Carers needing support themselves but are finding that since COVID-19, there has been a "reduced availability of local support groups, poor signposting to community resources and lack of provision." In this report Healthwatch England issue a national call for change which includes "easily accessible and affordable social care" and "further reforms to boost investment in services, address workforce challenges, and support councils to provide more proactive social care information and advice services. These should cover both pre- and post-assessment."

Locally, under 'Together for Devon' there is a system wide Commitment to Carers, with health and social care organisations signing up to the Commitment, based on the following seven principles:

1. Identifying Carers and supporting them
2. Effective Support for Carers
3. Enabling Carers to make informed choices re their caring role
4. Staff awareness
5. Information-sharing
6. Respecting Carers as expert partners in care
7. Carers whose roles are changing or who are more vulnerable.

Each local authority in Devon, Plymouth and Torbay has a Carers' Strategy and action plan in place, which are each informed by Carers' experiences and feedback. We hope this report provides additional insight into the day-to-day experiences of Carers in our local communities and that by sharing what Carers have told us would make a difference to them, it will help health and social care leaders to make changes to improve services to better meet the needs of Carers and those to whom they provide care.

Our Approach

Our Methodology

Following on from **our earlier report** published in November 2022, Healthwatch in Devon, Plymouth and Torbay agreed to undertake a follow up engagement project, focussing on **Carers who gave 20 hours or more in their caring role in a week**, to explore the links between:

- Carers' mental /physical health and wellbeing and number of hours unpaid care provided.
- How long a Carer had been providing this role (longevity).
- The type of care they provided e.g. physical caring, supportive caring, dementia/cognition caring or mixture.

Working in collaboration with **Devon Carers, Torbay Carers' Services** and **Plymouth Carers Services,** it was agreed to split the engagement activity into two parts:

1. A codesigned online survey
2. Individual guided conversations (with those who consented to being contacted).

Learning point: Despite the survey being aimed at Carers of all ages who provide 20+ hours of care each week, there were no responses from young people under the age of 18 and only 1 aged between 18 – 25.

For future engagement with Carers the working group will need to consider a more targeted approach to seeking feedback from young Carers and young adult Carers, in a way that is more accessible for them, to ensure their voices are heard.

Theory of change

Using a Theory of Change Model, and working with Carers Leads, we considered what the desired outcomes would be prior to planning the engagement activity. The desired outcomes were agreed as follows:

Desired Outcomes

1. Develop a risk scale for Carers to help medical professionals, social care teams, Carers services and Carers to identify when a Carer may be reaching a tipping point.
2. Develop support for Carers to enable them to support their own health - this has clear budgetary benefit for the NHS/Local Authority.
3. Develop services to respond to our improved understanding of the impact of different levels and types of caring roles.
4. Identify gaps in service provision and communications.
5. Provide research analysis in a published report to inform the goals above and identify gaps for future engagement/research.
6. Identify Carers and support them to register with relevant Carer and other relevant services during the engagement campaign.

The Survey

The survey was codesigned with representatives of Carers, Carers Commissioners and Carers Support Services in Devon, Plymouth and Torbay – Katy Heard and Rohan Davidson from Torbay Carers' Service, Jane Taylor and Josceline Leicester from Devon Carers, Kate Lattimore from Plymouth City Council and Lee Sewrey and Viktor Keaty-Korycan from Improving Lives Plymouth. The survey asked for information from the Carer about themselves and the person(s) they cared for, the impact on their own wellbeing and whether they thought that their caring role has led them to feel isolated.

The survey was available online with paper copies and alternative formats available on request. The survey was circulated through the three local Healthwatch networks and working in partnership through Devon Carers, Torbay Carer and Plymouth Carer networks. The survey offered to link Carers with the relevant Carer's groups and asked individuals whether they would take part in a Guided Conversation on the telephone to further explore their responses to the survey, particularly around their wellbeing and isolation.

Guided Conversations

A guided conversation with each Carer helped us to discuss in more detail how a Carer's role was impacting on their everyday life and their emotional wellbeing and to understand whether they were experiencing any potential feelings of loneliness or isolation, or if they felt well supported and connected.

In total 17 Carers kindly agreed to share their experiences and thoughts with Healthwatch through a guided conversation - 56% from Plymouth, 31% from Devon and 13% from Torbay – The analysis of the guided conversations is presented at the end of this report.

Key Findings

Our key findings are generalised* and based on 240 Carer responses (224 survey responses, 16 guided conversations) from across all of Devon, Plymouth and Torbay. They highlight the significant factors impacting not only on Carers' health and wellbeing, but also on their ability to provide care to the person(s) they care for.

The findings also identify key areas for improvement and what needs to change to enable Carers to feel better equipped to manage their own health and wellbeing and the health and wellbeing of those to whom they provide care.

******More detailed data segmented by locality, age and gender can be found later in this report.*

Carers' health and wellbeing

- **Many Carers are feeling overwhelmed by their caring role:** Nearly two thirds of Carers (62%) told us they have reached a point where they have been unable to manage, more than half of these (35%) told us that they regularly feel overwhelmed and unable to manage their caring role. Nearly a third of Carers (31%) said they were not aware they were reaching this point beforehand.

- **Carers use a range of mechanisms to help them to cope when they feel overwhelmed:** More than half (58%) have strategies in place to enable them to better manage their caring responsibilities. The most common being exercise, space and time away from the person(s) they care for, support from family and friends, breathwork / meditation and being outdoors / time spent in nature.

- **Tiredness, fatigue and lack of sleep** were the most common triggers to feeling overwhelmed, mainly due to a lack of time, energy and space to enable them to take break from their caring role. Overall, three quarters of Carers who responded told us that the most common reasons for reaching a point of overwhelm include:
  - tiredness and lack of sleep / fatigue (75%)
  - the behaviour of the person they are caring for (54%)
  - anxiety linked to their caring role (54%)
  - having no respite care in place (48%).

- **Some Carers feel their own safety is at risk:** A quarter of Carers (25%) told us that they felt their own safety was at risk due to either:
  - a decline in their own mental health and wellbeing,
  - Medication complexities, e.g. cared for person adjusting to new side effects, or
  - the behavior or the emotional wellbeing of the person(s) they care for.

- **Many Carers put the needs of the person(s) they care for before their own personal care and health and wellbeing needs:** Almost half (45%) of Carers told us they **do not prioritise their own health and wellbeing,** mainly due to:
  - their focus being more on the cared for person(s) rather than themself,
  - time and energy constraints,
  - difficulties accessing healthcare services, and
  - emotional barriers or a fear of negative consequences (e.g. hospitalisation).

Key Findings

Carers' health and wellbeing (continued)

- **Reduced working hours has led to a decline in Carers' health and wellbeing:** A third of Carers (32%) who had either given up work or reduced their working hours said it had negatively impacted on them. Reasons included a reduction in their finances, feeling socially isolated with a lack of purpose, or a decline in their self-confidence / self-worth.

- **Some Carers are experiencing negative feelings such as depression, anxiety and loneliness because they are unable to leave the house on a regular basis:** Around a third of Carers (37%) told us that they are unable to leave the house on a regular basis which is negatively impacting on their mental and physical health and wellbeing.

Carers' experience of the Caring Role

- **Administrative tasks are taking up a significant amount of time**: A fifth of Carers (20%) are spending several hours a day on administrative tasks such as arranging medical appointments, form filling and paying bills, with nearly a third (31%) spending several hours a week on such tasks. **'Less paperwork', 'less form filling' and 'less admin' were frequent Carer suggestions, as these have a huge impact on Carers' time and ability to manage**. Other issues mentioned include 'dealing with different departments', 'GP phoneline waiting times', 'chasing up appointments' and 'reams of paperwork'.

- **Carers' needs and the needs of the cared for person(s) are not always being fully met by paid care services:** A quarter of Carers (24%) told us that the paid care that they receive for the cared for person(s) does not meet their needs as a Carer or the needs of the person they are caring for.

- **Replacement Care (Respite) is difficult to access and inconsistent:** Guided conversations with some Carers revealed that replacement care and support had been either inconsistent and lacked the quality of care that they were providing themselves or was not suitable, appropriate or even available to meet the cared for person's needs. Of the 37% of Carers who said they are unable to leave the house on a regular basis, just under half (44%) said they are lacking:
  - access to and availability of affordable, good quality respite care or having more care and support in place for the cared for person(s)
  - peace of mind that the person(s) they care for will be safe whilst they were away.

- **The care provided by Carers is negatively affected by their inability to leave the house:** Nearly two thirds of Carers (61%) said the care they provide is negatively affected by being unable to have regular personal time and space. Common themes emerging from Carers' comments were:
  - Overall strain on their emotional wellbeing
  - Feelings of overwhelm and hopelessness
  - Impact on their personal relationships
  - Social isolation
  - Decline in their physical and mental health.

Key Findings

Areas highlighted for improvement or change

- **There is a need for improved access to training, information and advice:** Two thirds of Carers (65%) said they have not received enough training, information or guidance to support them in their caring role. **Uncertainty and lack of knowledge of what to expect following a diagnosis is impacting on the wellbeing of both patients and their Carers**. Carers said they want:
    - Clear, timely information and advice in relation to the conditions affecting the person(s) they are caring for and what to expect going forward with their condition. Dementia was the most common topic mentioned.
    - Information, advice and guidance to support Carers in their caring role, to include:
        - Practical support and signposting to reliable sources of information and services
        - Advice and guidance on navigating the system and care pathways
        - Advice and signposting to resources to support Carers in their caring role.

- **Carers need improved access to support for themselves:** Around half (51%) said 'yes', they do know where to go for support, with the most common responses being Carers Services, Social Services and the GP. However, around a third of Carers (37%) told us they do not know where to go for support and despite some being aware of where to go, they had either experienced difficulties or delays when trying to access support, support was unhelpful / unsuitable, or they didn't feel heard or understood.

- **Carers need more support to enable them to prioritise their wellbeing:** 53% of Carers told us that for them to be able to prioritise their own health and wellbeing they need:
    - More opportunities for respite and timely access to reliable and trustworthy replacement care for the person(s) they care for.
    - More support and better paid and practical care provision to help them and the person(s) they care for achieve a better quality of life. Carers mentioned having additional paid support, affordable night sitters, extra practical support would help.
    - Easier access to health and social care services, such as quicker medical appointments, access to counselling, local health checks.
    - More financial support or a choice of more affordable care options.

- **Having someone to talk to and / or access to online support groups would help Carers to feel less isolated:** A third of Carers (32%) said access to outside support and company in the home, by way of either online, or face to face visits, would help them to feel less isolated and alone.

- **Carers who live with the person(s) they care for need more support and better access to respite care because they are more at risk of reaching a point where they are unable to manage:** More than a third of Carers (40%) who live with the person(s) they care for said they feel unable to manage either sometimes, regularly or often and nearly a quarter of Carers (23%) who reached this point said they had not been able to take a break or respite within the last 12 months.

Detailed Findings

Survey respondent locality

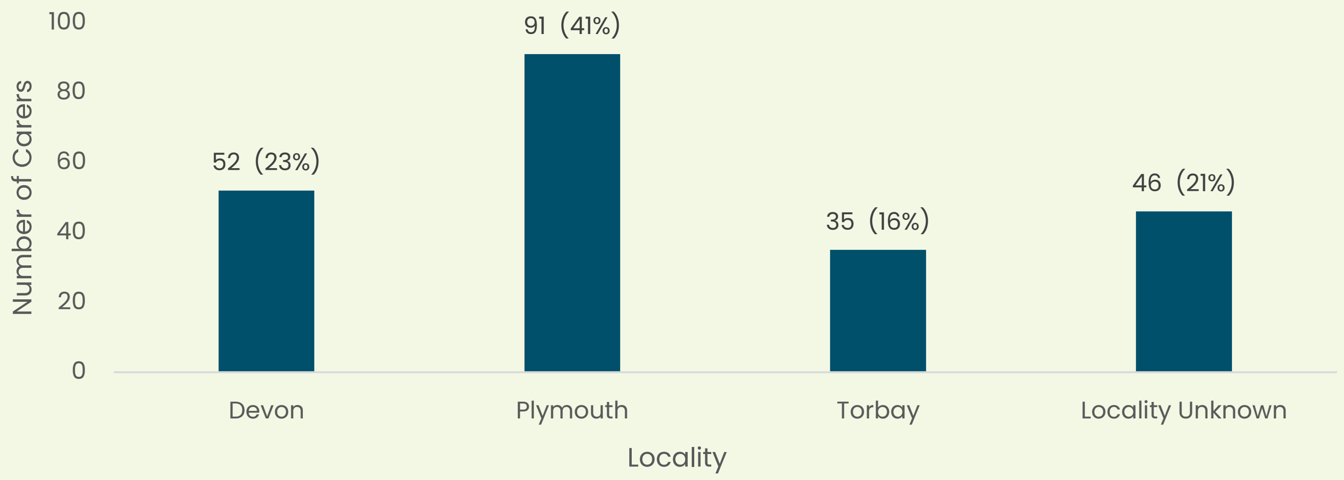
178 Carers (79% of the total cohort) provided their post code prefix which allowed us to identify which local Healthwatch area they live in. This is shown in fig 0 below.

- 91 Carers (41% of total cohort) live in Plymouth,
- 52 Carers (23%) live in Devon,
- 35 Carers (16%) live in Torbay.

44 Carers (20%) did not provide their post code prefix and 2 Carers (1%) live outside the area.

Further charts showing a breakdown of survey respondents by age, gender and ethnicity are provided in Appendix 1.

Fig 0: Breakdown of survey responses by locality



The next section of detailed findings is based on the analysis of 224 survey responses from Carers in Devon, Plymouth and Torbay. For this report, the data has been segmented by geographical area to show the results for each locality.

Only where significant differences occur within the results after filtering, where conclusions can be easily drawn, are they noted as observations within the analysis on the following pages.

Additional charts and tables for questions 16 and 30, where the data has been analysed by locality, are provided in Appendix 2.

Wherever possible, verbatim extracts have been used to ensure authenticity and the presence of a real Carer voice throughout. Not all comments are included, and some relate to more than one theme. Further Commentary for individual questions can be found in Appendix 5. Any featured quotes or commentary are from real Carers in Devon, Plymouth or Torbay and are not the view or opinion of HWDPT.

Detailed Findings

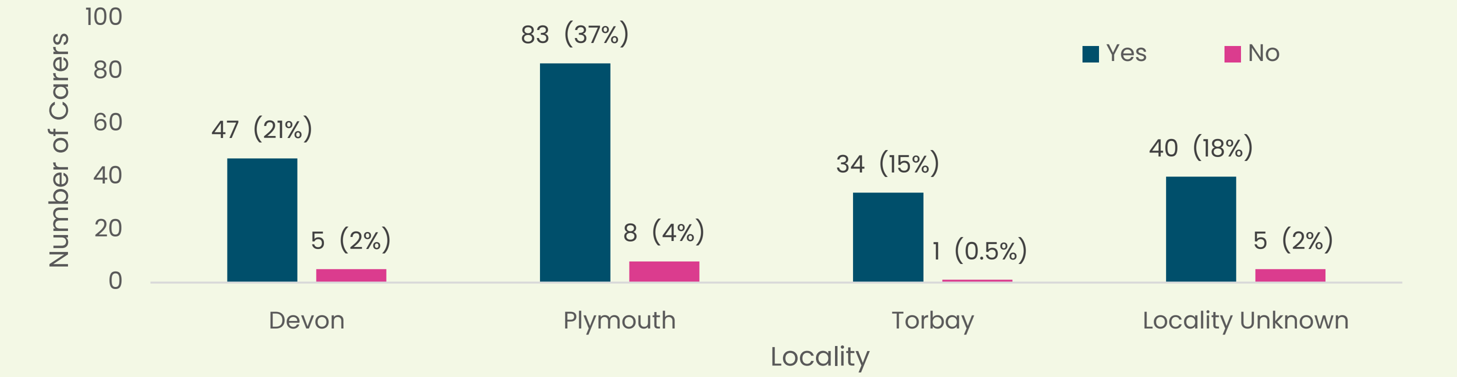
Question 1: Does your caring role impact on you for more than 20 hours per week?

223 Carers responded to this question. Of those,

- 204 Carers (91%) replied ‘yes’, their caring role does impact on them for more than 20 hours per week.
- 19 Carers (8%) replied ‘no’.

Fig 1 provides a breakdown of the responses in each locality. No observations to mention.

Fig 1: Does your caring role impact on you for more than 20 hours per week?



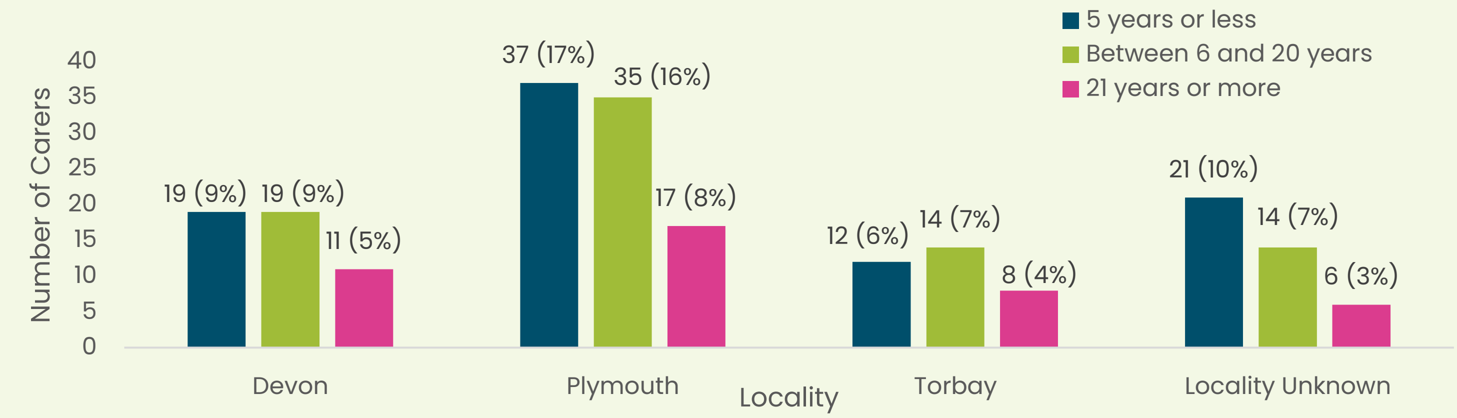
Question 2: What is the length of time you have been a Carer?

217 Carers (97%) provided a response to this question. 213 Carers provided a specific length of time that they had been a Carer. Of those,

- 89 Carers (40%) have been caring for 5 years or less.
- 82 Carers (37%) have been caring for between 6 and 20 years and
- 42 Carers (19%) had been in a caring role 21 years or more.

Fig 2 provides a breakdown of each category by locality. No observations to mention.

Fig 2: What is the length of time you have been a Carer?



Question 3: Do you live with the person you care for?

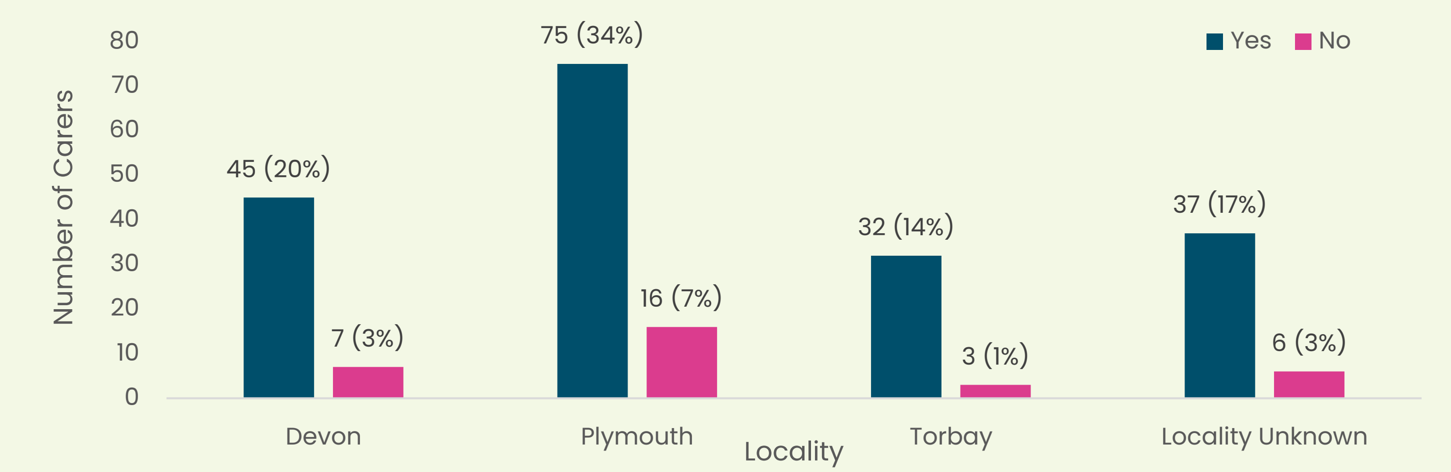
222 Carers (99%) responded to this question. Of those,

- 190 Carers (85%) replied 'yes', they do live with the person they care for.
- 32 Carers (14%) replied 'no'.

Fig 3 provides a breakdown of the responses in each locality.

Observation: In Devon, Plymouth and Torbay significantly more Carers live with the person they care for than those who do not live with the cared for person(s).

Fig 3: Do you live with the person you care for?



Question 4: If yes, does this impact on your ability to leave the house?

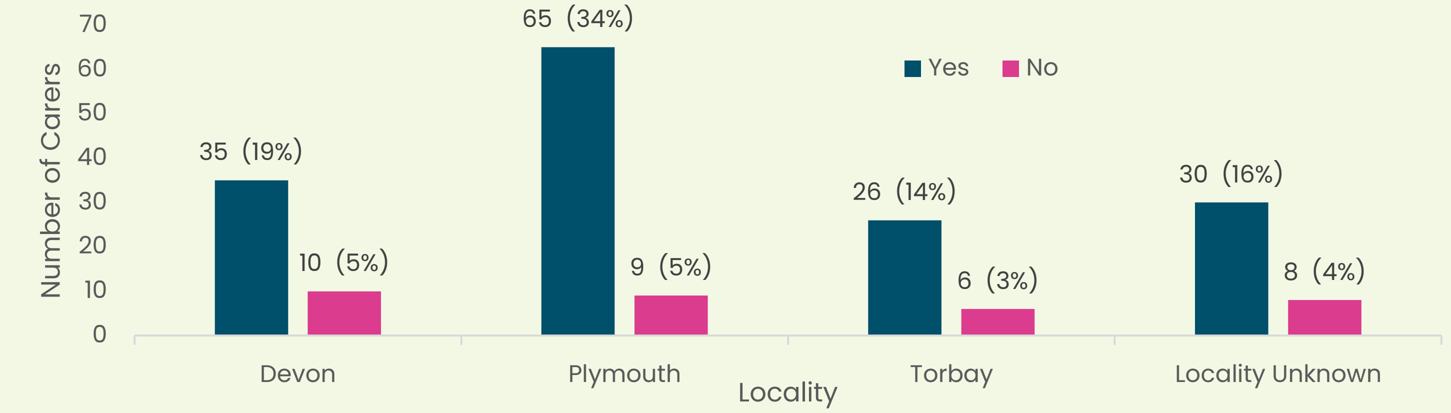
189 Carers (84%) who live with the person they care for responded to this question. Of those:

- 156 Carers (83%) replied 'yes', it does impact on their ability to leave the house,
- 33 Carers (17%) replied 'no' it does not impact on their ability to leave the house.

Fig 4 provides a breakdown of the responses from Carers who live with the person they care for, in each locality.

Observation: In all of Devon, Plymouth and Torbay significantly more Carers said their caring role impacts their ability to leave the house than those who said it doesn't.

Fig 4: If you live with the person you care for, does this impact on your ability to leave the house?



Question 5: If yes, does this impact on your ability to relax at home?

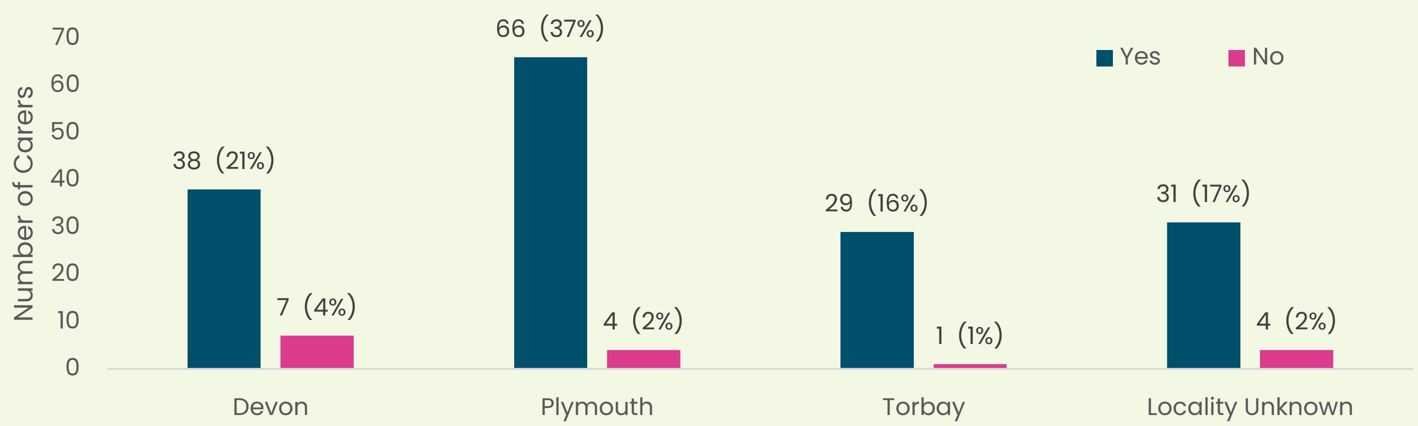
180 Carers who live with the person they care for (80% of the total cohort) responded to this question. Of those:

- 164 Carers (91%) replied 'yes', it does impact on their ability to relax at home,
- 16 Carers (9%) replied 'no' it does not impact on their ability to relax at home.

Fig 5 below provides a breakdown of the responses in each locality.

Observation: Significantly more Carers in Devon, Plymouth and Torbay said that living with the person they care for has an impact on their ability to relax at home.

Fig 5: If you live with the person you care for, does it impact on your ability to relax at home?



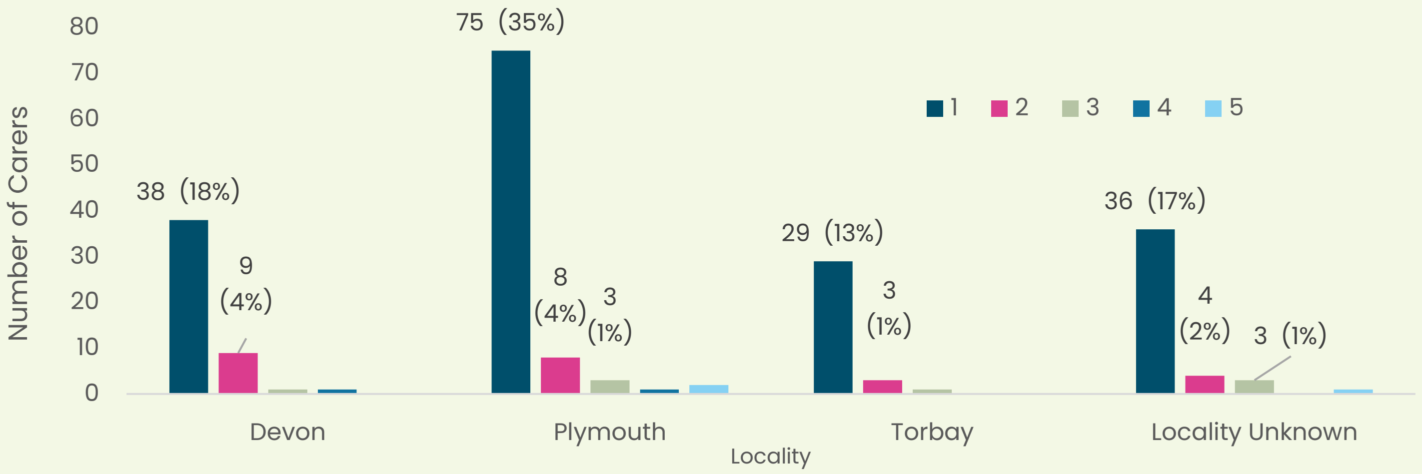
Question 6: How many people do you care for?

All but 1 Carers (223) responded to this question. Of those:

- 178 Carers (79%) are caring for 1 person,
- 24 Carers (11%) are caring for 2 people and
- 13 Carers (6%) are caring for 3 or more people.

8 provided another response. A breakdown of the responses by locality is provided in Fig 6.

Fig 6: How many people do you care for?



Question 7: What conditions or disabilities does the person you are caring for have?

Carers were asked to tick all that are applicable to the person(s) they care for. The most common conditions that those being cared for present with, include:

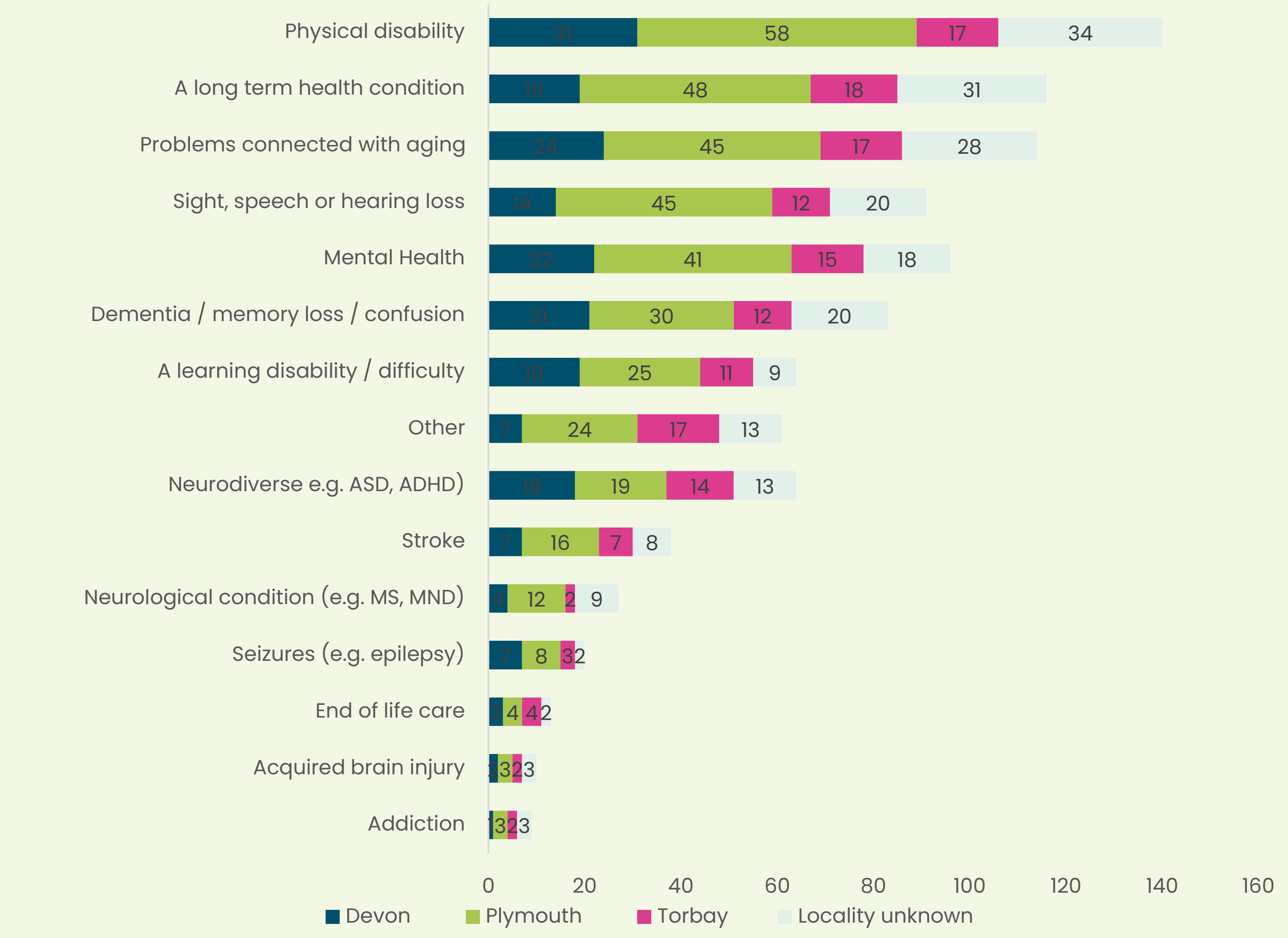
- A physical disability - 140 people (63%)
- A long-term health condition. (e.g., COPD, Diabetes) – 116 people (52%)
- Problems associated with ageing – 114 people (51%)
- Mental health condition – 96 people (43%)
- Sight, speech or hearing loss – 91 people (41%)
- Dementia – 83 people (37%)

Where Carers ticked ‘Other’ conditions, these include; cancer, broken limbs, complex / multiple conditions, undiagnosed but experiencing a range of symptoms, paralysis, pain, balance.

Fig 7 shows the breakdown of the cared for persons’ condition(s) by locality.

Observations: No significant observations to highlight.

Fig 7: What conditions or disabilities does the person(s) you are caring for have?



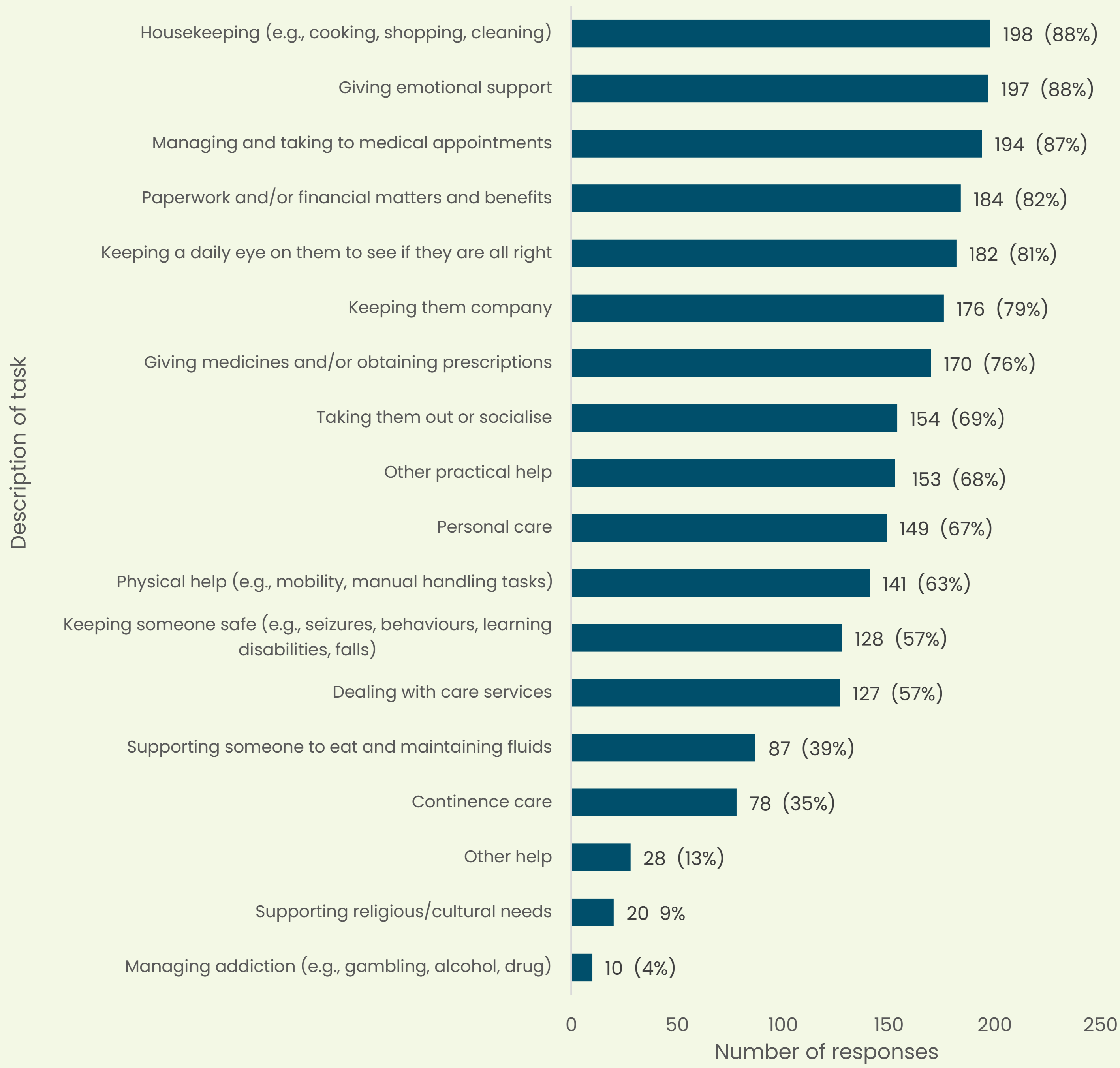
Question 8: Which of the following form part of the care that you deliver?

Carers were asked to tick all options applicable to their caring role. The highest number of Carers ticked the following options:

- 198 Carers (88%) provide housekeeping tasks, such as cooking meals, shopping and cleaning.
- 197 Carers (88%) provide emotional support to the person they care for.
- 194 Carers (87%) manage medical appointments booking and their attendance.
- 184 Carers (82%) manage paperwork and financial matters / benefits.

The responses showing overall percentages are presented in Fig 8 and responses within each locality are provided Fig 8.1 over the page.

Fig 8: Which of the following form part of the care that you deliver?

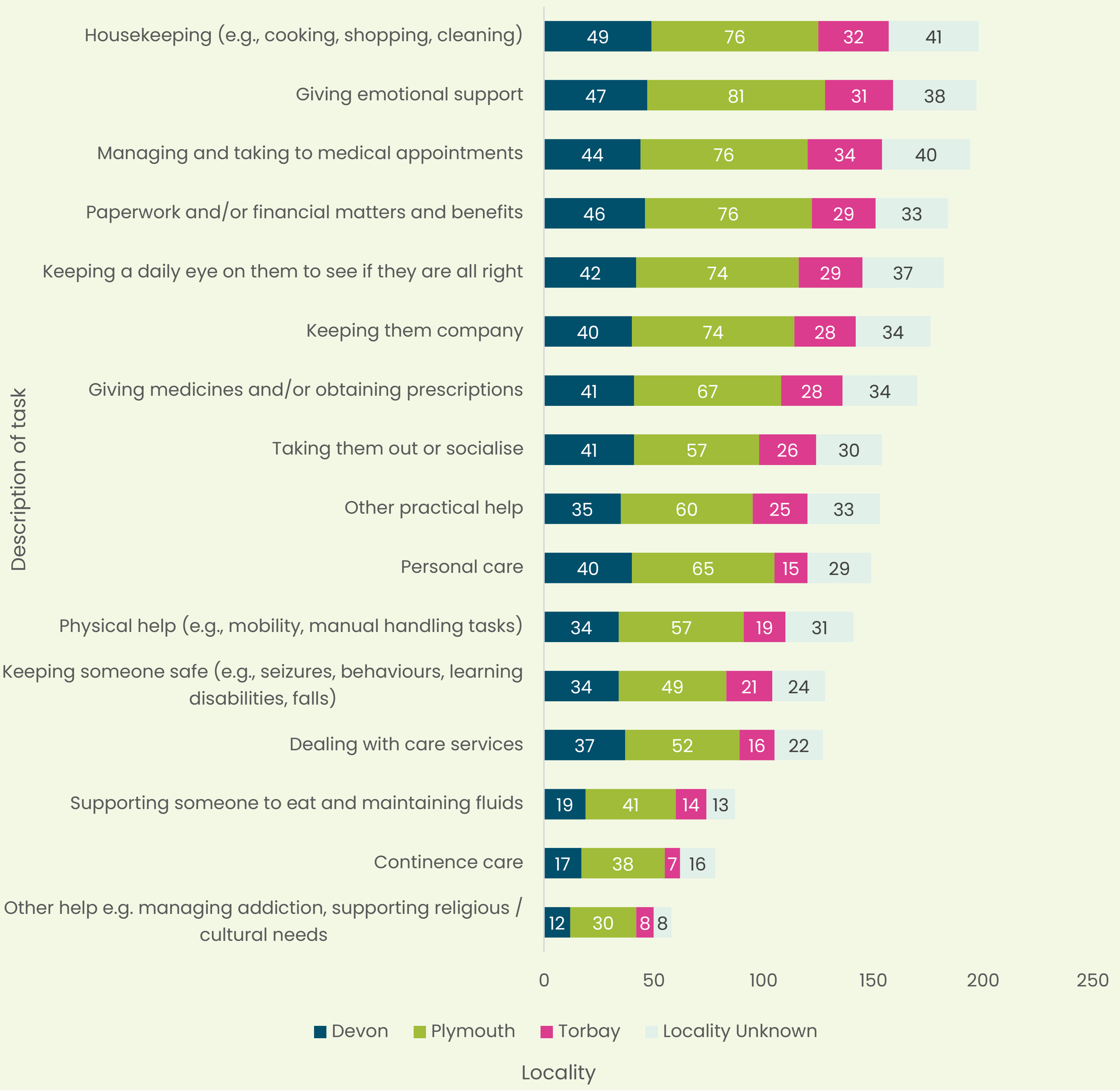


Observation: The most common tasks that more than three quarters of Carers ticked ‘yes’ to include housekeeping tasks, providing emotional support, managing medical appointments, paperwork, finances, keeping the person they care for company and making sure they are okay.

In addition to that, more than half of all Carers who responded to the survey also manage medications, prescriptions and dealing with care services, as well as taking the cared for person(s) out for social activities, providing personal care and other physical tasks and keeping the cared for person(s) safe from harm.

There are no noticeable anomalies to highlight from the results within each locality.

Fig 8.1: Which of the following form part of the care you deliver? Locality breakdown



Question 9: What is the time impact of weekly 'administration' tasks?

171 Carers (76% of the total cohort) responded to this question indicating a time impact. Of those:

- 70 Carers (41%) spend several hours a week on administrative tasks
- 45 Carers (26%) said that administrative tasks impact on them for several hours a day
- 23 Carers (13%) said the time impact varies from week to week
- 23 Carers (13%) said they spend up to 2 hours a week on administrative tasks
- 7 Carers (4%) were not sure of the impact or said it was difficult to quantify and 3 Carers (2%) said it had very little or no impact on them.

Fig 9 shows a breakdown of the overall responses to this question. Fig 9.1 shows the results for each locality.

Observation: There are no significant differences within each locality presented in Fig 9.1 compared to the overall results shown in Fig 9.

Fig 9: What is the time impact of weekly 'administration' tasks?

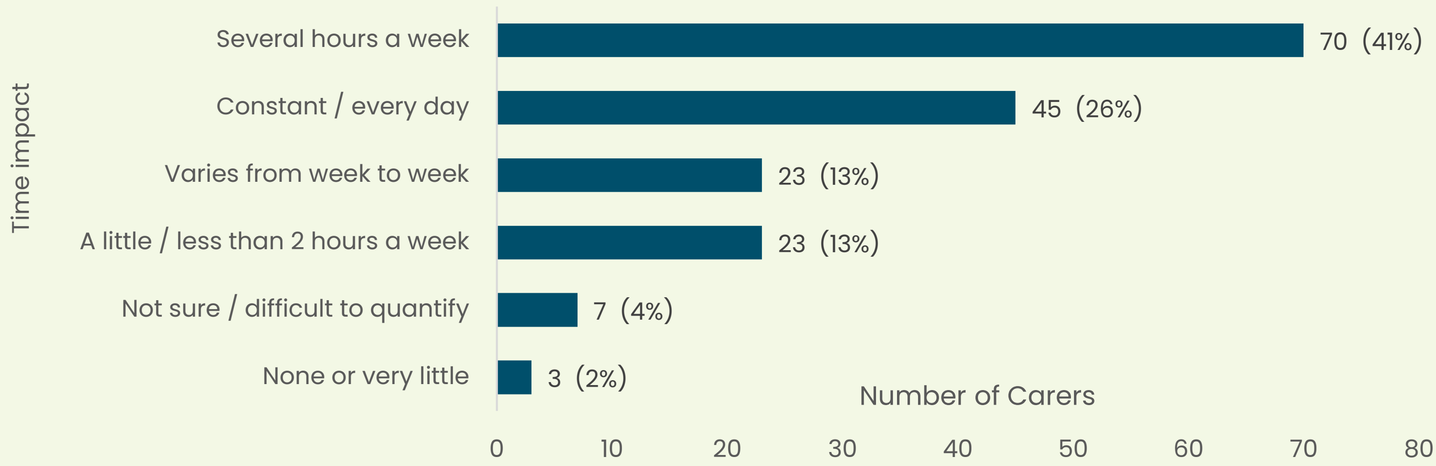
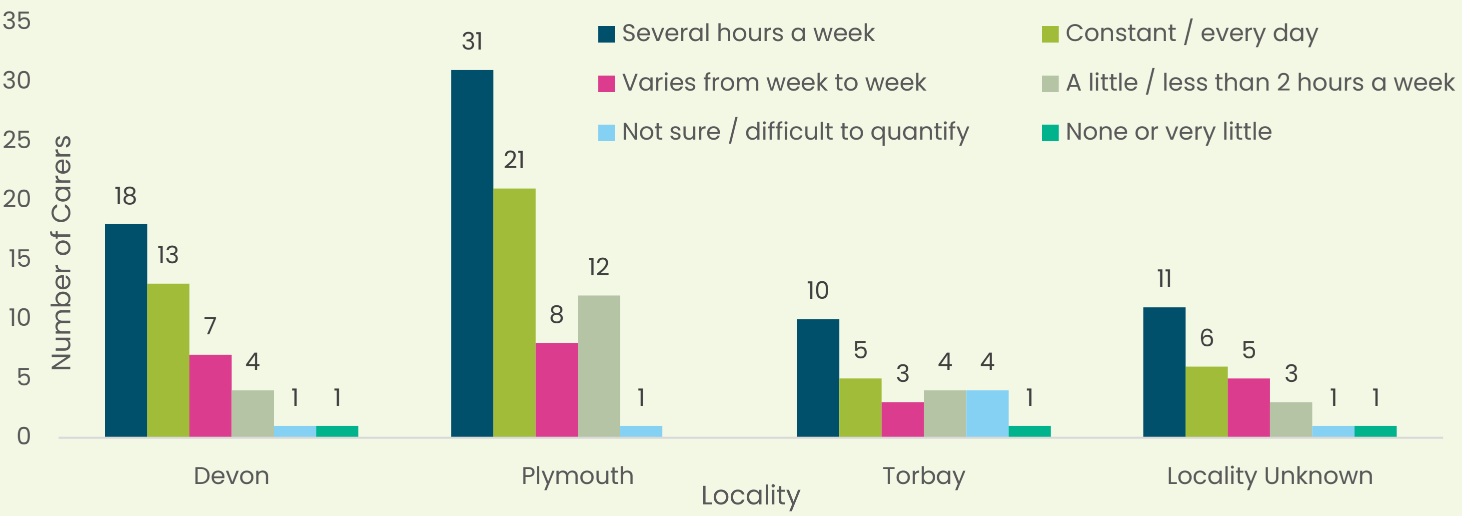


Fig 9.1: What is the time impact of weekly 'administrative' tasks? Locality breakdown



Several Carers provided more general comments in response to this question rather than a specific time impact. These comments can be found at appendix 9.

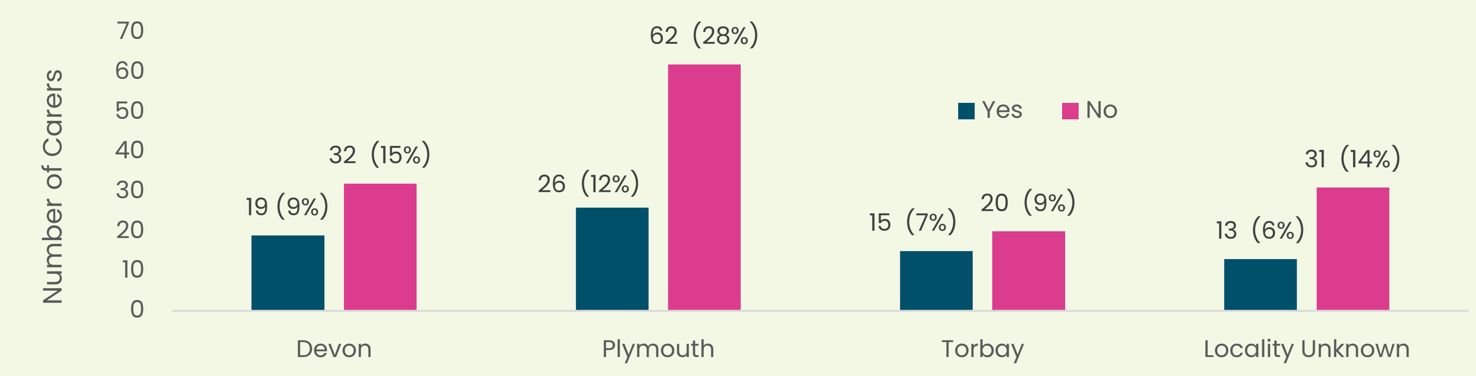
Question 10: Have you received enough training to support you in your caring role?

218 Carers (97%) responded to this question. Of those, 145 Carers (67%) replied 'no' and 73 Carers (33%) replied 'yes'.

Fig 10 provides a breakdown of the responses by locality.

Observation: In Devon slightly less Carers said they had received training compared to those who had not, similarly in Torbay. In Plymouth considerably less Carers had received training compared to those who said they had not.

Fig 10: Have you received enough training to support you in your caring role



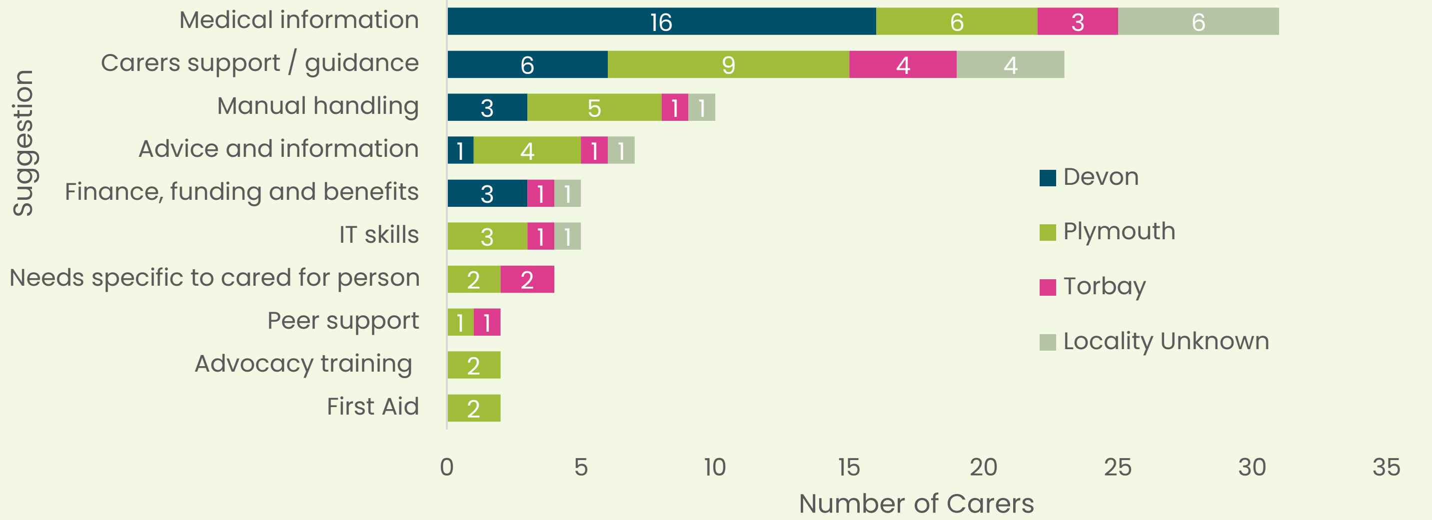
Question 10a: If no, what would be helpful?

91 Carers (40%) provided a suggestion as to what training they would find helpful. Of those, the top 3 topics were:

- Medical information in relation to the person they care for – 31 Carers (34%)
- Carers support and guidance to help them in their caring role – 23 Carers (25%)
- Manual handling training – 10 Carers (11%)

Fig 10a provides a breakdown of the responses within each locality.

Fig 10a: If you have had no training, what would be helpful?



Training relating to medical information

The most common suggestion for what would be helpful was information relating to managing the conditions that the person they are caring for has and what to expect. **Dementia** was mentioned the most, as well as **ADHD, Aspergers, self harm** and **stroke**. Advice in relation to treatments and medication was also mentioned by a few Carers.

Selected commentary includes:

"A frank conversation - without the person I care for - with the consultant, to give me more awareness of how the patient was likely to deteriorate and - if possible - a realistic time scale.
The patient and I are both fully aware that he is dying. He has not felt the need to question how or when. I believe it would help me to know."

"The dementia diagnosis is new so unsure of any helpful information that may be available."

"Knowledge about the impact of dementia and how to manage it knowledge and training in advance of an SGO for a child with a disability."

"Previous conversation with health professional on psychological consequences of stroke etc. would have been beneficial."

Training in the form of support and guidance for Carers

The main topics of advice and guidance that Carers said would be helpful in supporting them in their caring role include:

- Practical support and signposting to services
- Advice and guidance on navigating the system and care pathways
- Advice, support and resources to help Carers to cope better.

Selected commentary includes:

"Help on where to access information. An overview of what providing care will entail. Signposting to support available to me & the person I care for."

"A support worker who helped prop me up/guide me as to what to do next."

"Understanding how all the different health and social care teams work together, how they can refer to each other and what each of them does would be really good. It is a minefield for the layperson."

"Practical advice on how to balance demands on time and energy between being a full- time carer and my own health and well being."

"Practical information on eligible help, how to get help around the house (e.g. small repairs and adjustments to house)"

In response to question 10a, 21 Carers said that they had either never received any training, were not aware of any training, or were self taught / learnt as they went along. Selected commentary includes:

"When I have reached out for help, I have learnt more from Google. It would have been helpful to have learnt about aids, support and tips on how to cope."

"I care for someone in Devon and live in Torbay. I have fallen through the cracks."

"It's too late now we are self taught I would not know where to start in knowing what would have been helpful. Certainly, more understanding and kindness would have been gratefully received. "

"I have been caring for my wife for some ten years now, I know more about her needs than health professionals apart from medication."

"I don't know what is available so do not know what is needed."

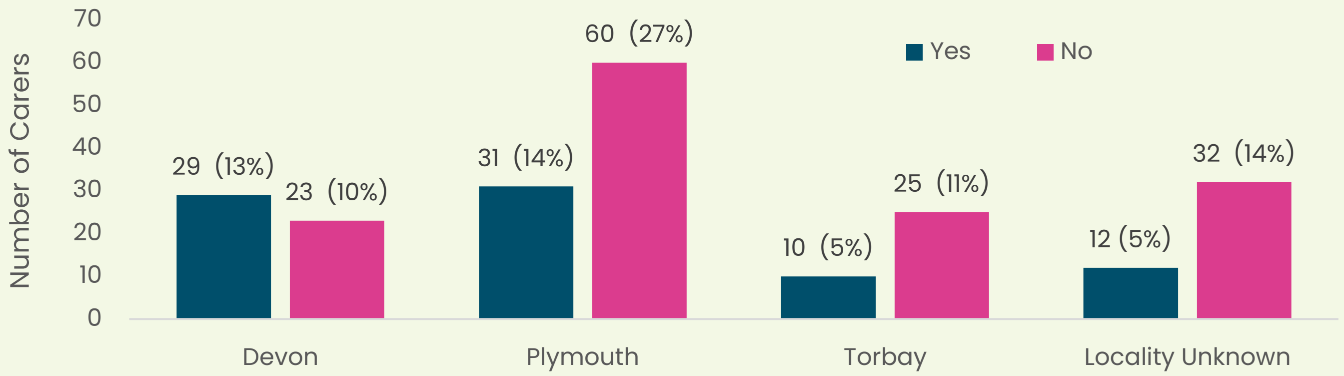
Question 11: Does the person you care for also receive paid care?

222 Carers (99%) responded to this question. Of those, 82 Carers (37%) replied 'yes' and 140 Carers (63%) replied 'no' .

Fig 11 provides a breakdown of the responses in each locality.

Observation: Slightly more Carers who responded in Devon receive paid care for the person they care for, compared to those who do not. In both Plymouth and Torbay, the number of Carers who said they receive paid care is much less compared to those whose who said they do not.

Fig 11: Does the person you care for also receive paid care?

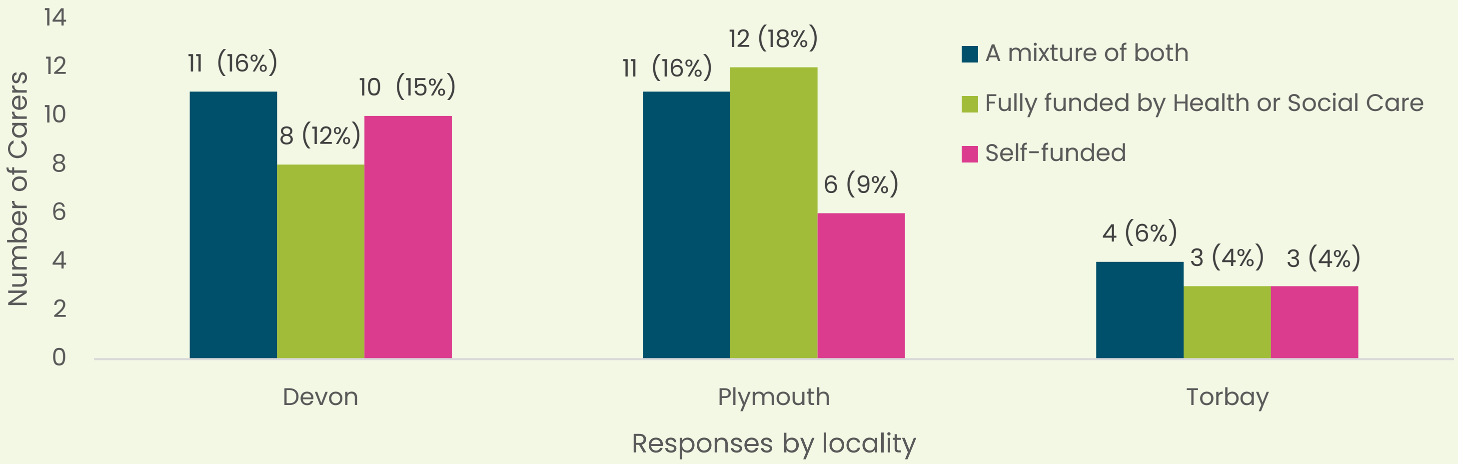


Question 12: If the person you care for receives a paid care service, how is this funded?

68 Carers (30%) responded to this question. (83% of the 82 Carers who told us the person they care for receives paid care). Fig 12 shows the breakdown of the results across Devon, Plymouth and Torbay, where Carers provided a post code prefix.

Observation: Slightly more respondents in Devon either part fund or fully fund the care that is paid for, compared to those for whom care is funded by the local authority. In Plymouth slightly more Carers said the care was either fully or part funded by the local authority. In Torbay, the results were about the same.

Fig 12: If the person you care for also receives paid care, how is it funded?

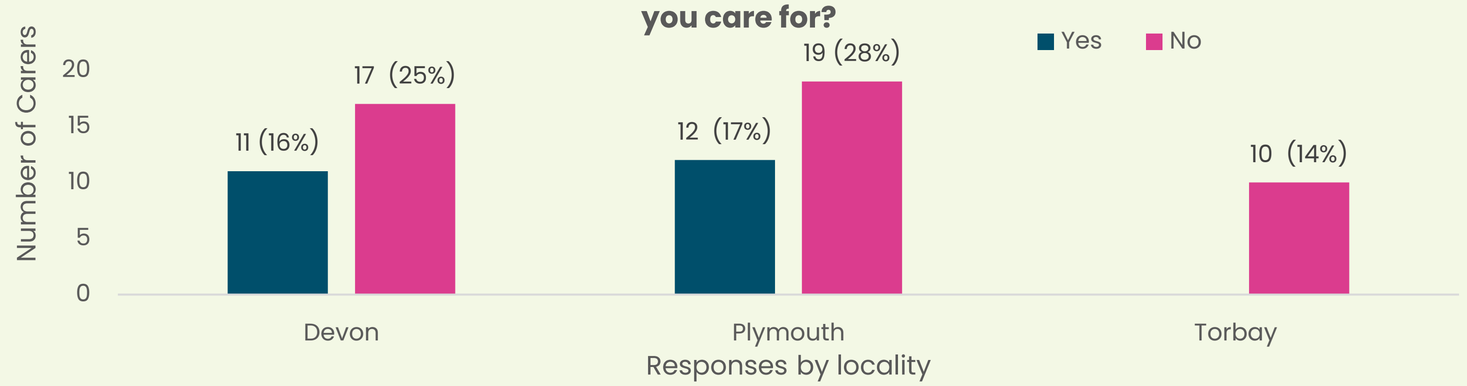


Question 13: Do you feel this meets the needs of you as the Carer and the person you care for?

81 Carers (99%) who's cared for person receives paid care responded to this question. 54 Carers (67%) replied 'no' and 27 Carers (33%) replied 'yes'. Fig 13 provide a breakdown of the results across Devon, Plymouth and Torbay.

Observation: The results show that in Devon and Plymouth, the number of Carers who said it met their needs was lower compared to the number who felt it did not meet their needs. In Torbay, no Carers said that the care they receive meets their needs.

Fig 13: Do you feel this meets the needs of both you as the Carer and the person you care for?

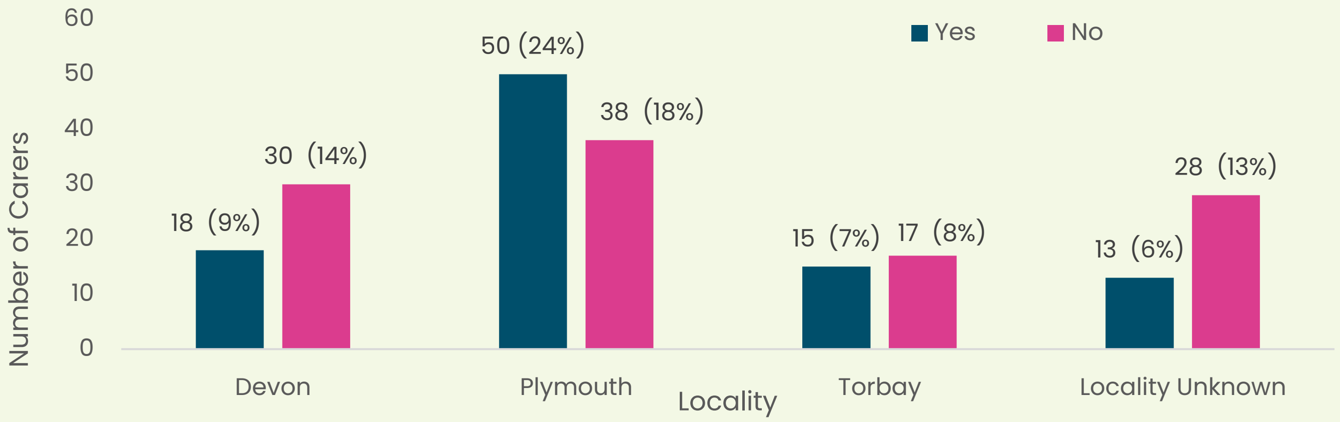


Question 14: Have you had to give up paid employment or reduce your hours of paid employment to provide care?

209 Carers (93%) responded to this question. Of those who responded, 113 Carers (54%) replied 'no' and 96 Carers (46%) replied 'yes'. Fig 14 provides a breakdown of the responses in each locality.

Observation: In Devon slightly less Carers have had to give up paid employment / reduce their hours compared to those who have not had to. In Plymouth, more Carers have had to give up work / reduce their hours compared to those who have not. In Torbay it is almost half and half. In total, 66 Carers (69%) of those who responded 'yes', were categorised as being of working age.

Fig 14: Have you had to give up paid employment or reduce your hours to provide care?



Question 14a: If yes, how many weekly hours have you reduced?

Of the 96 Carers (46%) who responded 'yes', they had either given up work or reduced their working hours, 91 Carers (41%) provided further details in response to this question. Of those:

- 18 Carers (20%) said that they had to give up full time work.
- 31 Carers (34%) said they had reduced their hours to part time (11 – 25 hours reduction).
- 11 Carers (12%) said they had reduced their hours by 10 or less.

31 Carers (34%) did not specify exactly how many hours they had given up, but said they had either taken early retirement, were not able to work, or could only work a set number of hours due to their caring responsibilities.

Fig 14a provides a summary of the overall responses to this question. Fig 14a. 1 provides a breakdown of the results within each locality.

Observation: In Devon and Plymouth and Torbay the results show that for those who have had to reduce their hours, the number of hours they have reduced by is significant, with more than half reducing their hours by at least 11 hours or more.

Fig 14a: How many hours per week has your paid employment reduced by?

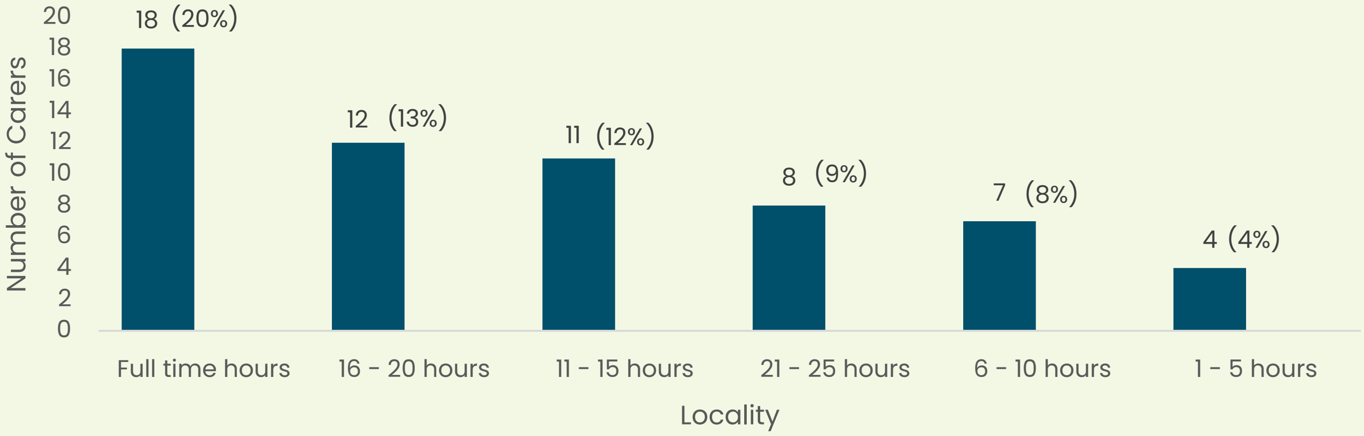
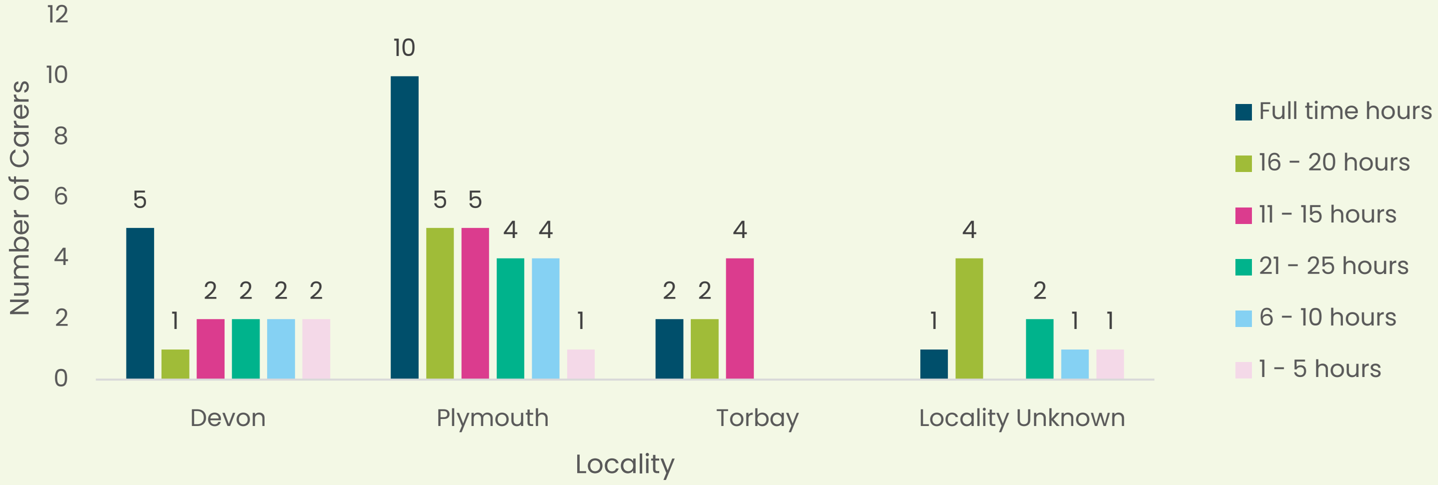


Fig 14a.1: How many hours per week has your paid employment reduced by?



Question 15: If you have reached a point where you feel you can't manage, how often does this occur?

152 Carers (68%) specified a times scale in response to this question. Of those,

The highest number of Carers (45 / 30%) said they reached this point regularly / or at least 1 or 2 times a week, followed by 39 Carers (26%) who said they reached this point occasionally or one to a few times a year. 33 Carers (22%) said they reach a point where they feel unable to cope often or every day.

Fig 15 provides a breakdown of the number of responses from often / daily, to never or not yet. Fig 15.1 provides a breakdown of the responses within each locality.

Observation: There are no significant anomalies to highlight from the results within each locality.

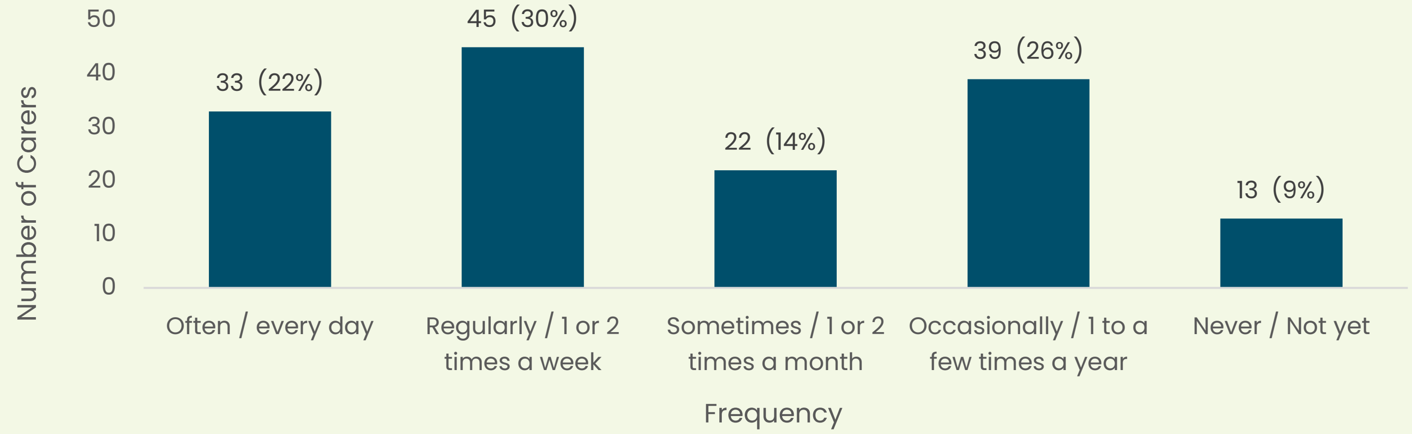


Fig 15: How often do you reach a point where you cannot manage?

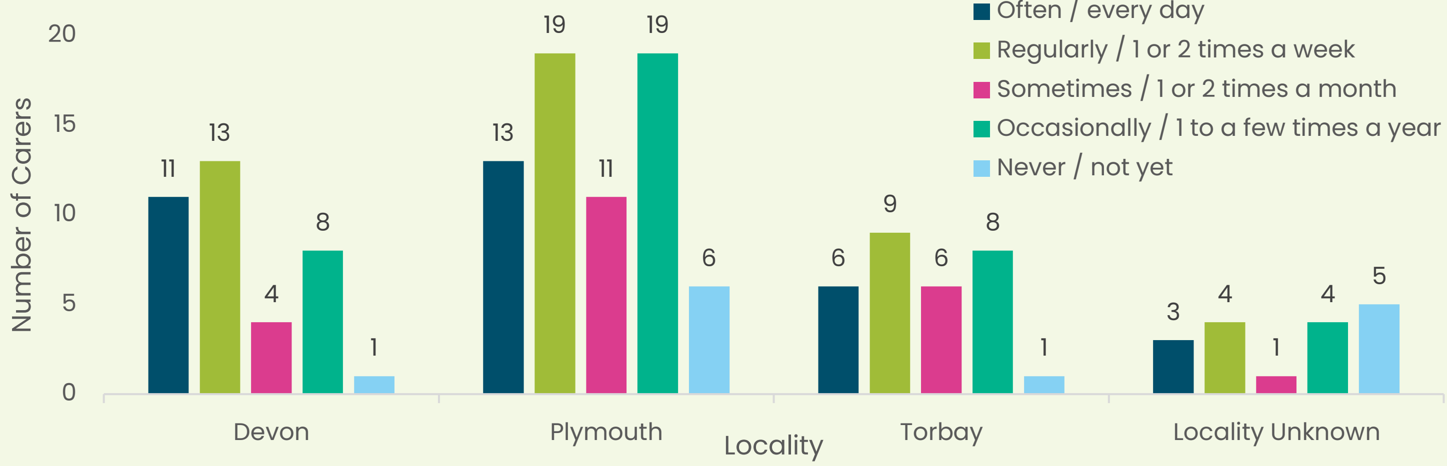


Fig 15.1: How often do you reach a point where you cannot manage – Locality breakdown

The results for question 15 are important in identifying whether there are any significant factors which contribute towards a Carer feeling unable to manage. For example, the Carer's age, whether they live with the person they care for, how long they have been a Carer and how many hours they provide care are all factors to consider when developing a wellbeing risk scale for Carers.

Question 15 (continued): **If you have reached a point where you feel you can't manage, how often does this occur?**

Overall, 78 Carers (35% of the total cohort) said they had reached a point where they felt unable to manage either **regularly** (once / twice a week) **or often** (daily).

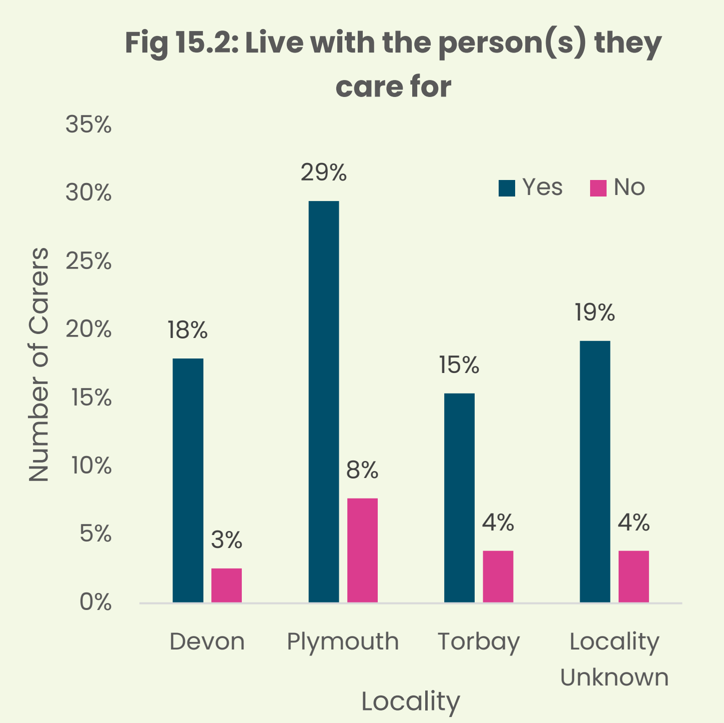
Of those,

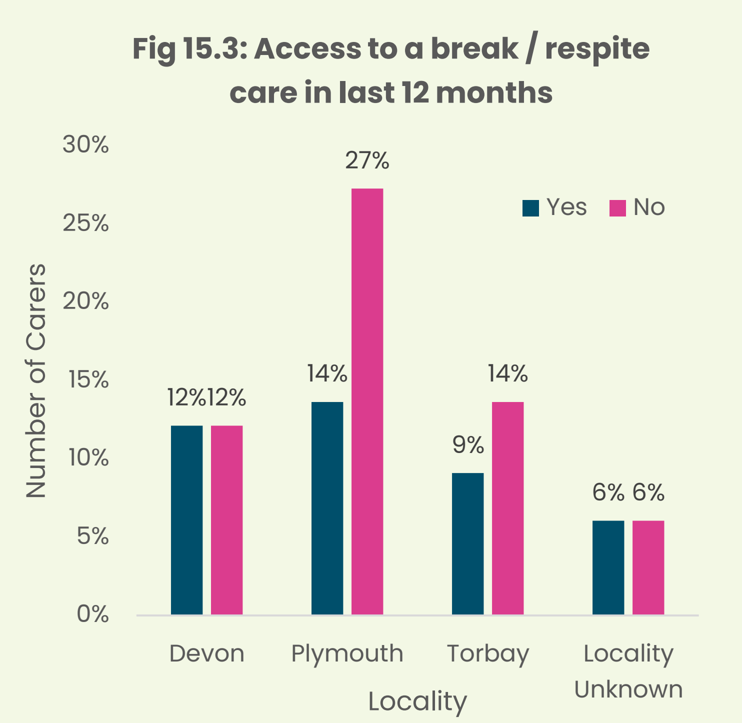
- 64 Carers (82%) live with the person(s) they care for.
- 39 Carers (50%) had **not** been able to take a break or respite within the last 12 months.

Figures 15.2 and 15.3 show the results for Carers who **regularly** or **often** feel unable to cope, broken down by each locality.

Observation: In all localities, the number of Carers who live with the person(s) they care for, who said they had reached a point where they could not manage, was higher than those who did not live with the cared for person(s).

With regards to respite, the number of Carers in Plymouth who were able to take a break was significantly lower than those who were not. In Torbay, the number was slightly lower and the Devon the number of Carers who could access a break was equal to the number who could not.



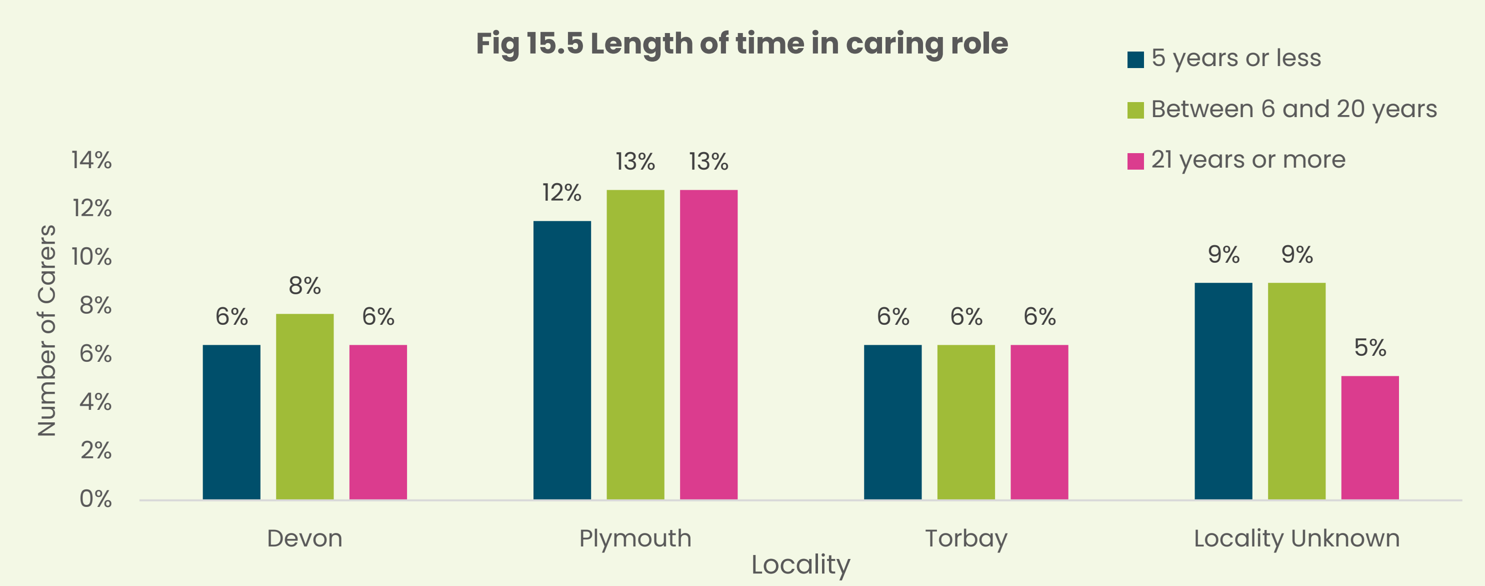


To note: Further analysis will be necessary to see if there are any significant findings in relation to the condition of the cared for person and whether this has an impact on the Carers' ability to manage. Similarly, further analysis will be necessary to establish whether the number of administrative hours provided by the Carer has any significant impact on the Carers' ability to manage.

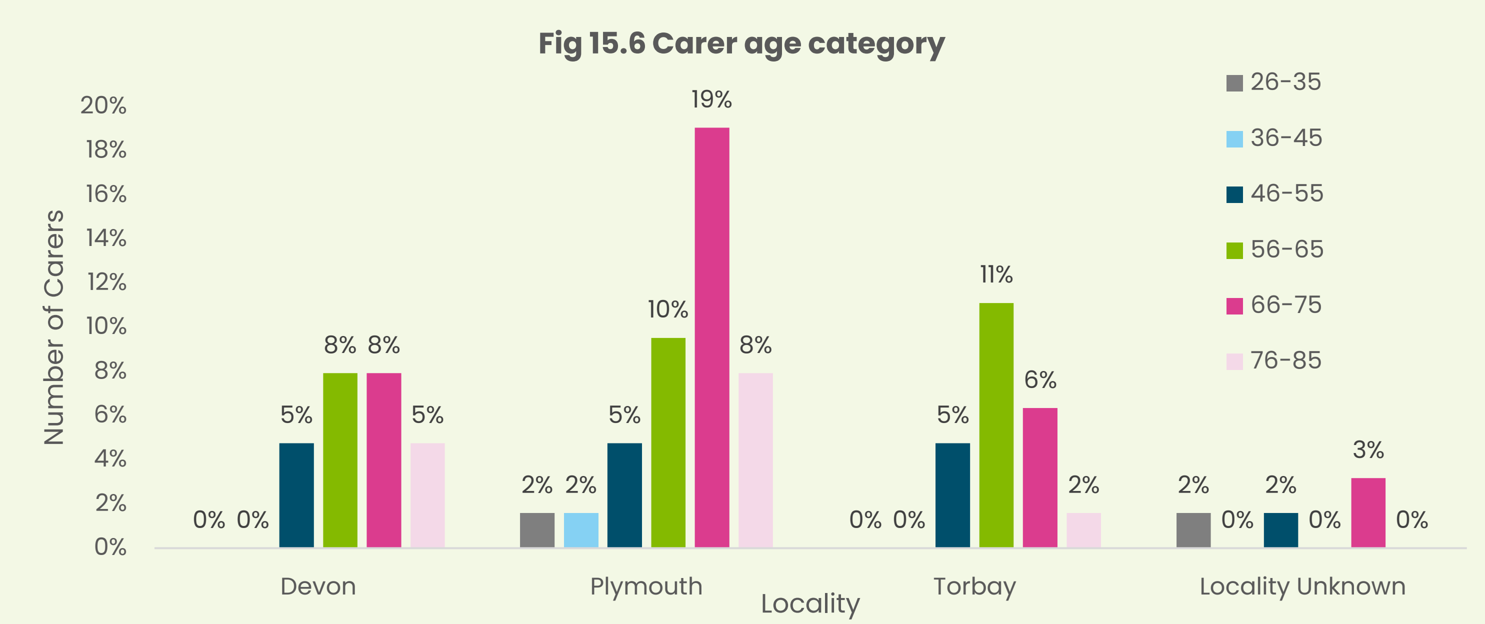
Question 15 (continued): If you have reached a point where you feel you can't manage, how often does this occur?

Fig 15.5 shows the results for the length of time Carers had been in a caring role, who **regularly** or **often** feel unable to cope, broken down by each locality.

Observation: The results suggest that across all three localities, the specific length of time a Carer had been in a caring role was not necessarily a significant indicator to a Carer reaching a point where they felt unable to manage.



Similarly, there are no significant anomalies to highlight in relation to the age of the Carer, where they often or regularly reach a point where they are unable to manage, except there are slightly more Carers in Plymouth who are aged between 66 – 75 compared to the number of Carers in other age groups. The results broken down by age category and locality are presented in Fig 15.6 below.



Question 15 (continued): **If you have reached a point where you feel you can’t manage, how often does this occur?**

This question required a free text response, so many Carers also added comments to accompany their answers.

Observation: Where Carers said they reached this point daily, some said they feel it less often when things are working properly, and they are getting the right support.

Selected commentary includes:

Often / every day:

“All the time. I have been fighting for two years to get my voice heard in my own right that I can no longer care for my husband, but they still expect me to carry on overnight alone!”

“Constantly. Dread, fear, terror at what might happen, what I might have to deal with. The stress also causes migraines and flare ups of IBS symptoms.”

“Daily, experiencing severe overwhelm, affecting my own house, mentally, emotionally and physically.”

Regularly / 1 or 2 times a week:

“About once a week post CBT counselling, pre-CBT it was almost every day.”

“At least every week or so, I get periods of depression.”

“Sometimes daily, but a least once a week.”

Sometimes / 1 or 2 times a month:

“Monthly. Have my own health problems at the moment, making it harder for me to care for mum. More than once, I cried myself wishing I wasn’t here anymore - not that I would act on that, it’s how I felt in that moment. “

“About once a month I feel completely overwhelmed.”

Other selected commentary:

“Every time I have to fight for services or when things are going wrong for the cared for person (get upset/angry or feel it is hopeless).”

“Several occasions in the past - much better now since access to support.”

“Yes, when I can't get the advice or help, I need to support my daughter.”

“Lord have I ever? It becomes harder as I get older. I have times when all I do is cry, I'm so tired. I pull myself up & carry on.”

“This has become more frequent as I've gotten older. I have now actively sought support from agencies however none have capacity due to shortage of staff.”

“I haven't reached that point but often wonder about it. You can’t reach that point without an alternative already in place. If I go down, we both go down.”

“It depends on what is happening for my cared-for - e.g., if they are more unwell. It also depends on the nature of the help and responses I get from outside agencies - if that is very poor, it can be really difficult.”

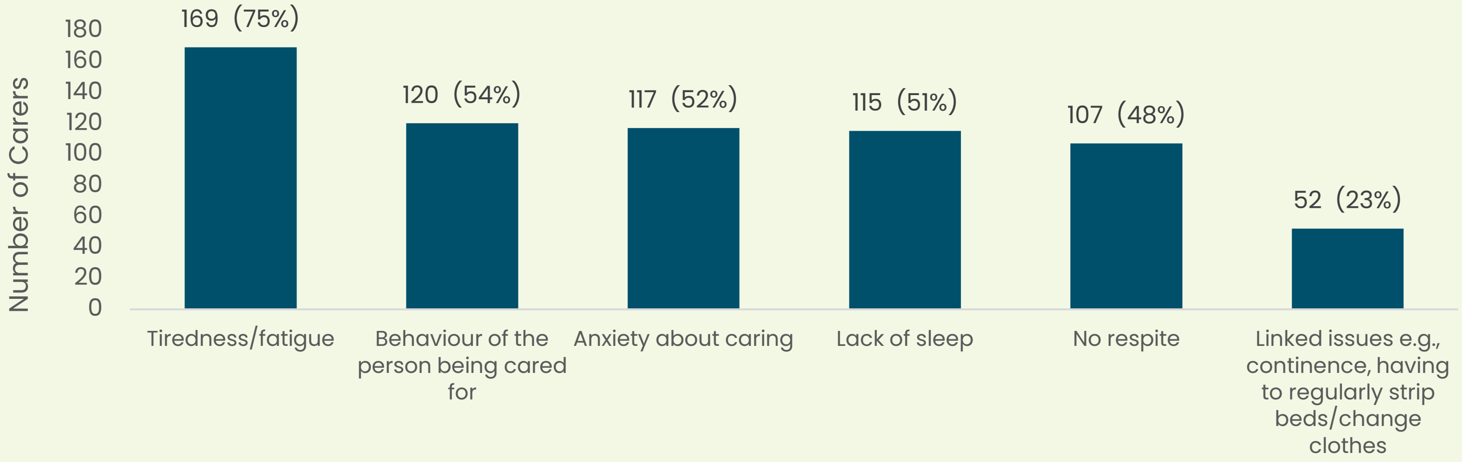
Question 16: What do you feel were the triggers that led you to feel unable to manage?

Carers were able to select more than one trigger in response to this question.

- The highest number of Carers 169 (75% of the total cohort) ticked tiredness / fatigue.
- 120 Carers (54%) ticked the behaviour of the person they care for
- 117 Carers (52%) ticked anxiety about caring
- 115 Carers (51%) ticked a lack of sleep
- 107 Carers (48%) ticked having no respite
- 52 Carers (23%) ticked linked issues, such as incontinence, having to strip beds / change clothes.

Fig 16 provides a breakdown of the responses. A further breakdown of the responses by locality can be found at Appendix 2.1. **There are no significant anomalies to highlight.**

Fig 16: What do you feel were the triggers that led you to feel unable to manage?



58 Carers (26%) ticked 'other' in response to this question. Most 'other' responses (25 Carers) related to feelings such as loneliness / isolation, worry, stress, overwhelm, anger and frustration. Another trigger mentioned by 10 Carers was dealing with outside agencies, such as the local authority or health care professionals. 6 Carers were triggered due to issues relating to their own health and wellbeing.

Some of the triggers that Carers told us lead them to feel unable to manage at times are:

"A lack of personal freedom and a life of my own."

"Lack of support/diagnosis/help."

"Both being ill together. No other relatives to call on."

"Feeling alone."

"Challenging behaviour on a level that nobody could ever understand/or understand the reasons why the cared for person was behaving the way they were."

"Dealing with county's slow and inept 0-25 Team and navigating transition from children to adult services."

"Health authorities who deal with the financial aspect of care but have no understanding of the role of a carer."

"Insufficient money coming in with carers allowance for the amount of caring I do. Extortionate weekly amounts of care home fees if we could afford it (we can't.)"

"Stress liaising with social services and other organisations."

"It's relentless, with no support and no end in sight."

"Seeing him getting worse and nothing happening to help"

"Seizures and hospital admissions, issues with GP and pharmacy issuing prescriptions correctly."

"Feeling tied to the house."

"Financial worries."

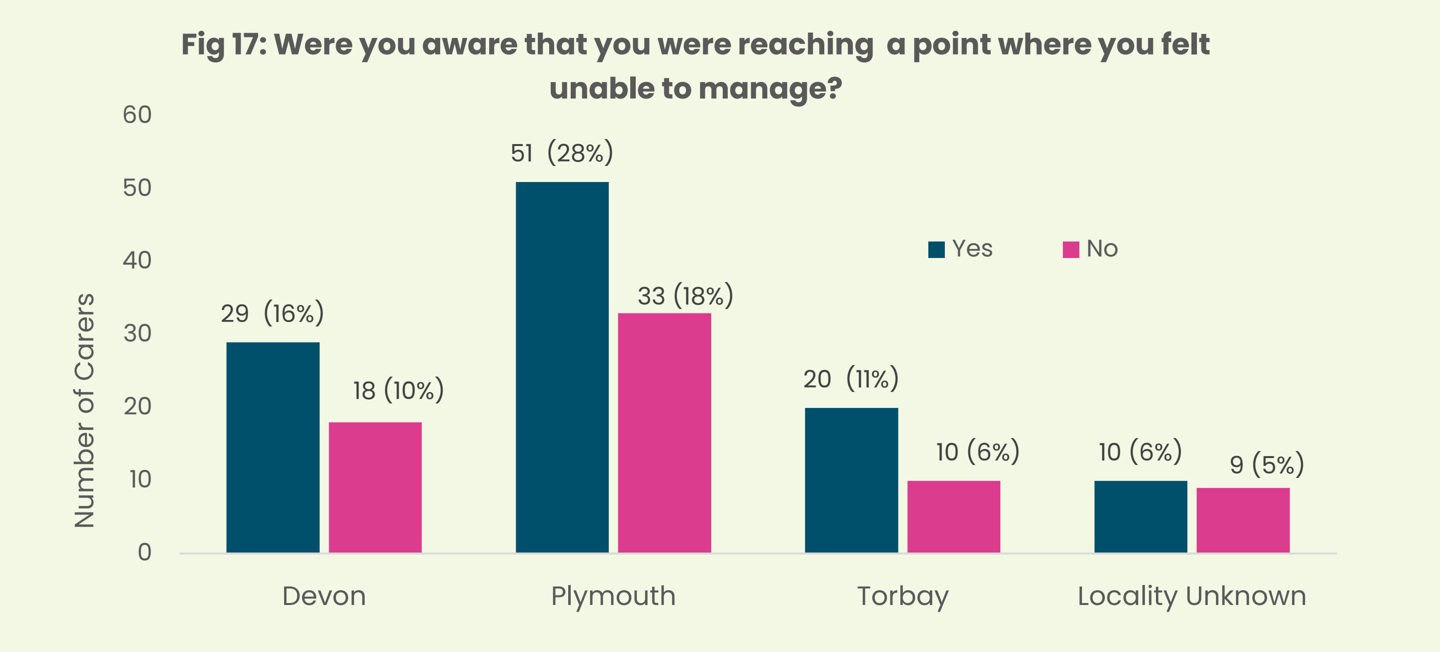
Question 17: Were you aware of reaching this point beforehand?

180 Carers (80% of the total cohort) responded to this question.

Of those who responded, 110 Carers (61%) replied 'yes', they were aware that they were reaching a point at which they were unable to manage. However, 70 Carers (39%) replied 'no' they were not aware.

Observation: The proportion of Carers who said they were aware was higher across Devon, Plymouth and Torbay compared to those who said they were not aware.

Fig 17 provides a breakdown of the responses across each locality.



Question 18: What do you feel would help you to avoid reaching a point where you feel like you cannot manage, or there is a deterioration in your own health and wellbeing?

162 Carers (72%) provided a response to this question. Some simply said, *"more help"* or **"**I *don't know"* or *''I wish I knew'*. The most common responses were:

- **Being able to take a break** / respite from their caring role – 45 Carers (20% of total cohort)
- **Having additional support in place** for the person they care for – 28 Carers (13%)
- **More support** for them as a Carer – 23 Carers (10%)
- **Better communication** with health and social care professionals – 16 Carers (7%)

Other suggestions include more information and advice, more sleep, having a plan in place to avoid reaching crisis and counselling / having someone to talk to.

Selected commentary related to the most common responses to this question are on the next page.

Selected commentary relating to taking a break / respite from their caring role:

“More opportunity to get out of house, opportunity to follow own interests/personal admin, more sleep.”

“Someone who can come into our home to look after mum so my husband and I can spend some time together.”

“Accessing affordable respite care to take a break from caring without extortionate care home fees.”

“Respite where husband is cared for either at home or in a care facility.”

“Respite care on a regular basis. I’ve not had a day off in 6 years.”

“Having overnight good quality respite away from our home.”

Selected commentary relating to additional support for the person they care for:

“Better Sitting Service so I can go out (it is very 'on and off'). I am supposed to get a sitter for 3 hours a week - but only get once every 3 weeks ish.”

“Better networks of support for those who will not engage with social services or respite carers.”

“Choice of paid carer, which there is none. Having activities and services that would be appropriate and enjoyable for my cared for.”

“Intelligent befriending for hubby. We have tried the local services and they are too banal for him. A care home for a day's respite is not stimulating, in fact it is a form of torture.”

Selected commentary relating to more support for me as a Carer:

“FREE weekly counselling sessions. This helped me cope before, but I can’t afford £30 a session when I’ve had to stop most of my work to care for mum. I can’t afford to look after me!”

“More outside help/funding…. the carers benefits are so low, I cannot afford to not work which then affects my ability to provide care.”

“Support from someone/ an organisation that I could contact and speak to for advice/signposting. Reassurance that I'm not alone and how caring can affect you. Support in place for my wellbeing. Something to look forward to e.g. free activities.”

“When mum came out of hospital there was a package of care for her but none for me.”

Selected commentary relating to better communication with health & care professionals:

“Not having to repeat stuff and spend hours doing paperwork/proving the need is there (papers to fill in regularly despite no changes, time consuming and worrying - will his help continue.”

“Recognition by social services of how much I have on my plate, and how much money I save them by caring for my daughter at home.”

“Doctors support is appalling and she has supposedly been referred for a mental health assessment, but that was over a year ago and nobody has contacted us and nobody supports us in any way.”

“At the moment, decent and coordinated services from the county council and clear information on the processes and services available around transition to adulthood.”

“Being listened to by social services rather than being questioned as to how much money I have.”

“Better support from the mental health professionals in Torbay for people who are ill. The lack of ongoing psychiatric visits and prescribing has brought me to breaking point.”

“Good collaborative working with any outside services involved (from GP onwards) in which I am respected, recognised as an expert in my cared-for's situation (as a daily carer) and listened to. So that outside services can vary or amend their input to help our balance and wellbeing at home.”

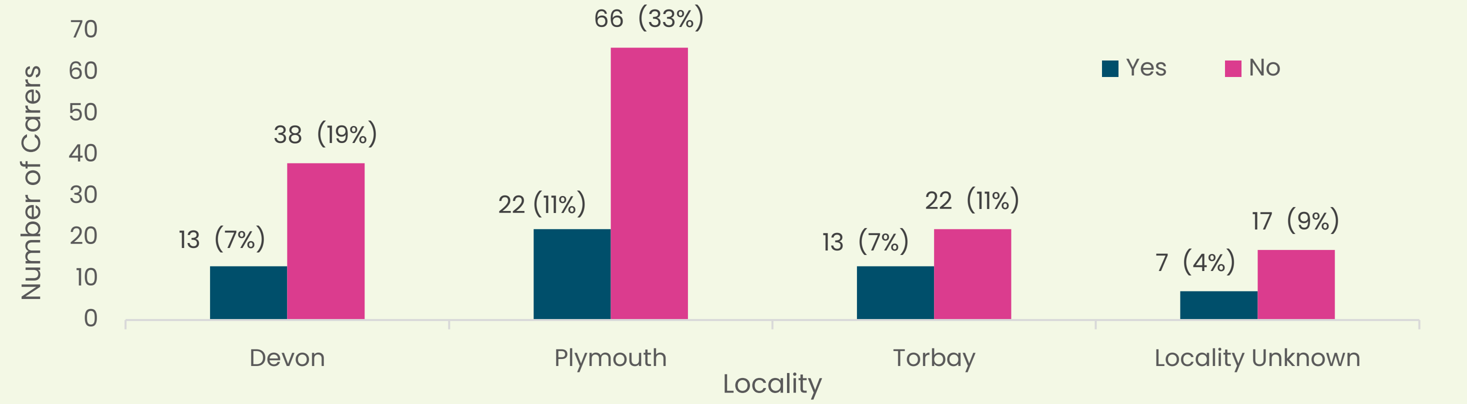
Question 19: Have you ever felt that your own safety was at risk?

198 Carers (88% of the total cohort) responded to this question. Of those:

- 55 Carers (28%) replied 'yes', they had felt their own safety was at risk.
- 143 Carers (72%) replied 'no' they have not felt their own safety was at risk.

Fig 19 provides a breakdown of the responses across each locality. **There are no significant anomalies to highlight.**

Fig 19: Have you ever felt your own safety was at risk?



Question 19a: If yes, how frequently does this occur?

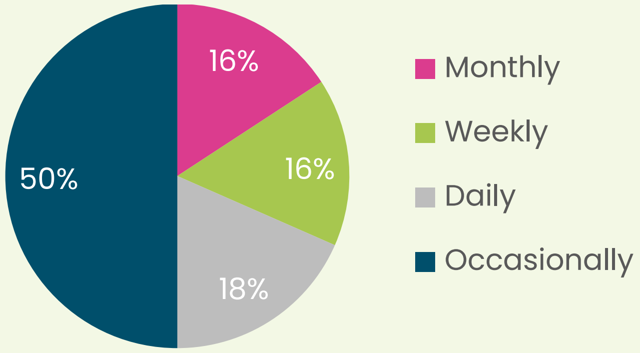
53 Carers (24% of the total cohort) provided a response to this question.

Of those, 38 Carers (72%) provided a specific frequency.

- 19 Carers (50%) felt their safety was at risk occasionally,
- 6 Carers (16%) said 'monthly',
- 6 (16%) said on a weekly basis and
- 7 Carers (18%) felt their safety was at risk daily.

Fig 19a provides a breakdown of the 38 responses as a percentage.

Fig 19a: How often Carers told us they felt that their own safety was at risk



19 Carers provided further comments relating to how frequently they felt that their own safety was at risk. Some comments relate to the Carer's own mental health and wellbeing and others relate to the complexities relating to medications, the condition, behavior or the emotional wellbeing of the person they care for. Selected commentary includes:

"Everyday. But we know how to manage the person we care for, but the risks are there, and they always have been."

"5 years ago, one of my cared for people was violent because he was put on the wrong medication. Now I feel at risk because I have PTSD (diagnosed and being treated)"

"I'm often alone all day with the person I care for, if I trip or fall there is no-one to help us!"

"My own safety has felt at risk on occasions, but only from myself. At times on bad days, I just feel the need to explode, to relieve the pressures on me, so I take it out on myself."

"Twice in the last 6 months I have had suicidal thoughts which despite dealing with depression and low mood for many years has not happened before."

Question 20: Do you know where to go for support?

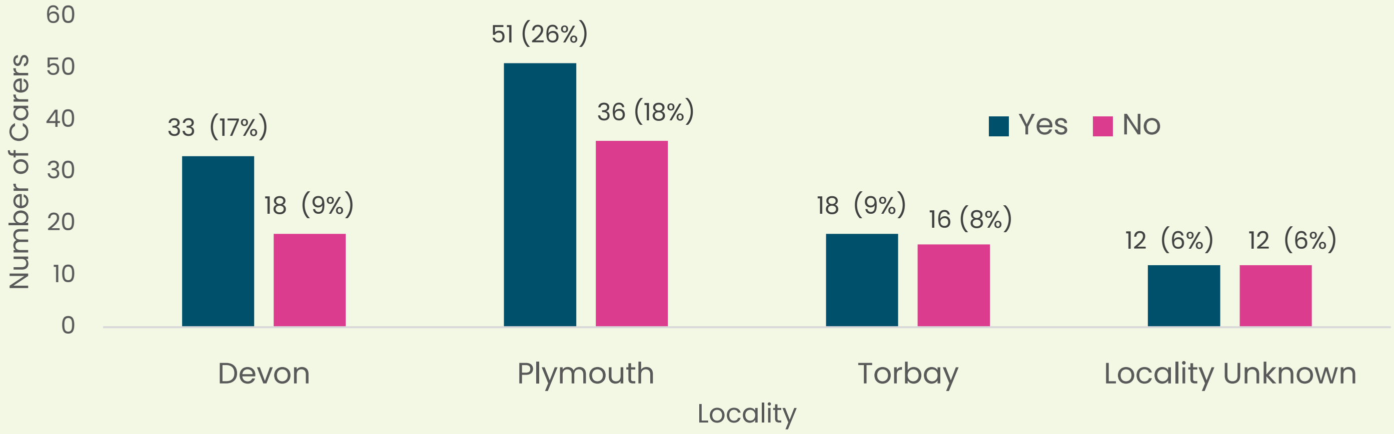
196 Carers (88%) responded to this question. Of those,

- 114 Carers (58%) replied ‘yes’, they do know where to go for support
- 82 Carers (42%) replied ‘no’.

Fig 20 provides a breakdown of the responses across each locality.

Observation: In Devon and Plymouth more Carers said they do know where to go for support compared to those who don’t. In Torbay the results were about the same.

Fig 20: Do you know where to go for support?



Question 20a: If yes, what support are you aware of?

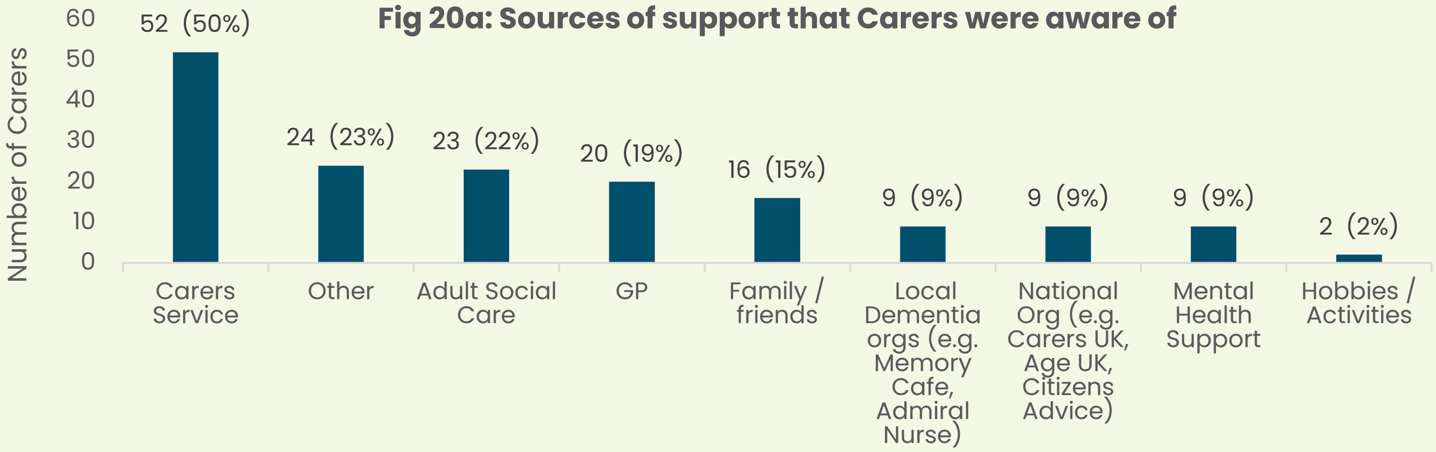
104 Carers (46% of total cohort) responded to this question. Some Carers gave examples of more than one type of service or source of support that they are aware of.

Carers Services were mentioned by the highest number of Carers (52), with several Carers specifically mentioning Devon Carers, Improving Lives or Caring for Carers.

Adult Social Services was mentioned by 23 Carers, 20 Carers said their GP. Other support mentioned was family and / or friends (16), Dementia support services (9), mental health support (9) and hobbies / activities (2).

Fig 20a provides a breakdown of the main sources of support which were mentioned by Carers. ‘Other’ refers to: Parkinson’s Nurse, Hospiscare, befriending volunteers, church, Police, Rowcroft Hospice, school and domestic abuse team.

Fig 20a: Sources of support that Carers were aware of

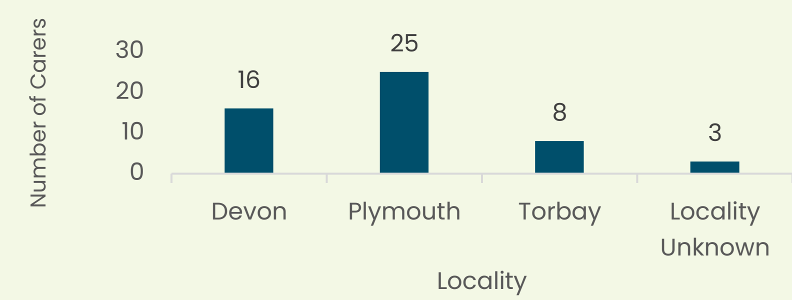


Question 20a (continued): If yes, what support are you aware of?

Fig 20a.1 shows a breakdown of Carers who mentioned Carers Services within each locality.

Observation: No significant anomalies to highlight from the result across the localities for any of the services mentioned in Fig 20a.

Fig 20a.1: Carers Services - Locality breakdown



Several Carers provided comments in response to this question. Some comments were negative, in that despite being aware of the services available to them, they had experienced issues when attempting to access support for various reasons, such as:

- **the services do not meet their needs**, or the needs of the person they care for
- **they anticipated a delay** in accessing a service,
- or when they have accessed a service, **they did not feel heard**.

Selected commentary related to services not meeting needs includes:

"There seems to be nothing out there."

"Tried doing carers form online but not much use just direct you to websites."

"I got a carers assessment with "Improving lives" which helped & had some advice from them. I've taken part in one support session, but it wasn't for me I had very little in common with the other attendees."

"The support that I'm aware of is useless to our needs. I can't bring myself to put my loved one in the care settings that are on offer due to the diverse needs of other service users."

"There is caring for carers who do 'activities' but that's not what I need."

Selected commentary relating to delays or difficulties accessing services:

"CAMHS but it takes too long."

"I would call our social worker, but wheels turn slowly!!"

"Carers support/social prescribing - but on contacting them was told that it is 7 month wait!"

"Social services and ask for an assessment, however it all takes too long."

"There isn't anywhere there is no personal touch anymore they don't know people personally."

Selected comments relating to feeling unheard when they accessed a service:

"When I did ring Caring for Carers one day when I felt I needed to talk to someone the lady who answered neither 'heard' or understood or cared and offered nothing. Chocolate teapot! The C for C emails aren't very helpful since I can't attend any of their arranged programmes."

"The attempt at support that was previously offered and took ages to find disappeared rapidly as previously mentioned. Doctors are not interested, do not offer advice or help and the carers based at Mayfield have not answered emails, so I gave up with them 2 years ago."

"I have spoken to Devon Carers many times. We also contacted Rowcroft when dad was sent home on end of life. No meaningful response from either. Rowcroft finally pitched up to help minutes before he died!"

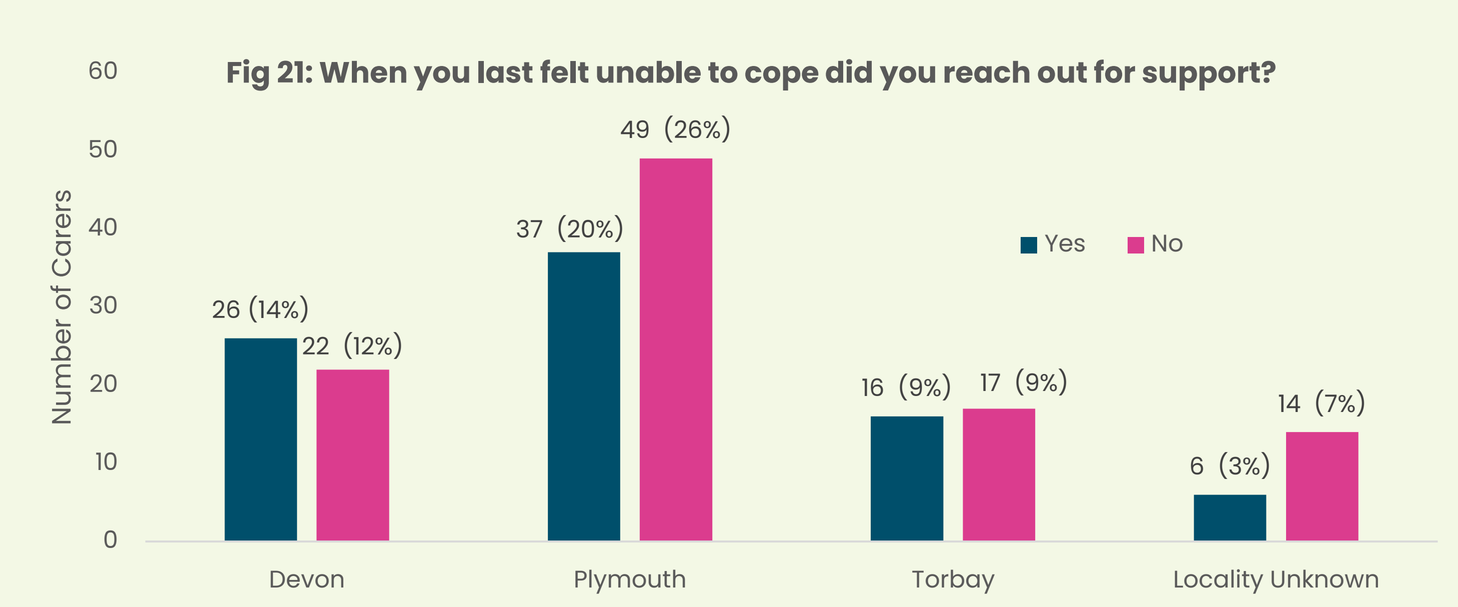
Question 21: When you last felt unable to manage, did you reach out for support? *(Including medical/ mental health support)*

187 Carers (83% of the total cohort) responded to this question. Of those:

- 85 Carers (45%) replied 'yes', they did reach out for support
- 102 Carers (55%) said 'no' they did not.

Fig 21 provides a breakdown of the results from Carers in each locality.

Observation: The results show that in Devon more respondents reached out for support compared to those that did not. In Plymouth less Carers reached out than those who did not and in Torbay the results were about the same.



Question 21A: If yes, why?

95 Carers (42% of the total cohort) responded to this question. 13 of those had tick 'no' to question 21. The main reasons given for not reaching out for support were:

- they did not feel it was necessary
- did not have time,
- did not feel they would be heard.

Of the 82 Carers who ticked 'yes', the main reasons they shared for why they reached out for support were:

- Recognition of a decline in their mental / emotional health (45 Carers)
- To avoid reaching crisis point (19 Carers)
- Frustrations with the health and social care system (9 Carers)
- Seeking help for the person they care for (3 Carers – *1 needed adaptions/assessment, 1 was no longer able to meet cared-for's needs, 1 required a transfer to adult social care*)

Selected commentary from these carers are on the next page.

Recognition of a decline in their health and wellbeing

Almost half of the Carers who responded to question 21a described how they reached out for help when they recognised that they were struggling with their own emotional, mental or physical wellbeing, due to overwhelming circumstances and the inability to cope alone at that time. Many mention health issues - both mental and physical - that necessitated seeking support so that they could continue their caring roles and for some who mentioned it, their employment. Selected commentary includes:

"Because I didn't know what else to do and was afraid my ability to care would be affected."

"Because I was unsure of what was causing my symptoms and was experiencing stress at work."

"Because it was affecting my mental health which in turn affects my cared for because my health was at risk, and that meant the people I care for were also at risk."

"I reached out for mental health support because I was tired of being so upset and frustrated all the time."

"Mental breakdown and signed off work - needed a change in medication and break from work stress to enable me to care effectively."

"I was emotionally exhausted , tired and became physically ill which enforced rest and recovery. Supported by my GP."

To avoid reaching crisis point

Crisis management was another common reason for Carers seeking support. Some Carers described reaching out before their situations could escalate into potential crises, highlighting the importance of timely intervention. Selected comments include:

"I tend to contact the care coordinator if things do go downhill - before it gets into crisis mode."

"Because I have to be OK to get through, there is no alternative and reaching out meant I could carry on."

"I couldn't carry on I was at breaking point with 3 care roles. I spoke to GP, DPT."

"I was concerned about our general welfare and safety."

Frustrations with the health and social care system

Systemic challenges were another reason for Carers to reach out for help. Frustrations with the health and social care system, a lack of support, and 'feeling invisible' were common themes among the respondents. Selected commentary includes:

"Because I couldn't get anyone to give me an answer around an operation my daughter was waiting for and the complete lack of any help was reducing me to tears even at the thought of ringing again to try and get answers."

"Concern for safety - rang Adult social care but gave up after an hour on hold."

"No choice I had no where else to go... I was on my last legs...but was not listened too. Help was yet again given to my husband and not me. I feel invisible!"

"We contacted the GP to arrange a memory assessment for the person cared for as it is obvious there is dementia. After assessment, they said there was no funding for an admiral nurse in our area East Devon. There is no practical support enabling me to get a rest."

"We were too scared to ask for help due to the behaviour of the social workers in our home who were meant to be assessing the cared for person and when I for instance broke down and cried in front of them and I was called pathetic and one said you'll be pretending you have mental health issues next."

Question 22: Is there anything that did make a difference to you?

115 Carers (51% of the total cohort) responded to this question. Of those:

- 98 Carers (84%) replied 'yes' and 80 Carers (70%) provided details as to what made a difference to them.
- 17 Carers (15%) replied 'no'.

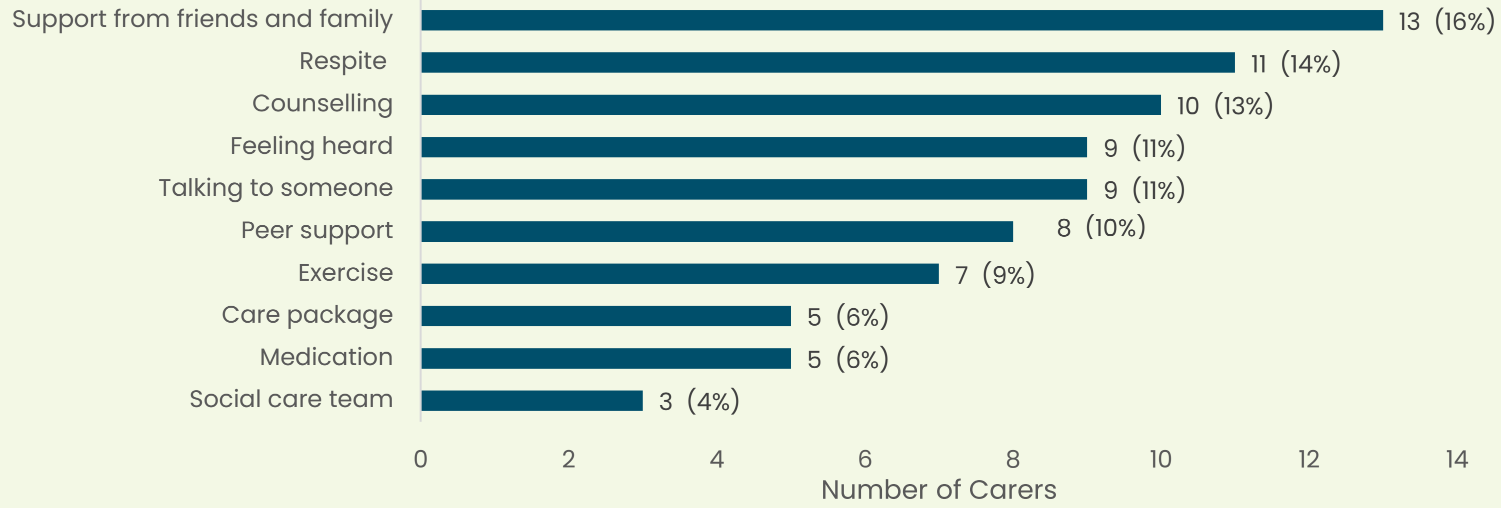
The most common responses from Carers were:

- Support from family and friends – 13 Carers
- Respite – 11 Carers
- Counselling – 10 Carers
- Talking to someone – 9 Carers
- Feeling heard – 9 Carers

Other factors that made a difference that were mentioned by less than 5 Carers were: a care package for the cared for person(s), love for the cared for person, practical help, arts and crafts, self care, their faith and acceptance of their situation.

Fig 22 provides a breakdown of the most common responses. **There are no significant geographical anomalies to highlight.**

Fig 22: Things that made a difference



Selected commentary includes:

"Without my family, possibly both of us would not be here. There is no other coherent support for our situation."

"TalkWorks helped me to change how I view / think about things - it has made it a lot easier to cope with the challenges I face now."

"Historically yes, Social Prescriber made a big difference - but 8 weeks of sessions and it ends - and then nothing. Need this to feed into something like a support group."

"Joining groups who understood and going out to events and functions."

"Speaking to Caring for Carers."

"Being taken seriously, respected, listened to and having a response that I could work with."

"The nurses. They have always cared and believed me. They are the ones who make me feel less alone with it even if they can't help with diagnosis/treatment."

"Very good, compassionate doctor who understands my illness and pressure stress I'm under and their illnesses. Social worker actually completing tasks, being able to ring improving lives and some financial help from the Carer's fund."

"I did get contact via the telephone from a carers support worker until about 18 months ago, and he was able to get me a carers respite break payment to go on a short holiday with my child."

Question 23: Do you use coping mechanisms?

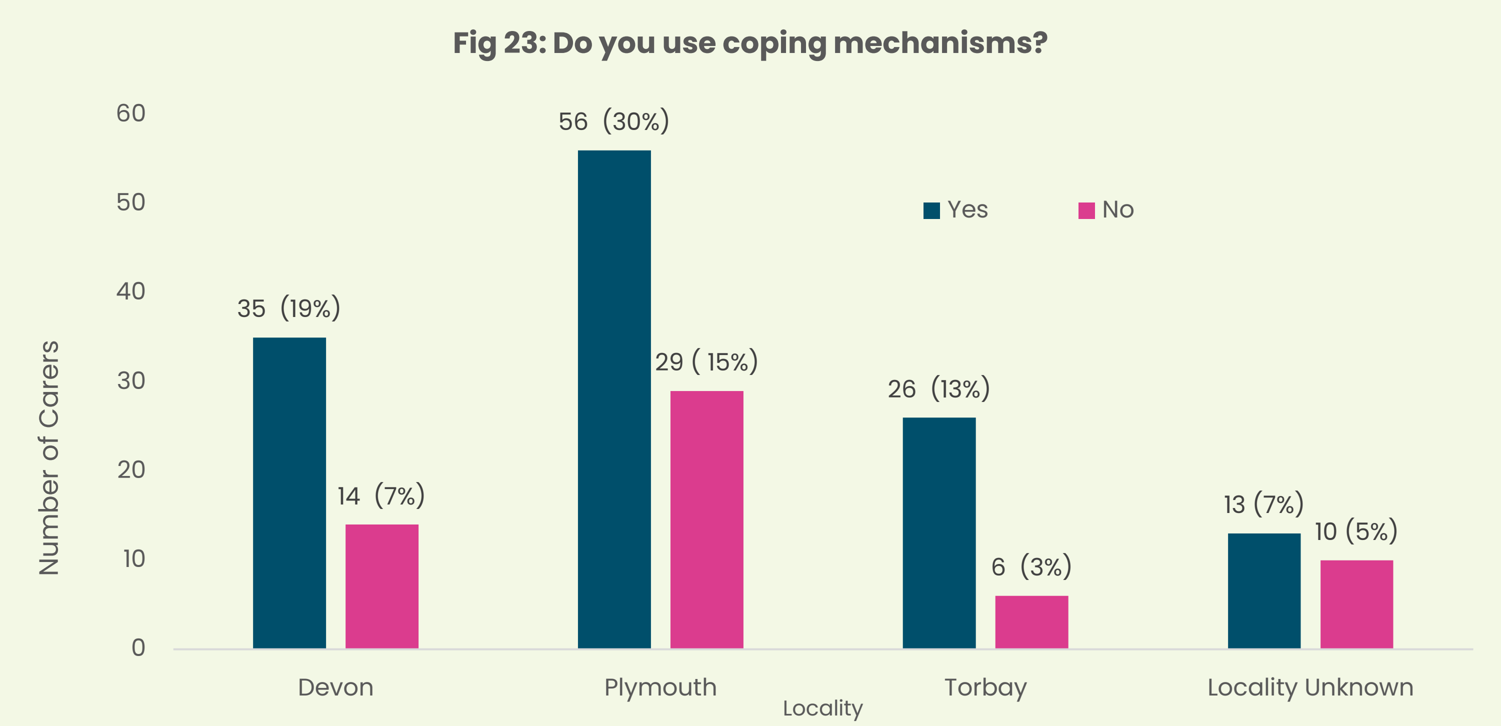
189 Carers (84% of the total cohort) responded to this question. Of those:

- 130 Carers (69%) said 'yes', they do use coping mechanisms and
- 59 (31%) said 'no' they do not.

Fig 23 provides a breakdown of the responses by locality.

Observation: The results show that within each locality the proportion of Carers who do use coping mechanisms is higher than those who do not, more noticeably in Torbay.

There are no anomalies to highlight in relation to length, of time caring, age category, or whether the Carer lives with the persons(s) they care for or not.



Question 23a: If yes, what do you find works well?

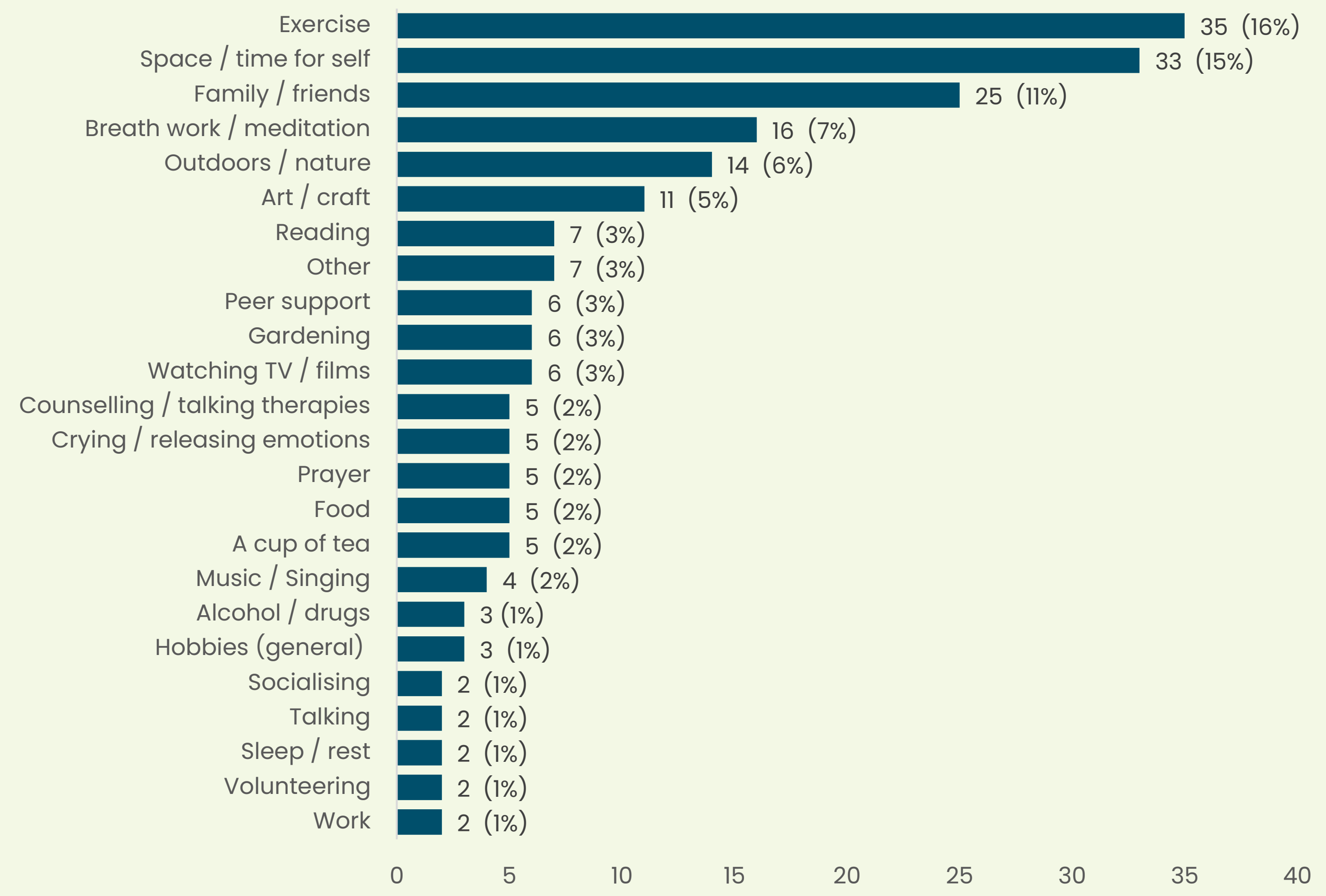
119 Carers (53% of the total cohort) responded to this question. Some Carers shared more than one suggestion. There were 219 suggestions in total.

The top 5 coping mechanisms that Carers shared were:

- Exercise (35 Carers / 16% of total number of respondents)
- Having space / or taking time away from the situation (33 Carers / 15%)
- Family / friends (25 Carers / 11%)
- Breathwork / meditation 16 Carers / 7%)
- Being outdoors / in nature (14 Carers / 6%)

The responses were themed, and the results are provided in Fig 23a (overleaf).

Fig 23a: If you use coping mechanisms what works well?



Selected commentary includes:

“Running. It's kept me off anti-depressants all these years but gets harder to do with age and with some health issues I have now.”

“Nothing works well, but certain things can alleviate the stress and symptoms, like a good night's sleep, walking with my dogs, friends, peer support.”

“Walking around my garden and breathing. I go to Devon Carers monthly peer group locally when I can. I find the online cuppas from Mobilise really helpful as they are just drop in for 45 mins and they run them every weekday. Feels like there is always someone out there.”

“I talk to my family and they to me. I smile. I try and stay as positive as I can and I hope for change. In the meantime, I work with what I have and that is an amazing family.”

“The replacement care can offer me a chance to relax while my cared-for is with them - but sometimes it backfires as sometimes their involvement ends up adding to my list of headaches - it's hard to explain why. I think it's because their role is limited - they need to refer to me to get things done and it can occasionally generate more 'administrative' work time for me organising things and activities for them.”

“Time in nature. Reading. Getting away from it all alone for a couple of days - can't afford it nor risk it at the moment.”

“I make sure the person is safe and walk away into another room for a while! Or I take her out just to be out in contact with others.”

“Take a time out in the garden on my own to gather my thoughts and think how it could be worse. This enables me to regain perspective of my situation.”

“Staying up until three in the morning on a daily basis to get some free time, me time and relaxing time for my own mental health and to wind down at the end of the day. This is the only thing to work for me, knowing that my wife is safe and sound asleep in bed at the same time.”

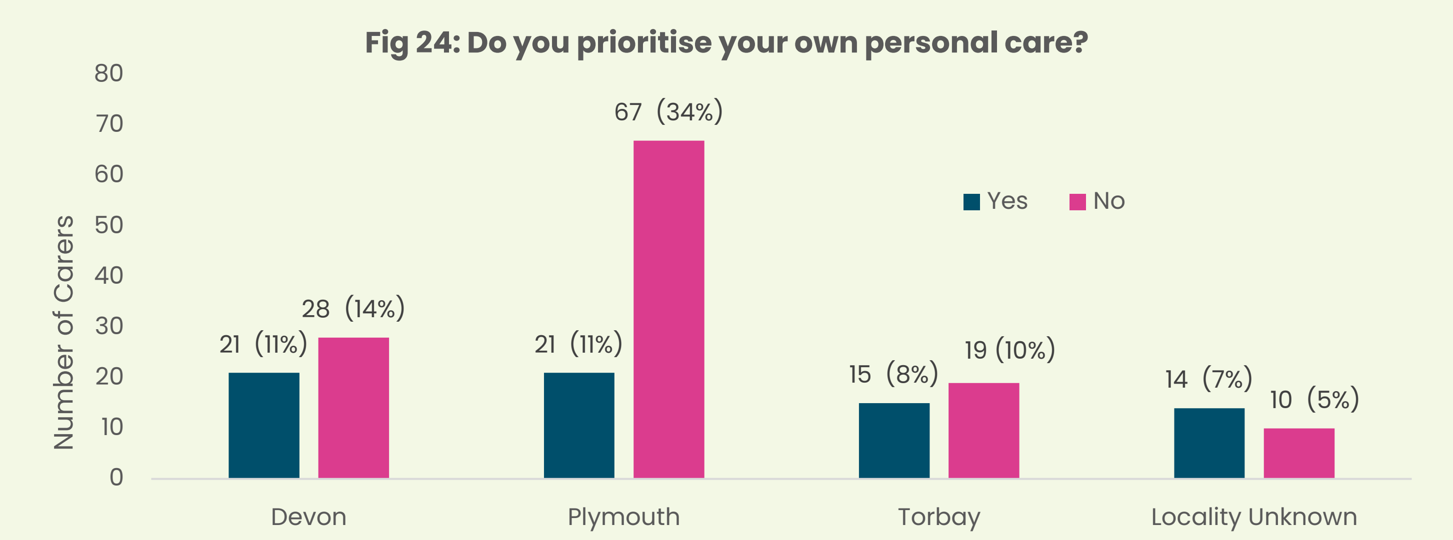
Question 24: Do you prioritise your own personal care?

195 Carers (87% of total cohort) responded to this question. Of those:

- 71 Carers (36%) replied 'yes', they do prioritise their own personal care
- 124 Carers (64%) replied 'no', they do not.

Fig 24 provides a breakdown of the responses across each locality.

Observation: In Devon and Torbay, the proportion of Carers who prioritise their own personal care is slightly lower than those who do not. In Plymouth, the proportion of Carers who do prioritise their own personal care is considerably lower than those who do not.



Question 24a: If no, what stops you?

116 Carers (52%) shared what it is that stops them from prioritising their own personal care. The most common reasons for Carers not prioritising their own personal care were a lack of time and no energy with many Carers commenting that they prioritise the needs of the person they care for above their own personal care needs. Comments were categorised by the following themes.

Time and Energy Constraints: A common theme is the lack of time and energy, which makes it difficult for Carers to focus on their own wellbeing. Some quite simply said 'time' or 'energy', others mentioned health issues that also impacted on their own abilities to maintain their own personal care.

Caring responsibilities: Many Carers commented that their caring role took precedence over their own personal care needs.

Neglect of their own personal care : Carers often mentioned neglecting their physical health, mental health, and hygiene due to the demands of caring for someone else and their commitment to putting their needs before their own.

Selected comments from carers responding to this question are on the next page.

Selected commentary relating to the Carer's caring responsibilities:

"Always think I'll get to the end of husband's current list of appointments/ needs and then I'll attend to my own. But that doesn't seem to happen. I'm not as energetic as I used to be."

"The person I care for needs comes first - he is unable to do anything for himself and is totally reliant on me."

"It's impossible to prioritise me. My husband does not prioritise himself either. That is just how it is for us. Again, I am hopeful that this will change as the older grown-up children are now playing a huge caring role themselves alongside their own careers and lives."

Selected commentary relating to time and energy constraints:

"Their care needs. Balancing 3 jobs and caring leaves no time for me."

"No energy for myself. It all goes on fighting for my adult children. They come first."

"Time, energy, lack of financial resources, lack of support."

Selected commentary relating to neglect of their own personal care:

"Feeling like I have nothing left for myself."

"Worry, anxiety, lack of quality and consistent sleep and exhaustion from care roles. Feeling I am on duty 24/7 I noticed I didn't keep up with my hygiene and appearance."

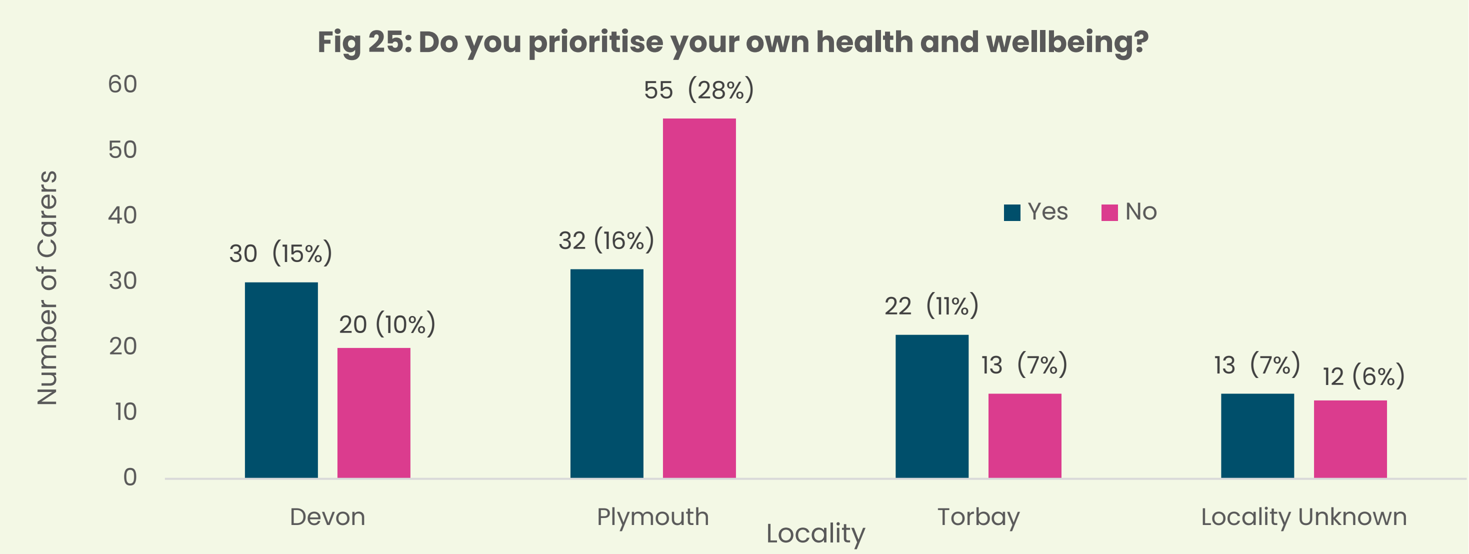
Question 25: Do you prioritise your own health and wellbeing?

197 Carers (88% of the total cohort) responded to this question. Of those:

- 97 Carers (49%) replied 'yes', they do prioritise their own health and wellbeing and
- 100 Carers (51%) replied 'no' they do not.

Fig 25 provides a breakdown of the responses across each locality.

Observation: In Devon and Torbay, the number of Carers who prioritise their own health and wellbeing is higher compared to those who do not. However, in Plymouth, the number of Carers who do not prioritise their own health and wellbeing is noticeably higher than those who do.



Question 25a: If no, what stops you?

92 Carers (41% of the total cohort) responded to this question.

Prioritising the needs of others before their own: this was the most common reason that Carers gave for not giving priority to their own health and wellbeing needs, leading them to neglect of their own personal health. 29 Carers provided this as a barrier. Selected comments include:

"Appointments for the person that I care for seem to come at the same time, so I have often had to cancel my own and then give up trying to make any."

"Can't leave my daughter with anyone and have to fit my life around hers. Can never be sure how she is feeling day too day, so find it hard to make plans."

"Constant caring with no break no respite and no one to cover me. Carers allowance isn't enough."

"Nothing can be planned due to the person we care for unpredictability. We cannot plan anything, and most apps get cancelled."

"Focusing on hubby's needs. When it's serious I'll sort it, but usually wait until I know it's serious."

Time and energy constraints: Lack of time and /or energy was the second most common reason provided by Carers for not prioritising their own health and wellbeing. 25 Carers cited this as a factor that stops them. Selected commentary includes:

"There isn't enough time. I haven't had my bowel cancer check; I haven't done my well persons check."

"Time and its overwhelmingly difficult and draining to make appointments and navigate the system."

"Time, exhaustion, had enough of medical appointments with my cared for - so don't want to go to Docs for myself with what little time I get. Hard to get out of house to go to appointments."

"Finding the time or finding someone to sit with the person I care for while I go to an appointment."

Access to Healthcare services: Difficulties in accessing healthcare services, such as getting GP appointments or dental care, were mentioned by 12 Carers. Selected comments:

"Difficulty getting to see GP. They tend to prioritise husband rather than us both together."

"I'm too afraid to go on my own, I can't make appointments myself either these days because you can't just go and speak to someone. My dentist isn't NHS anymore and I can't afford private care."

"Not enough appointments available when I am not working or caring."

"When a hospital appointment comes through, I do my very best to make that appointment and not cancel or rearrange because it is so hard to get hospital appointments these days and you have to grab your chances when you can."

"I would have to be in real need - the time-consuming business of trying to contact a doctor now just puts one off. I self medicate and hope for the best."

Emotional Barriers: Feelings of guilt, low self-esteem, and fear of negative consequences (like hospitalisation) were also reasons that prevent 9 Carers from seeking help for themselves. Selected commentary includes:

"When you prioritise everyone else it's hard to find motivation for self care."

"I ignore any ailments and just get on with it! Until my back became too painful to ignore then I had to see about it."

"Medical - yes but afraid if I raised concerns with doctor I might be sent into hospital - catastrophic for my wife's wellbeing."

Question 26: What would enable you to prioritise your own health and wellbeing?

118 Carers (53% of the total cohort) responded to this question. Some provided more than one suggestion that described what would help them to prioritise their own health and wellbeing. These are detailed below.

To have a break or time for themselves / respite: The most common response from Carers was more time for themselves or a break from their caring roles. 37 Carers said that time / a break / respite would enable them to focus more on their own health and wellbeing needs. Selected commentary includes:

"More time for me. To be able to go out and not have to worry how long I'm going to be."

"More time, being able to give up work and be able to focus only on my caring roles."

"Proper respite (being allowed to use his Direct Payments to pay for respite at time that suits us)"

"Some respite where I can concentrate on myself and not have to worry about anyone else."

More support for themselves and for the person they care for: 29 Carers expressed a need for more support and better paid / practical care provision to help them and the person(s) they care for achieve a better quality of life. Selected comments include:

"Night sitters/sleepers that wouldn't cost a fortune."

"Better support service from GP/NHS"

"Extra paid support to pay extra / other specialist carers to care while we go to apps / out etc."

"Extra practical support to ease the care burden. Mental support from the physical presence of an Admiral Nurse."

"For my mother to have someone else to express her views and constant negativity to, to take her out, to have a local community centre for her to go to in her area."

Better access to health and social care services: 12 Carers said that easier and quicker access to appointments and health checks would help them to better manage their health and wellbeing. Selected commentary includes:

"Better access to medical, dental and health professionals. Priority as carers."

"Better access to healthcare. 4 weeks wait to see an audiologist when my hearing aids are not working properly!"

"Had cancer last year- chemo and radiotherapy. Under oncology. Still waiting for counselling. Never heard from a GP."

"Having local glaucoma check-ups instead of having to go into Exeter."

Financial support: 11 Carers said more financial help would enable them to prioritise their health and wellbeing. More affordable care services was also mentioned as a factor.

Making self care a priority: 9 Carers suggested that practicing self care would benefit them.

15 Carers made other suggestions, such as not being in the situation they are in, being more organised or being able to talk to someone. 14 Carers were not sure what would help.

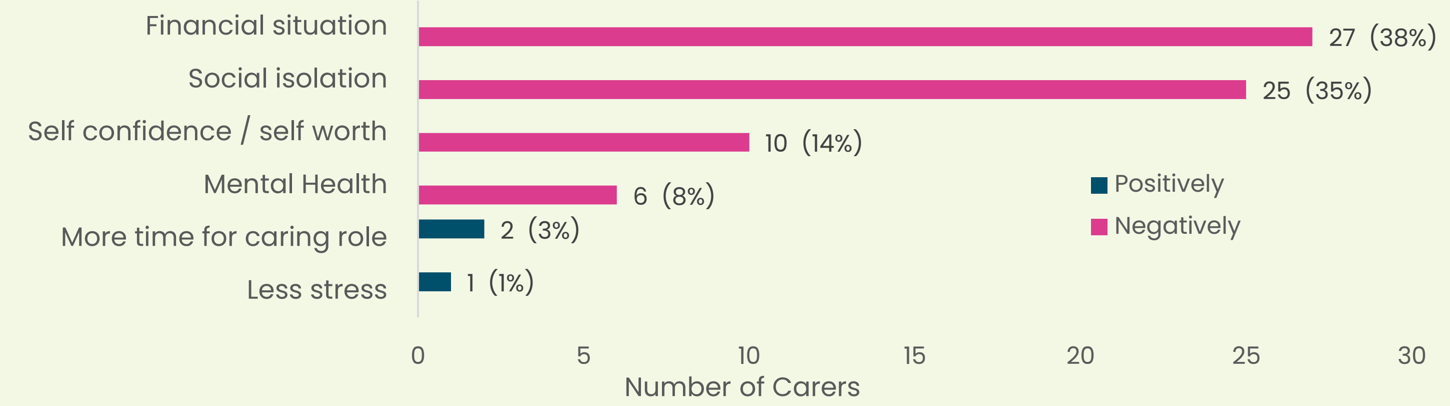
Question 27: If you had to give up paid employment or reduce hours, how has this impacted on your wellbeing?

71 Carers (32% of the total cohort) provided a response to this question. The top 3 things that Carers said had negatively impacted on their wellbeing include:

- **Their financial situation – 27 Carers** (12% of the total cohort)
- **Social isolation – 25 Carers** (11%)
- **Self confidence / self worth / purpose - 10 Carers** (4%)

Fig 27 provides a breakdown of the most common themes. Selected comments are below.

Fig 27: How has giving up employment or reducing your hours impacted on your wellbeing?



“It impacts financially. Unable to work full time, unable to claim CA because of part time work, but need to work for my own mental health.”

“It has lowered my self esteem and left me anxious and depressed. It has impacted our family financially.”

“Feel unproductive as not contributing financially. Demoralised as have to ask for money. Lonely as no social life or others to talk to. Seen by others as not working so lazy which is crushing.”

“Reduced my income significantly, so less able to do anything non-essential. Also, work was a break, its a sociable job. Being at home more is very isolating.”

“I wish I worked again a normal job to be able to have set holiday leave and mix with my own age group. Also, financial security. Its horrible having little money and having my finances stopped if they are in hospital longer than a month.”

“I loved my job. it was everything to me. I feel like I lost a big part of myself. As well as losing my financial independence. We are jointly assessed for Universal credit - he doesn't get it due to his pension and his pension stops me getting it too. I am 62 and my only income is my carers allowance.”

“Well, I don’t have a career/job and therefore no pension and no hope of money to do things that I want which is a lifelong negative impact on my wellbeing. As well as the fear of what will happen when I die.”

“Affects one’s mental health and makes you feel isolated and trapped.”

“I feel somewhat cut off from the outside world and that I don't have a life of my own anymore.”

“I miss the structure of a working day, the camaraderie, job satisfaction.”

“I feel I've lost myself! I'm just a Carer not a person in my own right.”

“It killed our well-being. It stripped us of our pride, self esteem and confidence.”

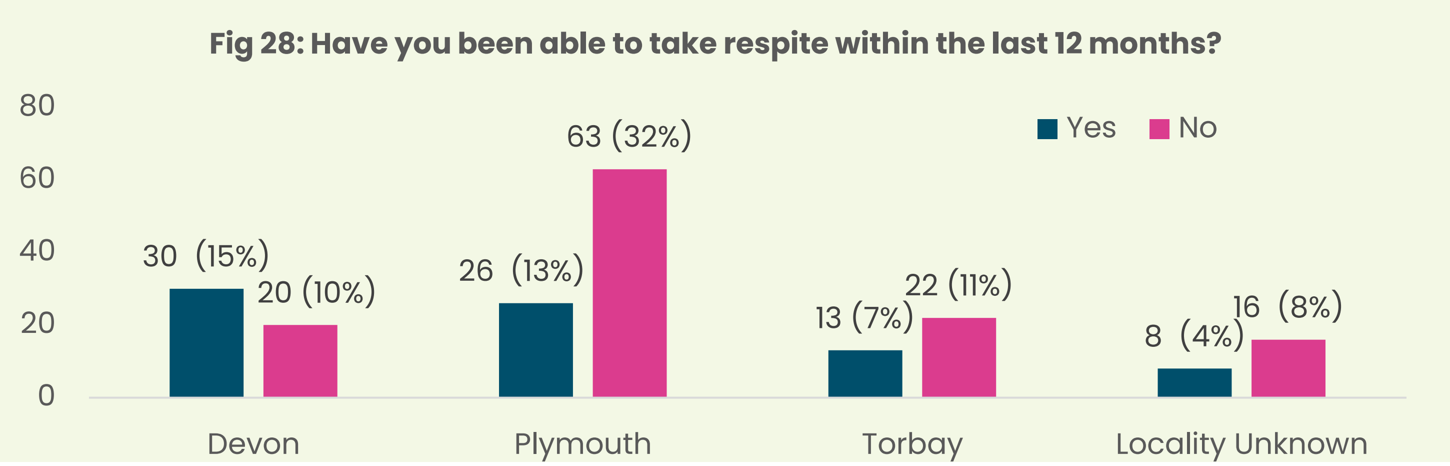
Question 28: Have you been able to take a break or respite in the last 12 months?

198 Carers (88%) responded to this question. Of those,

- 77 Carers (39%) replied 'yes'
- 121 carers (61%) replied 'no'

Fig 28 provides a breakdown of responses from each locality.

Observation: The number of Carers who said they have been able to take a break compared to those who have not is slightly higher in Devon and slightly lower Torbay. In Plymouth the proportion of Carers who have been able to take a break is considerably lower compared to those who have been able to take a break.



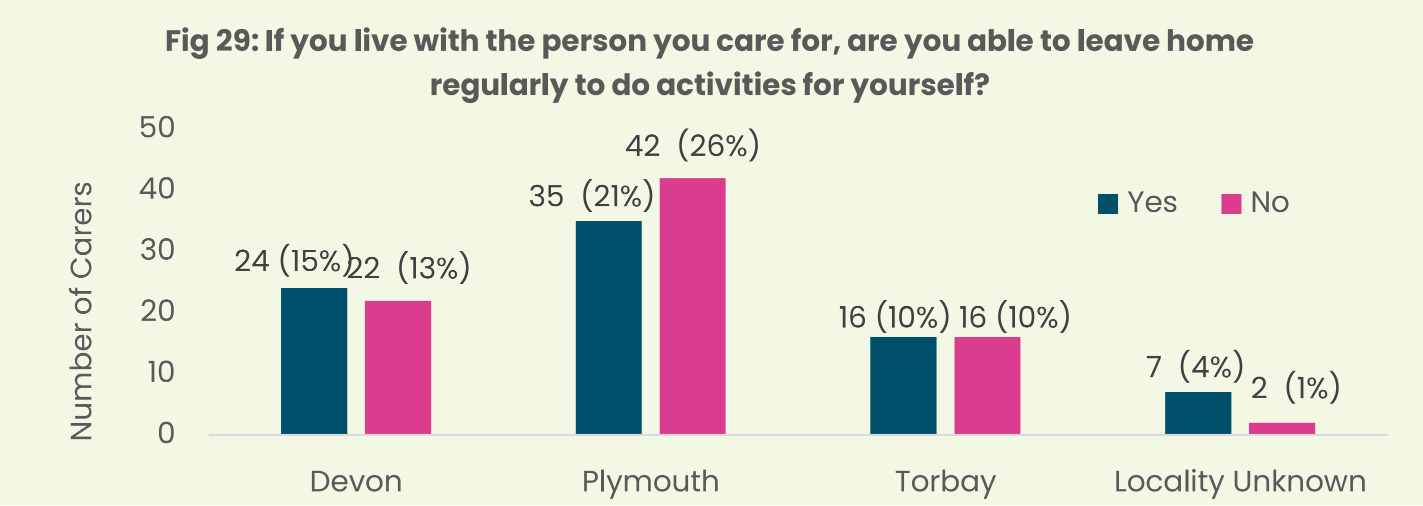
Question 29: If you live with the person(s) that you care for, are you able to leave home regularly to do activities for yourself?

164 Carers (73%) responded to this question.

Of those, 82 Carers (50%) replied 'yes', they are able to leave home regularly to do activities for themselves. 82 Carers (50%) said 'no' they are not able to.

Fig 29 provides a breakdown of the responses across each locality.

Observation: In Devon, the number of Carers who said they were able to leave home regularly is slightly higher compared to those who are not able to. In Plymouth the number who said they can leave home is slightly lower.



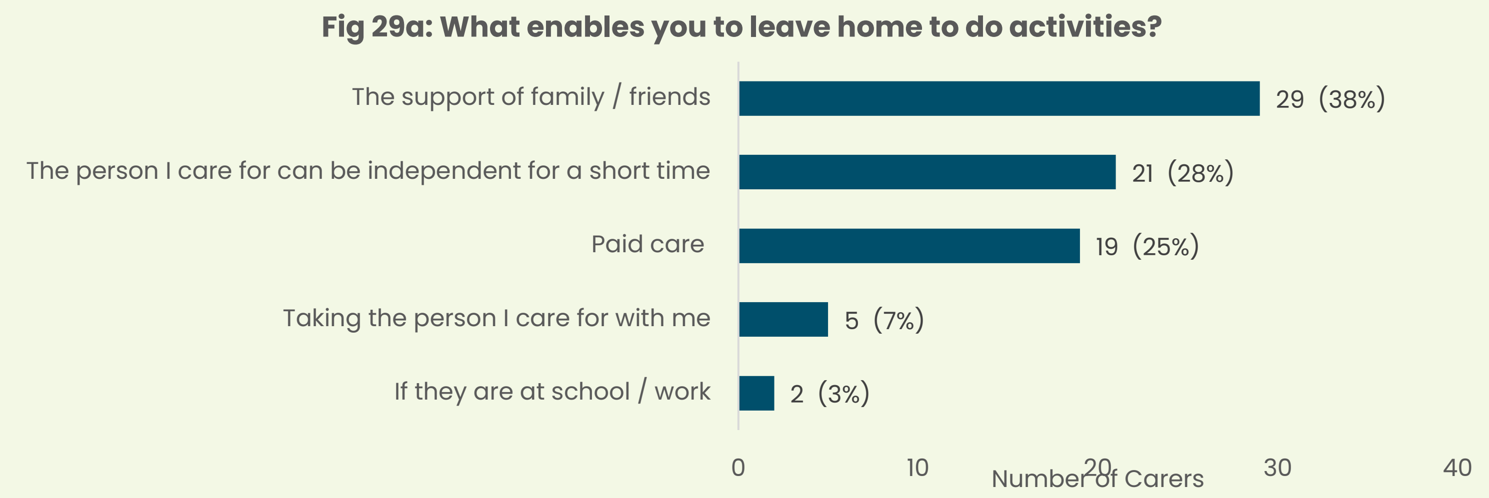
Question 29a: If yes, (you are able to leave home) what allows you to do this?

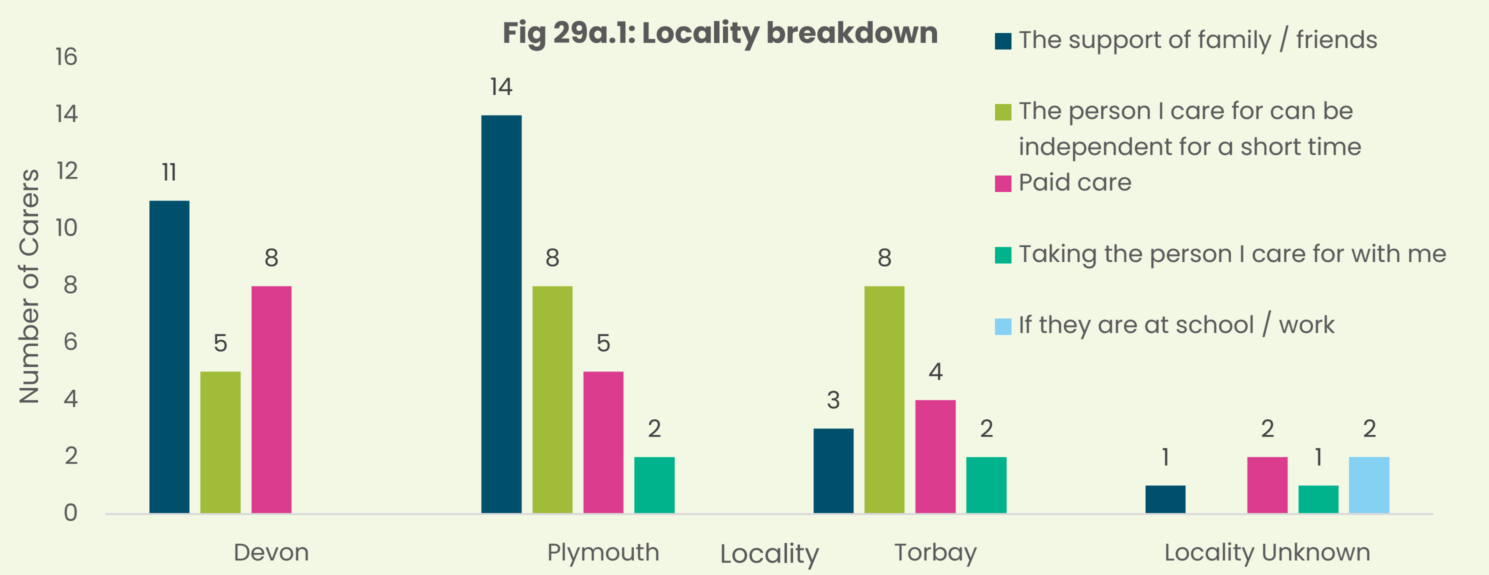
76 Carers (34%) provided details as to what enables them to leave the house. Of those,

- The highest number of Carers (29/ 38%) said the support of family and / or friends enables them to do this.
- 21 Carers (28%) the person they care for can be unaccompanied for a short space of time.
- 19 Carers (25%) said they can leave the home with the help of a paid care worker or enabler
- 5 Carers (7%) said if they take the person(s) they care for with them and 2 (3%) said if the person they care for is at school or work.

Fig 29a provides a breakdown of the responses overall and Fig 29a.1 provides a breakdown of responses within each locality.

Observation: Numbers are small therefore no significant anomalies to highlight. Variations in the results across the localities are fractional.





Several Carers provided commentary to explain their situation. Some Carers mentioned that they took it in turns with their husband / wife to have a break, which meant that they were limited as to when they could do activities together. Others, who could leave the house with the person they care for mentioned that they would do activities to suit the cared for person rather than what they wanted to do. Selected commentary included overleaf.

"Support from friends coming to the home to enable me to go out and my care recipient encourages me to take time away, even if it is somewhat short in timescale."

"I do leave him to go to W.I. meetings. He has an emergency button but always feel a bit guilty."

"I can leave Dad on his own for a few hours, but I don't feel I have enough time to meet my friends and relax. I feel I have to prioririse everything Dad needs over my own to keep up with everything that has to be done.

"Sometimes when we have paid carers, but only at times that suit the service, we're not allowed by Direct Payments to save up hours to go away for weekend for example, even though some of the carers wouldn't mind that occasionally. Family not local, only use them in dire need (e.g. other family member ill)."

"Day service for my daughter but fighting to keep this. No family nearby, so means my husband and I don't do much as a couple."

Question 29b: If you are not able to leave the house, what impact does this have on your own physical and mental wellbeing?

75 Carers (33% of the total cohort) provided a response to this question. Most of the Carers who responded described the negative feelings they have if they are unable to leave the house. The most common feelings expressed were:

- Loneliness (due to social isolation) (22 Carers)
- Anxiety / depression (13 Carers)
- Tiredness / fatigue / drained (12 Carers)
- Frustration / resentment (5 Carers)
- Sadness (3 Carers)

Other feelings Carers said they experienced because of not being able to leave the house include; hopelessness / despair, guilt, trapped, stressed. Some Carers described how it was having a negative impact on their overall physical and mental health and wellbeing. One Carer said, *"my physical health is getting worse"* another said, *"my health is failing I don't want to live this life anymore"*. Further selected commentary includes:

"It has had a massive impact on my physical and mental wellbeing with my husband and I talking of separation many times."

"Not being able to go away on holiday or a break is hard. I feel angry at my dad because that's what's stopping us but then guilty that I feel like that. There's nothing to look forward to. It makes me feel low and jealous when I see others go away. "

"Huge impact. I am isolated, bored and constantly stressed. I have children who cannot leave the house and can't be left alone. As a widowed parent I am trapped."

"I feel lonely, very isolated. I am not very fit as it is hard to go out and if I do only for short durations so do not get to have a nice long walk. My mental well-being is poor, I cry frequently."

"I often feel depressed and lethargic, and sometimes I feel like opting out."

"It's very tiring, both mentally and physically. It affects my mood and I have noticed a decline in my physical health."

"Causes me to get stressed and resentful. Causes problems between my husband and I."

"Frustration. Anxiety. Resentment. Sadness."

Question 30: What would need to change for you to take a break or go out?

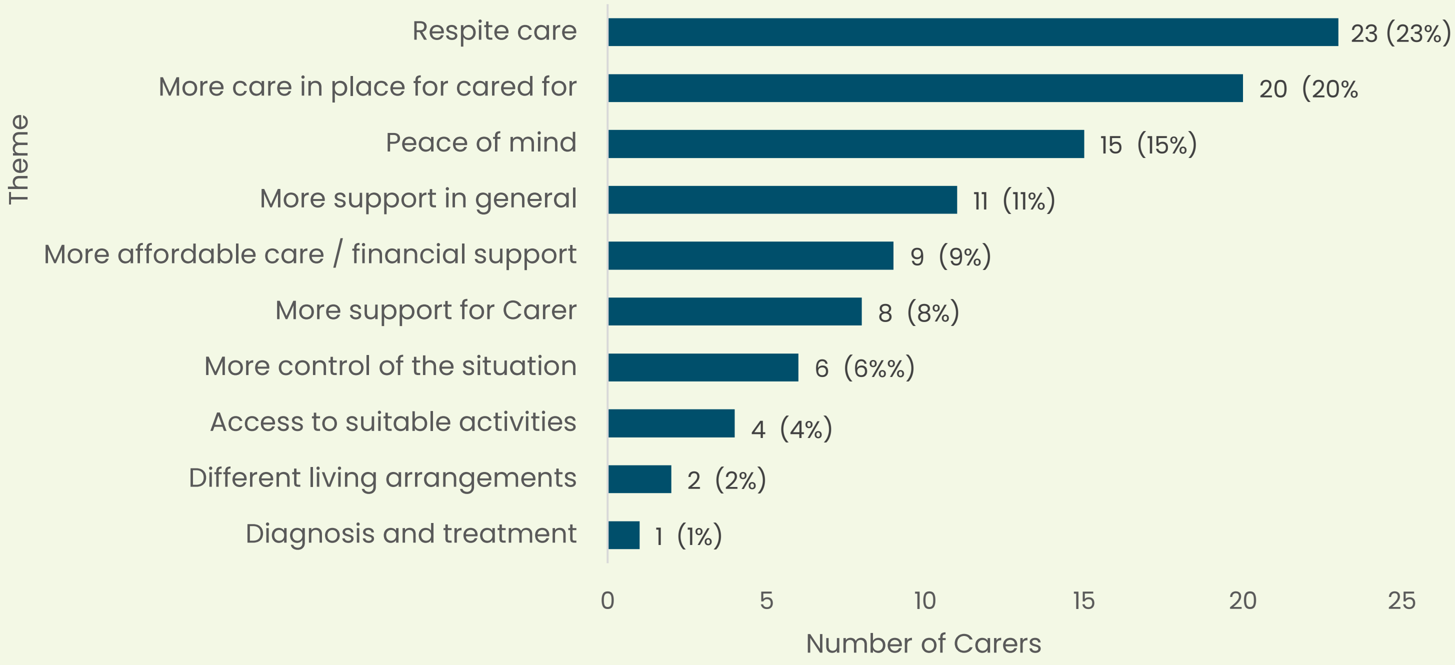
99 Carers (44% of the total cohort) gave a suggestion in response to this question. The most common responses were:

- Respite care (23 Carers)
- More care in place for the Cared for (20 Carers)
- Peace of mind (15 Carers)
- More care and support in general for both the Carer and Cared for (11 Carers)

Fig 30 provides a breakdown of the themes that the suggestions relate to. A further breakdown of the themes by locality is available in appendix 2.2.

Observation: The most common response from Carers in Plymouth and Torbay was respite care. In Devon the most common response was having more care in place for the cared for person(s).

Fig 30: What would need to change for you to take a break or go out?



Respite / replacement care to enable Carers to have a break: Many Carers expressed a need for more support for the person they care for, to allow them some respite time to enable them to engage in outside activities with peace of mind / without worry. Selected commentary includes:

“Have someone stay with my care recipient to allow me to relax if I am away from home, who I know and trust to provide the support that my family member requires.”

“Direct Payments being more flexible with how it is used (supposed to be used for set times/days, if they get missed through sickness or lack of support being available, we can’t use it to fund respite breaks. The money is recalled if not used. His days out are seen as our respite (which they are and we are grateful for that) but it doesn't allow us to attend a wedding away or have a night out or weekend away on our own. We don't go out at night on our own due to caring for son.”

Question 30 (continued)**: What would need to change for you to take a break or go out?**

More suitable care and support for the Cared for: Many Carers expressed a need for more care and support services for the person they care for, including paid carers, sitting services and facilities in the local community that are safe, reliable and affordable.

Selected commentary includes:

"More regular practical support. Overnight care enabling me to sleep for 8 hours, and not have to deal with the persons calling out, falling out of bed, demands for food a cooked meal and entertainment at 2am, and they sleep during the day and still expect me to work through the day to care for them."

"My wife getting the mental health support she needs, that may improve her, my and our situation. If anything happened to me, she would need astronomical amounts of support, I do not think that she is capable of living on her own, it wouldn't be safe for her to do so."

"Only more paid specialist carers - but nobody can come into our cares for persons home while he lives with us (due to his reaction to staff / carers he does not know & how he reacts afterwards in our home) which is just too dangerous and not in his best interests - so in reality the only way this could be achieved would be if he had his own house with carers going in - but this would mean 8 rolling staff & his own private safe quite large house... and that's not possible on his current support."

Peace of mind: Several Carers said a change they would need is for them to feel less anxious, have more control over their caring situation and for their loved one to be stable and well supported with safe and reliable care and support in place. Selected comments include:

"Knowing she was safe and happy without me."

"Would need to be confident my charge would not be anxious about my absence or when I was returning."

"Mother would need to allow a stranger in, and I would need to feel totally comfortable leaving her alone with them. I would rather not bother because I would be hearing about it every day thereafter because it stresses her too much."

"My own anxiety issues."

Financial support / affordable care and support: Carers mentioned the need for more financial support to afford more stable, reliable and affordable care and social support in the community. Selected commentary includes:

"If I had funding to pay an enabler to support the person I care for."

"To be able to go out for longer periods or an evening we have to pay privately and to expensive."

"Afford more childcare. But 1-2-1 childcare for children with needs is £14 per hour."

"Someone to come in and sit here regularly. Someone I can trust, someone who knows what going on. It is unfair for the government to allow the burden of care for older people to fall on people of working age without proper compensation. I have lost thousands of pounds of income and who will support me when I need help that I can't provide for myself now."

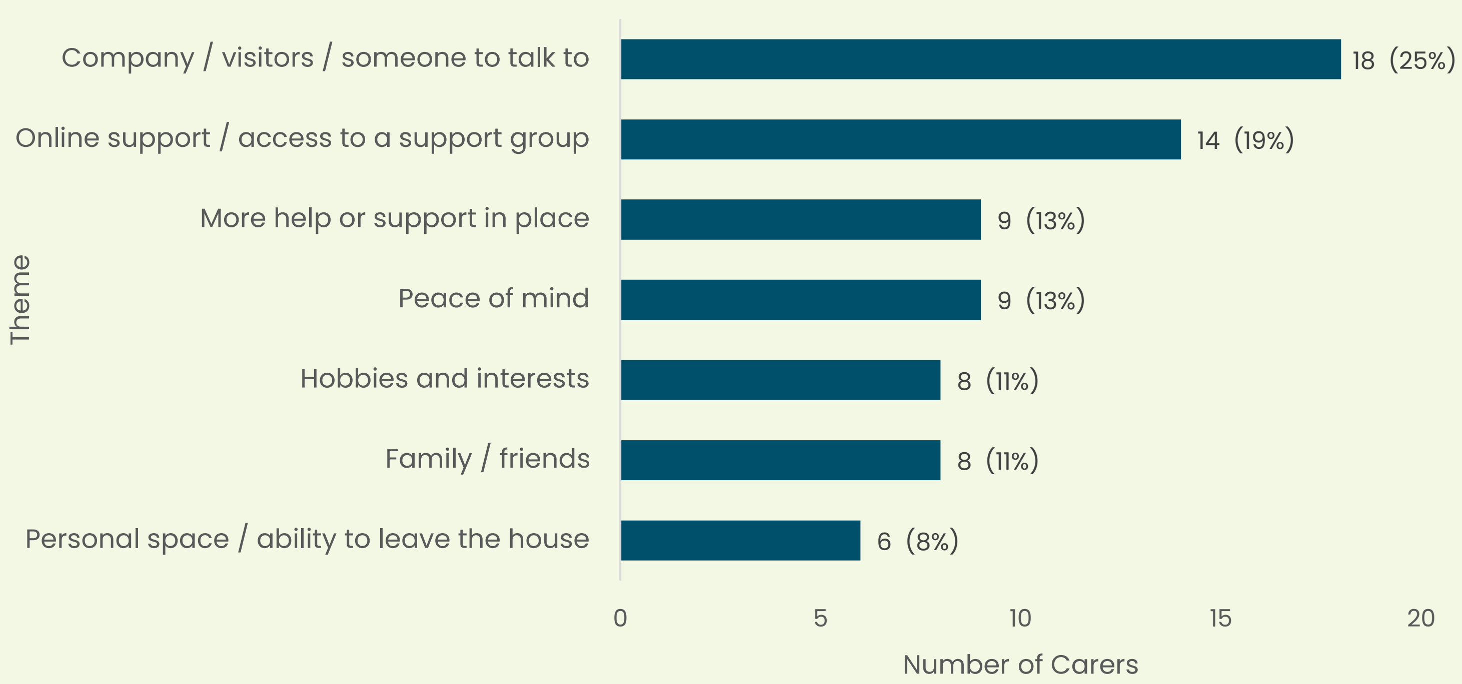
Question 31: What would enable you to feel less isolated at home if you could not go out?

72 Carers (32% of the total cohort) provided a response to this question. Of those, the most common suggestions were:

- Company / visitors / someone to talk to – 18 Carers (25%)
- Online support or access to a support group – 14 Carers (19%)

Fig 31 provides a breakdown of all responses by theme.

Fig 31: What would enable you to feel less isolated at home if you could not go out?



Selected commentary includes:

"Regular home visits from a support worker who can assist with household tasks, as well as to "offload" and talk to as a supportive friend."

"Internet access where I could call family and friends and see them."

"Online support groups, particularly online health initiatives. Maybe a free befriending service like new parents can access in some areas."

"More practical support. More carers allowance, more overnight support enabling me to sleep. Cheaper respite care £1,300 a week for a care home for respite is too much. Its cheaper for a package holiday but no one would care there."

"Linking up with others through zoom meetings. A carers network."

"I do read the carers quarterly newsletter and know in a lot of ways I am better off than some but would imagine that regular 1 -2-1 contact with a Carers Support person would be beneficial."

Question 32: Do you feel that the care you provide is affected by being unable to have regular personal time and space?

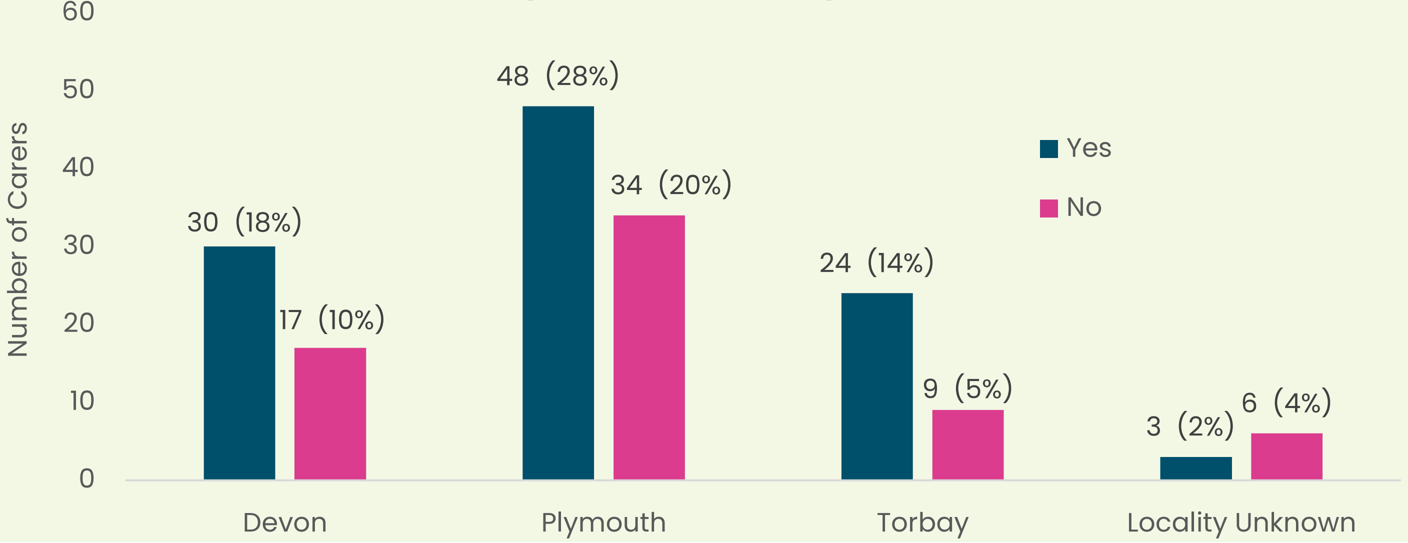
171 Carers (76% of the total cohort) responded to this question. Of those who responded,

- 105 Carers (61%) replied 'yes,' the care they provide is affected by being unable to have regular personal time and space.
- 66 Carers (39%) replied 'no'.

Fig 32 provides a breakdown of the responses across each locality.

Observation: Responses from across Devon, Plymouth and Torbay show that the number of Carers who said the care they provide is affected by a lack of personal time and space is higher than those who are not affected.

Fig 32: Do you feel that the care you provide is affected by being unable to have personal time and space?



Question 32a: If yes, how is this affecting you?

98 Carers (43%) who said they are not able to have regular space and time for themselves described the impact it was having on their life and how it made them feel. The most common themes emerging from the comments were:

- **Overall strain on their emotional wellbeing**
- **Feelings of overwhelm and hopelessness**
- **Impact on their personal relationships**
- **Social isolation**
- **Decline in their physical and mental health.**

The commentary provided by Carers in response to this question highlights the significant challenges Carers face in their day-to-day lives. Selected comments illustrating these themes are included on the next page.

Question 32a (continued): If yes, how is this affecting you?

Emotional Strain: Many Carers told us they experience feelings of resentment, impatience, and guilt, often resulting from exhaustion and the constant demands of their role. Other feelings they describe include tiredness, stress, short-tempered, impatient, irritable, drained, worried, fed up and depressed. Selected comments include:

"I am tired, stressed and low. I cannot provide the care I would like to in this state."

"I become short tempered, resentful and a real nag"

"You mentally shut down, and just learn to smile/nod/be positive when you feel anything but."

"I struggle to cope with caring when my mental health is not good, due to the amount of pressure that I am under."

"I tend to get more frustrated with situations and approach things in either a more defensive or depressed way - that can be a tricky thing when I am trying to deal with outside agencies on behalf of my cared-for. Sometimes it helps when they see how frazzled I am but, depending on the agency, it can have the opposite effect. Also, my cared-for sees my stress/distress and it upsets him - and that is not good for him, and I feel bad about that and want him to feel happier, calmer and more reassured."

"Caring is now full-time - constant supervising means it is hard to have any personal space, even to go to the toilet!"

Feelings of overwhelm and hopelessness: Carers frequently mention the difficulty of finding personal space and time for themselves, leading to feelings of overwhelm, hopelessness, desperation and burnout. Selected commentary includes:

"When I am unable to obtain regular personal time and space, I begin to feel burnt-out and overwhelmed, and therefore lacking the energy and patience required in providing the care which is needed."

"No break whatsoever. I am at breaking point with no support."

"Trapped in never ending cycle."

"I'm not so enthusiastic, energetic or motivated - stuck in a rut with no escape."

Impact on Relationships: Several Carers describe how their lack of space and time for themselves affects relationships, which has resulted in them feeling isolated, less patient, and grumpy towards their loved ones, which several then say results in them feeling guilty. Selected commentary includes:

"I'm constantly exhausted which means my tolerance is lower. By the evening I'm fed up with being around people and being touched, so need personal space both physically and mentally."

"The daily chore (and it is a chore now) of having to shower, dress and cook etc. for the person I care for takes its toll. I can't have a 'lie in' of a morning. I often feel like I'm constantly nagging and moaning which isn't fair on him, ultimately, it's not his fault that he had a stroke."

"Get depressed and blame person who you are caring for."

"I am tired and so get impatient with him sometimes - I hate that and feel guilty when I have been."

Question 32a (continued): If yes, how is this affecting you?

Physical and Mental Health decline: The physical demands and constant stress of caregiving are taking a toll on Carers' own wellbeing, with many mentioning increased physical health issues and a decrease in their ability to provide care.

Selected commentary includes:

"Feeling constantly under stress is detrimental to my health. The physical demands have increased and this is no longer good for my own well being Feeling isolated is not helpful for my mental and social well being."

"It's very hard to be patient with a child when you're exhausted and emotionally drained- though I have never hit nor would I. Sometimes, when he's really struggling and so am I, I have to dig so deep to give him the help and compassion he needs, and sometimes I can't do it as well as I want to because I have so little left in the tank."

"Of course, there are times when both my husband and I know that we could have had a better day and done things better if maybe we had been to sleep the night before but at this present time there is nothing that we can do to change the status quo. At next years review we will once again request social care and NHS CHC for more support. But the continuous explanations over the last 17 years have browbeaten us so badly and taken up so much of our lives that we are not sure can find the time to go through it all again."

Social Isolation: Some Carers also explained how they feel like they are missing out on social activities resulting in feelings of isolation and loneliness.

Selected commentary includes:

"Do not want to go out or do anything sometimes as feel drained and exhausted."

"I feel resentful sometimes. I get envious of other people's freedom and I hate myself for that."

"I feel guilty if I want to watch something other than what we usually watch. Or if I want to go to a quiz, for example and I have to persuade my cared for to come with me."

"I've missed so many family occasions. Birthday parties, weddings, friends BBQs just general social activities others take for granted."

"I'm not reciprocating with friends. We have a huge social overdraft."

Guided Conversation responses

Survey participants were offered the opportunity to take part in a follow-up conversation over the telephone. The conversations were designed to allow us to understand carers issues, with the aim to develop a risk scale for carers to help medical professionals, social care, parent-carers services and carers to identify when a carer may be reaching a tipping point and to develop support for carers to support their own health and wellbeing.

We used a guided conversation approach to allow exploration of the Carers' survey responses to provide in-depth, rich information not captured by the survey. The conversation allowed the carer to express some of their experiences and feelings about their situation, in their own words. This also allowed space for them to raise support needs and ask questions. The Carers were offered information and signposting to local Carer support, and other relevant services.

We based the guided conversation on a strengths based Appreciative Inquiry approach; the things that work well, or that will prevent carers from reaching a crisis point. Each conversation was individually tailored around the person's responses to social isolation and wellbeing questions in the survey. Initial open questions such as What do you value most about your caring role?; What helps you manage the pressures of caring?, and Could you tell me about the times when you struggle?' allowed us to guide the conversation around the person's concerns.

The conversations were recorded in written note form on a sheet with the conversation prompts, or by typing directly into the spreadsheet during the call. The person's answers, as a summary and in direct quotations were put into the spreadsheet for thematic analysis.

The conversations were carried out by HWDPT staff and three volunteers. The volunteers all had some engagement experience, talking with people over the phone, and some are carers themselves. We held a training session with each of the volunteers in which the guided conversation model was outlined, providing suggestions on how to prepare and manage the call. Before ringing the carer, the volunteer/staff would spend some time reviewing the survey responses to tailor the conversation questions to the individual situation.

We estimated that the phone conversation would take up to 40 minutes and participants were give this as a guide. Some conversations were brief while others took closer to an hour in length. We tried to factor in the time pressures Carers face and asked them to agree a time slot suitable for them ahead of time. As a thank you for their time, Carers were offered a £15 shopping voucher. In the survey carers were asked if they would like to be contacted by their local Carers service and referrals were made on their behalf.

16 Carers provided demographic information relating to their locality, age and gender. The demographic breakdown of participants involved is included in Appendix 3.

A summary of Carers' experiences from the guided conversations

The 17 Carers taking part in the guided conversations spoke about a wide range of themes related to their caring role, these are summarised below and are further detailed later in this section in separate categories. Any interviewer quotes included are taken verbatim from their conversation with the Carer.

- Many Carers mentioned they managed the pressures of caring by getting support from family and friends, but those working age Carers spoken to seemed less likely to have this support network in place. The need for more caring support was frequently mentioned.
- The need for and benefits of receiving financial support and respite care was frequently mentioned by Carers, with some older Carers mentioning being able to self-fund private care.
- A lack of guidance, respite and support – particularly financial support – was mentioned by many Carers as causes of struggle. Some Carers mentioned that inconsistent care provision was a trigger to feeling that they couldn't manage, along with feeling ill or tired – which was cited as a trigger by all Carers interviewed.
- Many Carers interviewed stated that more caring support and respite care would help them manage better or improve their health and mental wellbeing. Some stated that better communication, information & advice and a clearer assessment process would also help them.
- When reaching out for support, some Carers said that services and support were not always available, or the wait was too long. Some others were concerned about the lack of quality support available, flexibility in care arrangements and choice in facilities.
- Some of the Carers interviewed stated that the demands of their caring role takes priority over their self-care but that speaking with friends, family or people in similar situations and trying to make time for social relationships, exercise or hobbies helps. However, more older Carers mentioned having time to do this than working age Carers.
- A few Carers mentioned the negative impact of having to give up work to care for their loved one, how they miss working, adult conversations and how they feel isolated without work.
- A few Carers also mentioned the negative impact of not being able to go out or receive respite care, citing worries about the quality of respite care and support on offer and their need for reassurance that their cared for person will be well taken care of before they can go out.

Analysis of the guided conversations

This section provides a summary of the most common themes identified through the guided conversations, presented under the following headings:

1. What works well?
2. What are the challenges?
3. What are the triggers that lead to feeling unable to manage?
4. What needs to change?

What works well?

Common themes

- Having the support of family and friends.
- Receiving financial support or being able to afford private care.
- Having hobbies or personal space and time to focus on own needs, e.g. exercise
- Access to respite care.
- Speaking people in similar situations.
- Maintaining social connections.

Observations

- Older Carers mentioned being able to fund private care more than working age Carers, who mentioned needing financial support.
- Working age Carers mentioned respite more than older Carers did.
- Older Carers mentioned having time to go out to visit places whereas working age Carers did not.
- Older Carers mentioned more successful coping mechanisms - such as speaking with friends and family and doing hobbies – than working age Carers did.

Interviewer comments taken from Carers

“Carer said they have the means to fund care privately. This is a 30-minute visit in the morning which "provides structure to the day”. The agency provides regular male Carers (this is important to cared-for person), and the daily visit was described as a “ray of sunshine”. They also pay for a private physiotherapist, after being faced with "16 month waiting list". Carer described feeling "lucky" to have a garden which spends a lot of time working on and this is a therapeutic outlet for her. They also have friends who “pop in regularly.”

- Older female Carer of a loved one with Physical Disabilities

“Carer said that the enabling service her younger son receives is helpful. She said, "You just get up and do your best everyday". She uses breathing techniques taught on a CBT course via Talkworks. Carer works part time which she sees as time to herself. She uses online Autism support groups and finds the anonymity helpful.”

- Working Age female Carer of her young son

What are the challenges?

Common themes

- There is a lack of good quality support, flexibility in care arrangements and choice in facilities.
- Services and support not always available or the wait is too long.
- Carers feel overwhelmed and exhausted.
- Demands of caring role take priority over self care.
- Difficulties trying to access financial support and respite care.
- There is no time to research or seek help.

Observations

- Working age Carers mentioned financial pressures and issues accessing financial support more than older Carers did.
- Working age Carers mentioned a lack of support and guidance more than older Carers did – this included a lack of support from friends (as all were still working and had no time for them).
- A few older Carers mentioned difficulties filling out 'overwhelming' number of forms and accessing GP Appointments with a new online system as barriers to improving their personal care.
- Working age Carers cited a 'lack of support available' and 'long waiting times' more than older Carers.
- Older Carers were more concerned with the quality of caring support available.
- Older Carers mentioned having support from friends and family more than working age Carers.

Interviewer comments taken from Carers

"Carer expressed feeling "extremely tired" and mentioned his age (72) as a factor. Described the challenge of trying to find his partners' clothes, jewellery, etc. when trying to help her dressed - not being able to find things around the house - as cared-for memory declined. Also dealing with her collections of ornaments. The emotional toll/overwhelm of trying to de-clutter/clear out. Cared-for also had tucked cash away in safe places which were unknown. Described feeling like "trying to live someone else's life for them."

- Older male Carer of his wife with mental health needs

"When son was diagnosed, they received a letter with brief information, "and that was all" Carer had to find everything out herself. At the time when he moved from education, Carer said that they received no advice, guidance or support for this transition. Regarding both situations, Carer said, "I couldn't believe how little support there is" and that felt like they had been "left to their own devices"."

- Working age female Carer of her young son

What are the challenges?

Interviewer comments taken from Carers continued

“Asked for help at their 2022 assessment and the social worker acknowledged that it was needed. 6 hours a week of help was granted, but this took 12 months to be put in place. Carer felt that this wait was manageable for them as they were able to keep chasing, but for many it's too long and would push them over tipping point. They did have some initial engagement work but the woman doing this also had a second job and was often called away during the time she was supposed to be with the cared for - leaving the Carer on constant stand-by. Carer explained that although this 6 hours of support has now been given, it is important that the support is flexible enough to actually help out the Carer. Initially it wasn't so the Carer had to work with the team/rotas to find a pattern that worked for them. Carer also explained their surprise that a lot of the staff arrive to do their hours with no ideas of what is going on in the local area/where they can take the cared for out to. They often find themselves having to give them ideas. All these small things sometimes make asking for support less preferrable.”

- Working age female Carer of a loved one with learning disabilities

“Carer said her own needs are "at the bottom of the list". Carer does use her GP when needed. Carer said she feels that unpaid Carers are often overworked and isolated which impacts their mental health and when they reach out to GP, they're prescribed an antidepressant to manage these feelings/symptoms. Carer feels that this can mask the issue as if the person was better supported, they might not need medication. She felt that unpaid Carers might seek medical help when they don't know where else to turn but the help needed is more social and practical. She said Carers need to be taught how to take care of their own mental and physical health.”

- Working Age female Carer of her young son

“Time and energy is a big factor. She said she is so busy trying to keep up with jobs and care, there is no time and she is too exhausted to do anything else beyond that. She tries her best, but she said some of the forms are so overwhelming to complete. She said she is not stupid. She said she has been asking for help for her husband for a long time. The problem is she said, she speaks to different professionals at the GP Practice and they don't know him. They don't know his history. She said most of the problems she is experiencing is down to the problems with the NHS in general. You don't' see your own doctor and there is no continuity and nobody overseeing the support from start to finish.”

- Older female Carer of a loved one with mental health needs

What are the challenges?

The impact of giving up paid employment

Common themes

NB. There was much less feedback given for this question, with most answers provided by working age Carers

- Miss the camaraderie of working and adult conversations.
- Feel isolated without work, like there is 'No reason to leave the house anymore'.

Observations

- Only one Older Carer mentioned missing work, the rest of the feedback was from working age Carers, who all mentioned not working as having a negative impact on them.
- Some working age Carers mentioned feeling isolated and alone after leaving work.

Interviewer Comments taken from Carers

"Carer did have to give up employment due to caring responsibilities. She said she finds the most difficult part of this is isolation that ensues, and the lack of adult conversation in daily life. Explained that employment gave her a pattern and schedule, as well as a good reason to get out the house. It's hard when this is taken away."

- Working age female Carer of a loved one with learning disabilities

""Giving up work has had a massive impact on this Carer. Carer explained that she loved her job and colleagues and had to give up work a long time before retirement age. Her life was turned upside down very suddenly when husband received the diagnosis - Carer expressed that it would have been easier to have been told that he had cancer than this. Carer said she needs more time for herself - to go for a walk - to go out for pleasure. She has a volunteer sitter through Devon Carers but only comes about once in every 3 weeks. This is because there aren't enough volunteers. Carer believes Devon Carers should advertise for their volunteer roles better."

- Working Age female Carer of a loved one with physical disabilities

What are the triggers?

Common themes

- Being ill or tired, or overwhelmed.
- Cared-for person needing constant supervision.
- Lack of support – including isolation and inability to see family or friends.
- Inconsistent care provision and not knowing when help will arrive.

Observations

- Being ill or tired was cited as trigger by all Carers interviewed.
- Lack of support and inconsistent care provision was mentioned more by working age Carers than older Carers.
- Older Carers mentioned the "loss of the relationship and 'shared decision making'" as a trigger more than working age Carers.

Interviewer comments taken from Carers

"Carer spoke about his worry for the person's safety and being unable to leave them unsupervised. He mentioned the loss of both the relationship and shared decision making and that his Cared-for person needs constant supervision. For example, the cared-for would try to take their dog for a walk but then be found wondering much later, despite being unsteady on feet and at risk of falls. Carer said they are tired and in extreme pain due to arthritis and that they feel they need time to the need to sit down and rest."

- Older male Carer of his wife with mental health needs

"Carer said the inability to see friends who are still of working age and therefore unable to meet up during the day is hard. Once Carer 'totally collapsed' on the floor of the GP's reception area and feels she 'has an inability' to relax."

- Working Age female Carer of a loved one with physical disabilities

What could be improved?

Common themes

- More caring support or respite care.
- Better communication, information & advice.
- Clearer assessment process with less admin.
- Increased digital skills.

Observations

- More support for Carers and respite care was cited by both working age and older Carers throughout. The phrase ‘more time to myself’ was used frequently.
- The assessment process was mentioned by both older and working age Carers, including ‘less paperwork’ and ‘better access to financial support’.
- Increased digital skills was mentioned more by working age Carers than older Carers.

Interviewer comments taken from Carers

“To get at least one half-day a week when she could leave the house - and be confident in the knowledge that her husband was ok. Carer says she is so tired all the time that she has little interest in looking after herself - the demands are continuous. She has had 3 days off in the past 5 years - and this was to attend a niece’s wedding. To do this they paid £800 for live-in care - so this is 'not an everyday option'.”

- Working Age female Carer of a loved one with physical disabilities

“Carer described feeling concerned about the quality available for daughter. Carer said there was a lack of flexibility in care arrangements for replacement care and a lack of choice in facilities available.”

- Older female Carer of a loved one with learning disabilities

“Carer said it would be really helpful to know what Carers are entitled to, from day one, like a list of entitlements, or a guidebook. He said it is a strain and a worry to not know what help is available. Carer also described stress of ambiguity in diagnosis timeline, including that following an initial MRI the cared-for didn't receive a "clear diagnosis" but vascular dementia was mentioned. They then received a letter from the "Dementia Pathway" stating that the wait list for assessment was 2-3 months. They waited 18 months until an assessment was done with a mental health nurse. Following the MRI scan the Carer resorted to using Google to learn about his partner's condition. This was how he discovered that she might not be legal to drive and that the DVLA need to be informed. No one told him this. Carer described feeling confused by the process and not being updated/informed appropriately. Feels there needs to be information and advice given in the early stages.”

- Older male Carer of his wife with mental health needs

Healthwatch Recommendations

Based on the **key findings** in this report and considering the **desired outcomes**, we recommend the following actions to health and social care leaders in Devon, Plymouth and Torbay to work with Carers to improve services for them and those they care for:

1. **Draw on the valuable insight and suggestions from Carers in this report to develop and improve access to training and awareness resources to help Carers to manage their own health and wellbeing.** Easier access to consistent and reliable sources of advice and support systemwide would help to prevent Carers from feeling unable to cope, whether that be mentally, physically, emotionally, or financially. Carers told us they want:

- More information and advice relating to medical conditions of the cared for person, e.g., dementia, ADHD and stroke, so that they know what to expect and can better support their needs.
- More information and advice about financial support and what they are entitled to,
- More contact from support workers who can provide them with or signpost them to reliable information, advice and guidance.

The tools and coping mechanisms included in this report, demonstrate what works well for Carers when they are faced with challenges and could be helpful to other Carers and shared through peer support sessions, training for Carers, Carers support workers, experts by experience and any professionals or volunteers who are supporting Carers.

2. **Improve access to health and social care services for Carers** – paying attention to specific challenges faced by Carers such as GP and hospital appointment booking systems, delays in getting through to services, requirements for longer appointments if accompanied by the person they care for, difficulties accessing suitable replacement care and good quality paid care services. For example, Carers report of systems not 'talking to each other', duplication of bookings causing Carers to have to contact the service to address and rebook.

3. **Draw on the evidence in this report to codesign with Carers and Carers Ambassadors a risk scale or checklist for Carers** to help medical professionals, social workers, parent-Carers services and Carers themselves to identify when a Carer may be reaching a tipping point in their ability to manage their caring role and their own health and wellbeing and for this to be reviewed on a regular basis, either through Carers' health and wellbeing checks or Carer's annual review. For example, *which coping mechanisms do they have in place? Do they have a back up plan if they become ill? Are they able to take a break?*

62% of Carers said they have reached a point where they have felt unable to cope. This tool and regular check-ins with Carers to monitor their scores could help to reduce this risk and help to improve Carers health and wellbeing as well as those in their care.

Healthwatch Recommendations

4. **Develop a systemwide publicity campaign** to:

- Identify Carers and raise awareness of Carers Services and
- Support Carers to register with relevant Carer's services raise awareness of the full range of support available to them.

5. **Identify why, in some areas, Carers and / or the cared for person's needs are not being met by paid care services –** we urge health and social care commissioners to work with care providers, Carers services, patient experience teams and Carers themselves, to explore the reasons why their needs are not being met and to identify if there are any other areas where there are gaps in evidence to help develop future engagement/research.

6. **That NHS and Adult Social Care Leaders in Devon, Plymouth and Torbay use the evidence and the findings in this report to further inform local Carer strategies, and action plans as they move forward** and that service leaders take a joined-up approach to ensure local plans for Carers are aligned across the whole Devon system. Where feedback and experiences featured in this report are specific to dementia, this evidence can help to inform the new dementia strategy for Devon, alongside National guidance such as the **NICE guidelines for people with dementia, their family and carers** and the **Well Pathway for Dementia.**

> ***"The care we provide is all consuming and 24/7. There are no breaks unless we physically leave the house or the environment he is in. The person we care for is mobile and so is always within our bubble, such is his nature and cognition. He has no awareness of personal space and so we do not have any personal time or space. But this is our life, and this is what we do. It is a way of life. Its not for everyone. But we did not choose this life as so many have said as an excuse so as not to give support. But at the end of the day, he needs us, and whilst ever we can provide his care and support, the way he wishes to be cared for, by people he trusts and who understand him and why he is as he is, then we will keep on going. Thank you."***
>
> *- A Carer's reflection on their role as a Carer*

Stakeholder responses to the report

Response from the Devon wide Carers Leads Development Group

Firstly, thank you to Healthwatch for their work in undertaking the survey and particularly to Lorna Sinfield for the detailed analysis and report. There are a number of provisos about the context of the work which are listed below. Notwithstanding these, it provides a clear picture of the issues for Carers across the whole of Devon, reinforcing the National Carers Survey data, Carers UK State of Caring Survey and local Carers' Strategy surveys for Plymouth and Devon. Primarily there is a reduction in Carers' quality of life, with increasing impacts on their health and wellbeing, their self-neglect and their feelings of isolation.

Some of these are issues for Carers' Services / Commissioners of Carers' Services, and each area will build the findings of this report into local Carer Support. However, most of the issues which affect Carers are with the wider system and so a joined-up system-wide response / commitment is required. These include:

- Replacement care
- Information about medical conditions and support at diagnosis
- Information and support to navigate complex systems

The recommendations at page 57-58 need to be considered across the Devon footprint to maximise their impact.

Agreed actions to take forward:

1. Healthwatch to cross-reference the questions of those who feel overwhelmed 'every day' against proportion of those who answered lived alone / years caring / age / condition of person cared for etc. This is to identify potential triggers e.g., if 60% of Carers live with person that they care for and 100% of them say that they feel overwhelmed every day, and this is higher than for those who do not live with the person that they care for, then that may be a potential trigger.
2. Extraordinary meeting of relevant parties to take place in September to debate the issues system-wide.
3. Each of the Carers Local Authority Leads to compare the report with national Carers Survey data
4. Torbay and Plymouth are both in the process of creating action plans linked to their Carers' priorities for their Carers' Strategies, so will ensure that actions address the report's findings.

Provisos:

1. Due to low numbers of responses compared to the numbers of Carers across Devon, the data is not statistically significant.

2. Responses varied significantly by area - 23% Devon, 41% Plymouth, 16% Torbay, with 20% unknown. The ratio of those with known post codes is 29:51:20 whereas the 2021 Census population ratio is 67:22:11.
3. The Healthwatch survey allowed for all age groups of carers including young carers (Under 18s). However, no responses were received from any young carers in Plymouth, Devon or Torbay, so the report only reflects the views of adult carers.
4. The Healthwatch Survey was undertaken at a similar time to the National Carers Survey 2023 and Torbay Carers 2024-27 Strategy Survey. To maximise value and impact, timing of any future Healthwatch surveys should enable detailed investigation of issues identified from other such sources.

Next steps

This report will be shared with:

- One Devon and NHS Devon Integrated Care Board
- Carers Services Leads and Carers Support Organisations – Devon Carers, Torbay Carers' Services and Improving Lives Plymouth
- Health and social care Commissioners and NHS Provider Trusts in Devon, Plymouth and Torbay and Livewell Southwest
- Health and Wellbeing Boards in each locality
- Overview and Scrutiny Committees in each locality
- Healthwatch England
- Care Quality Commission (CQC)
- Carers who took part in the survey, The Healthwatch Assist Network and the wider public.

We will continue to monitor feedback from Carers and ensure any new issues or concerns raised or further suggestions are shared with service leaders for their response.

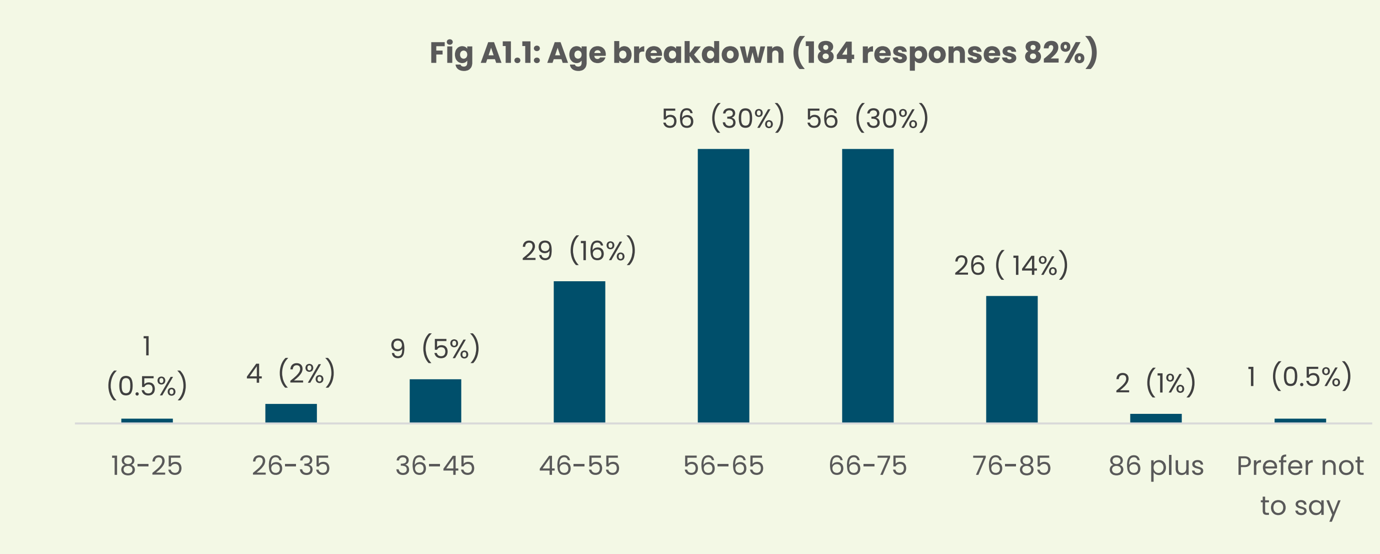
Acknowledgements

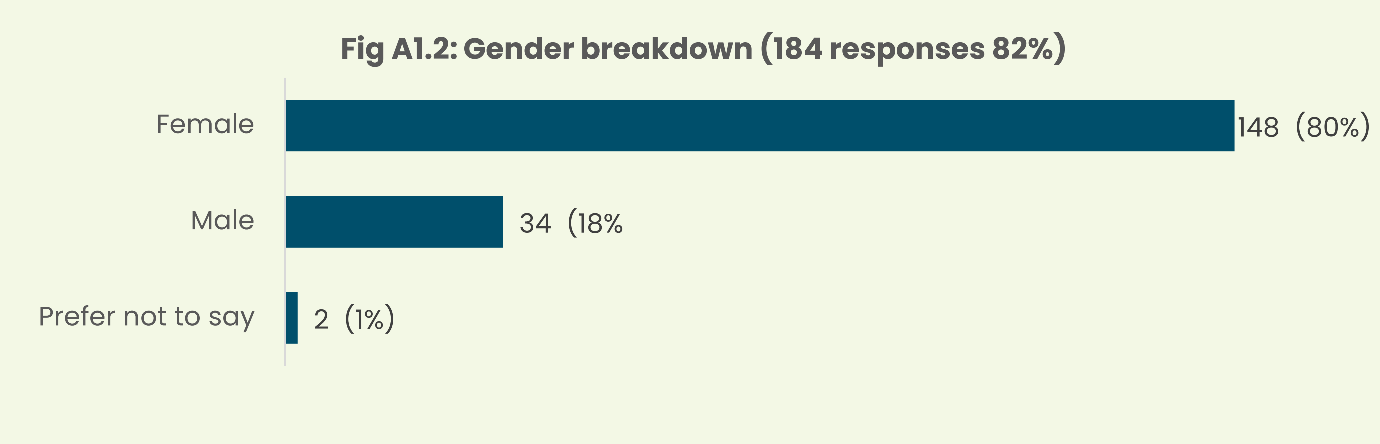
Healthwatch in Devon, Plymouth, and Torbay would like to thank every Carer who took the time to complete the survey and share their experiences with us. In particular those who shared their experiences with us through telephone conversations.

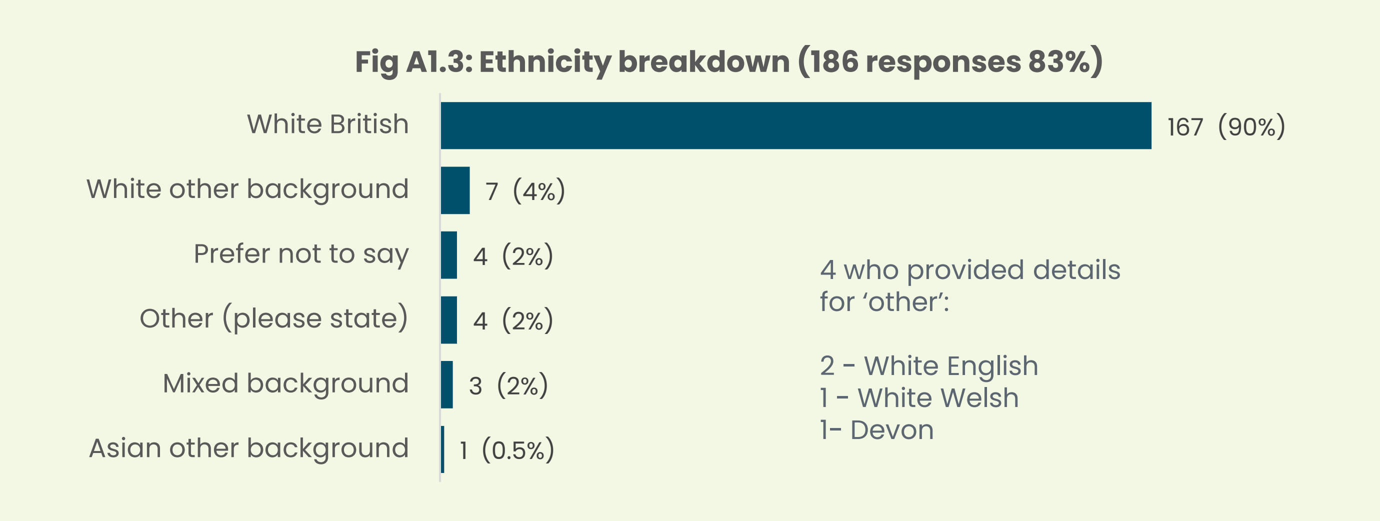
We would also like to thank Devon Carers, Improving Lives Plymouth and Torbay Carers' Service for working with us to design this project and for circulating the survey through their own networks.

Appendix 1

Survey respondent demographics







4 who provided details for 'other':

2 - White English
1 - White Welsh
1- Devon

Survey respondent demographics by locality

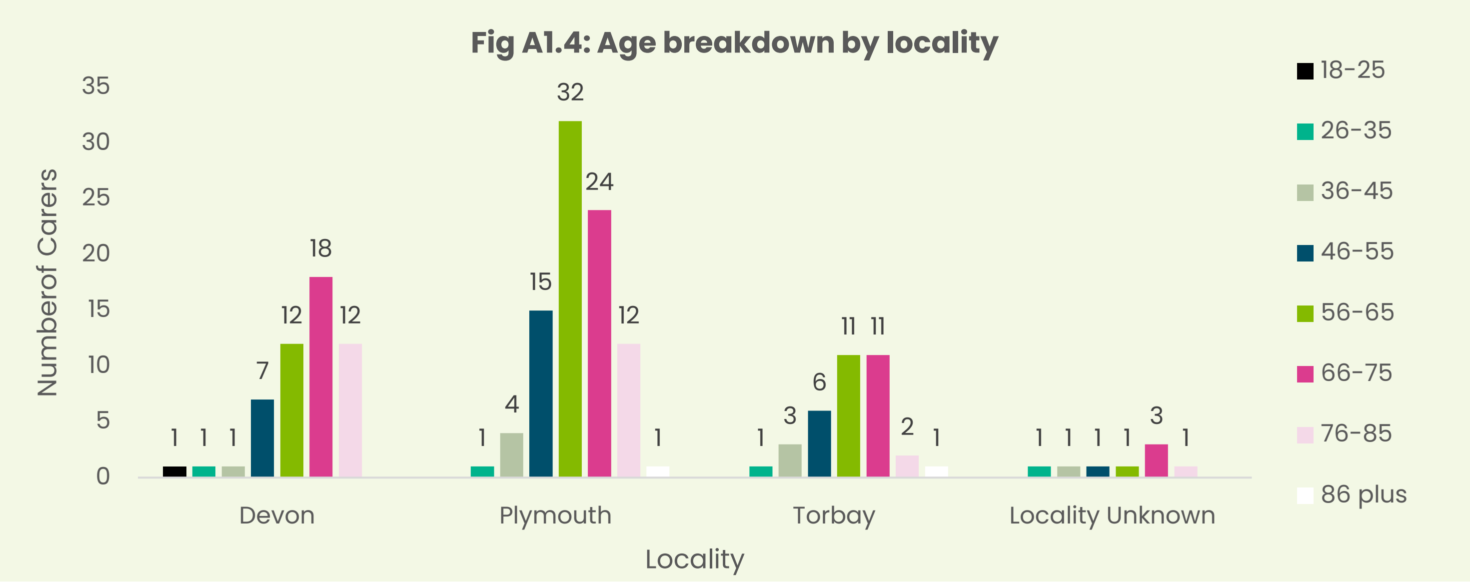


Fig A1.4: Age breakdown by locality

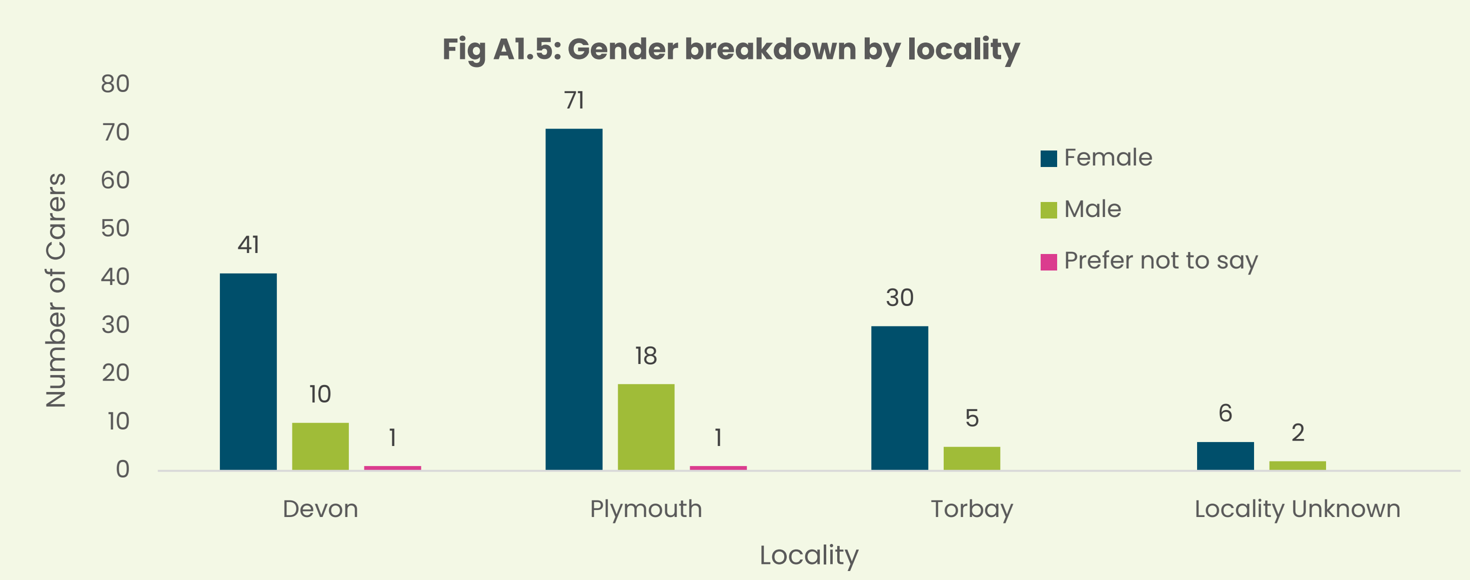


Fig A1.5: Gender breakdown by locality

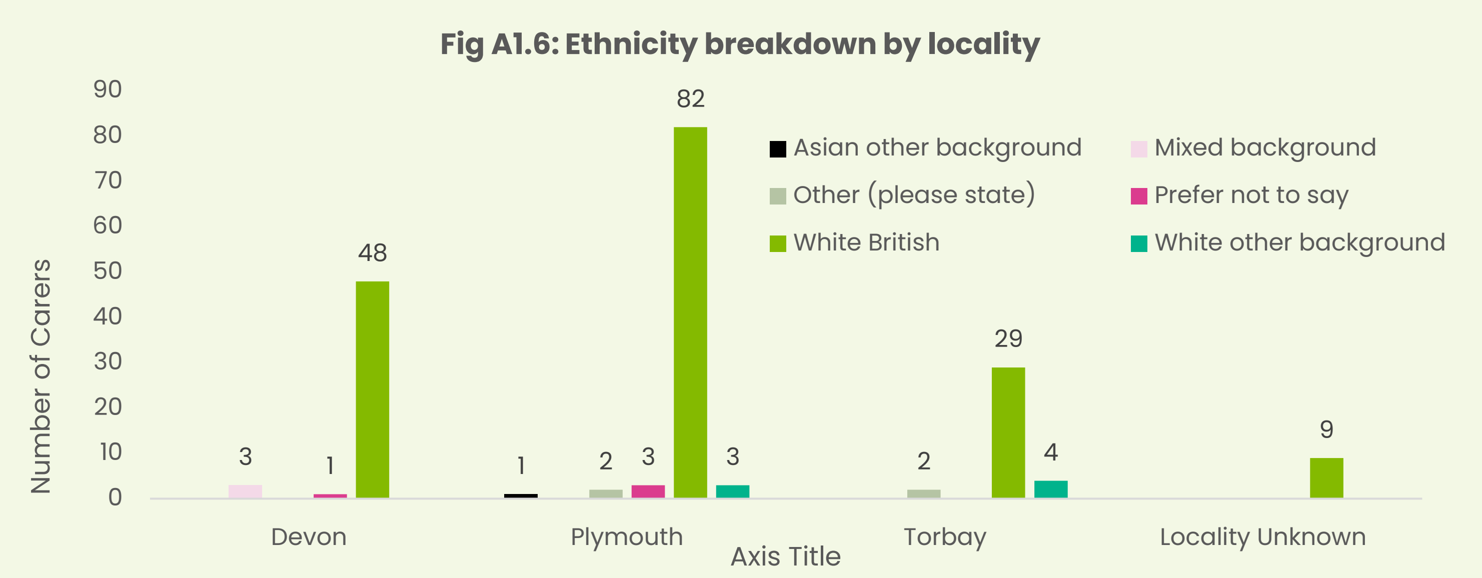
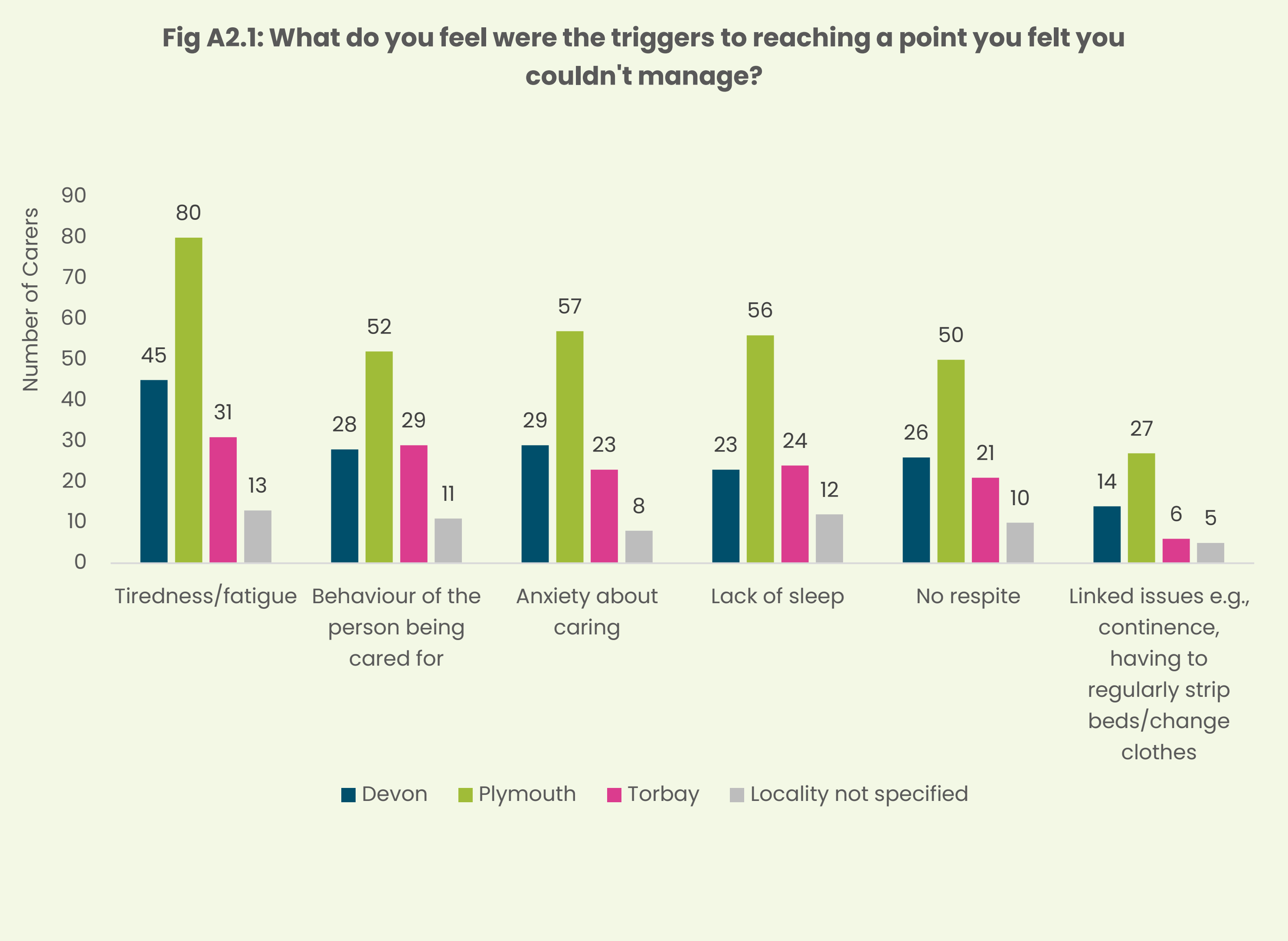


Fig A1.6: Ethnicity breakdown by locality

Appendix 2

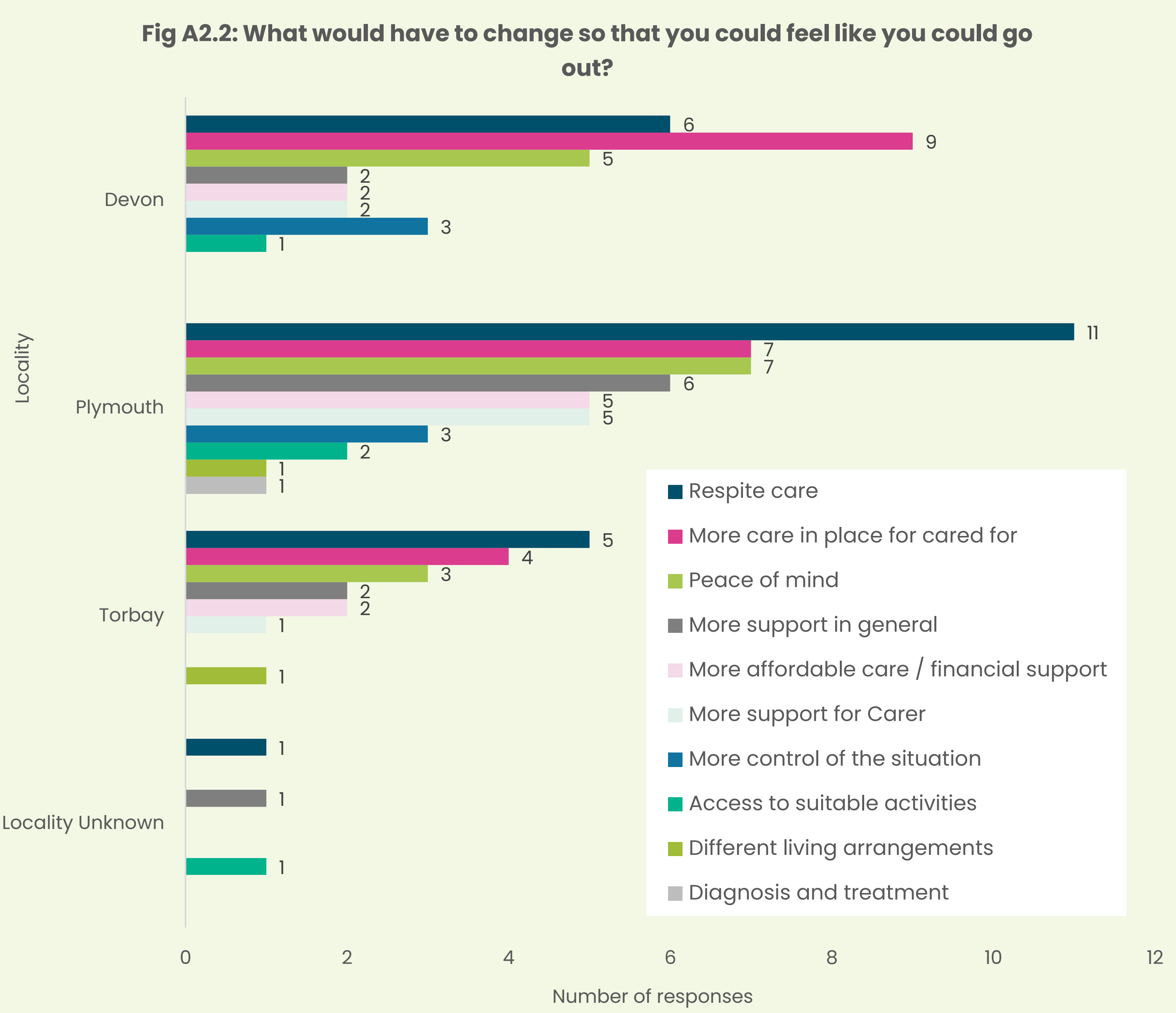
A2.1: Question 16 locality chart and data table



Trigger	**Devon**	**Plymouth**	**Torbay**	**Locality not specified**	**Total number of Carers**
Tiredness/fatigue	45	80	31	13	**169 (75%)**
Behaviour of the person being cared for	28	52	29	11	**120 (54%)**
Anxiety about caring	29	57	23	8	**117 (52%)**
Lack of sleep	23	56	24	12	**115 (51%)**
No respite	26	50	21	10	**107 (48%)**
Linked issues e.g., continence, having to regularly strip beds/change clothes	14	27	6	5	**52 (23%)**
Total	**165**	**322**	**134**	**59**	**680***

*Carers could tick more than one option.

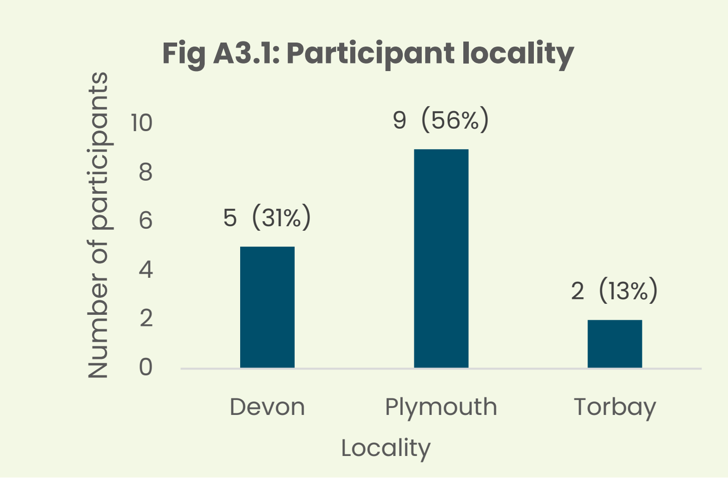
A2.2: Question 30 locality chart and data table

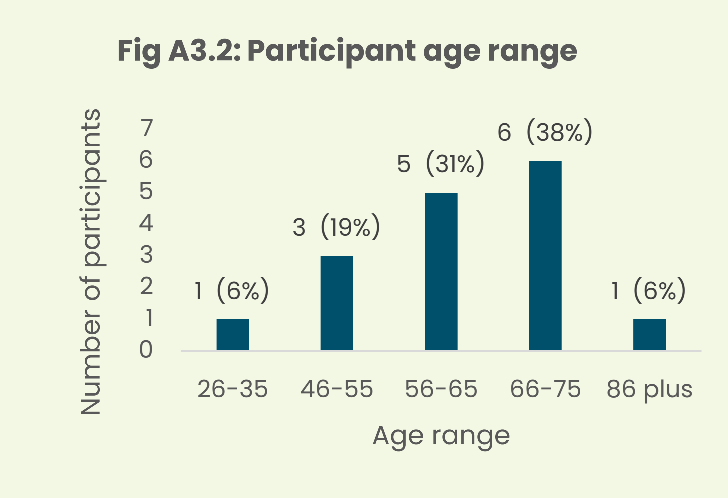


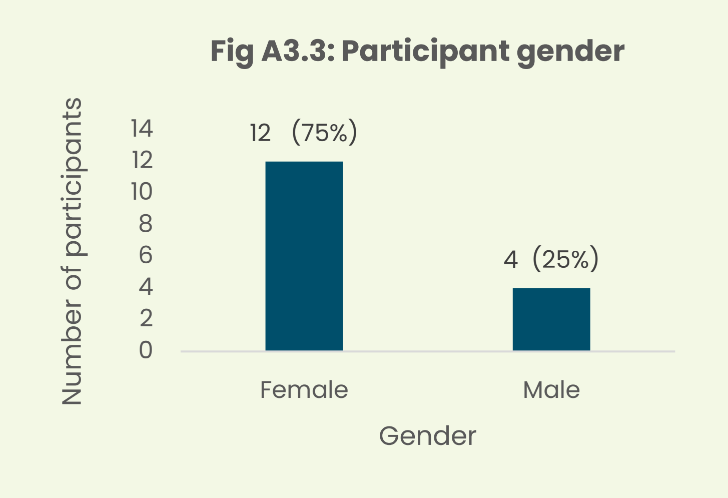
Theme	**Devon**	**Plymouth**	**Torbay**	**Locality Unknown**	**Total**
Respite care	6%	11%	5%	1%	23%
More care in place for cared for	9%	7%	4%	0%	20%
Peace of mind	5%	7%	3%	0%	15%
More support in general	2%	6%	2%	1%	11%
More affordable care / financial support	2%	5%	2%	0%	9%
More support for Carer	2%	5%	1%	0%	8%
More control of the situation	3%	3%	0%	0%	6%
Access to suitable activities	1%	2%	0%	1%	4%
Different living arrangements	0%	1%	1%	0%	2%
Diagnosis and treatment	0%	1%	0%	0%	1%
Grand Total	**30%**	**48%**	**18%**	**3%**	**100%**

Appendix 3

Guided conversation participant demographics







Appendix 4

Survey template

The impact of providing unpaid care at home on carers wellbeing and feelings of isolation

About Healthwatch and the background to this survey

Healthwatch in Devon, Plymouth, and Torbay (HWDPT) are the three local independent consumer champions for people using health and social care services across Devon.

The scope of HWDPT is to listen to what people say about their local health and social care services, to identify what works well and what could be improved, and to make those views known to those involved in the commissioning and scrutiny of health and social care services; ensuring the voice of the community is used to influence and improve services for local people.

In November 2022 we published a report titled 'The impact of providing unpaid care at home'. Working in collaboration with Devon Carers, Caring for Carers Plymouth, and Torbay Carers services, we have reviewed the findings and have agreed to follow up this report with further work around the impacts on carers especially around their wellbeing and feelings of isolation.

The information that we are seeking from this survey will be used anonymously to help Healthwatch Devon, Plymouth & Torbay and carers groups in Devon, Plymouth and Torbay explore the links between:

- carers mental /physical health and wellbeing and number of hours unpaid care provided.
- how long a carer had been providing this role (longevity).
- type of care role provided e.g., physical caring, supportive caring, dementia/cognition caring or mixture.

It will allow us to:

1. Develop a risk scale for carers to help medical professionals/social care/parent-carers services/carers to identify when a carer may be reaching a tipping point.
2. Develop support for carers to support their own health.
3. Develop services to respond to our improved understanding of the impact of different levels and types of caring role.
4. Identify gaps in service provision and communications.
5. Provide research analysis in a publicised report to inform the goals above and identify research gaps for future engagement/research

Survey Questions

Part 1 – About you and the person(s) you care for

1. Does your 'caring' role impact you more than 20 hours per week?
Yes No

2. What is the length of time you have been a 'carer'?

3. Do you live with the person you care for?
Yes No

4. If Yes, Does this impact on your ability to leave the house?
Yes No
5. If Yes, Does this impact on your ability to relax at home?
Yes No

6. How many people do you care for?
1 2 3 Other (please state)

7. What conditions or disabilities does the person you are caring for have?
(please tick all that are applicable)

o Dementia (e.g., memory loss/confusion)
o Physical disability
o Sight, Speech, or Hearing loss
o Mental health
o Neurodiverse (e.g., ASD, ADHD)
o Problems connected to aging
o A learning disability or difficulty
o Long term health conditions (e.g., COPD, Diabetes)
o End of Life care
o Addiction (e.g., Alcohol, Substance abuse, or gambling)
o Seizures (e.g., Epilepsy)
o Acquired brain injury (e.g., fall, accident, tumour)
o Stroke
o Neurological (e.g., Parkinsons, Huntington's, MS, MND)
o Other (please specify)

8. Which of the following form part of the care that you deliver?
(Please tick all that are applicable)

o Personal care
o Continence care
o Physical help (e.g., mobility, manual handling tasks)
o Dealing with care services
o Paperwork and/or financial matters and benefits
o Other practical help
o Housekeeping (e.g., cooking, shopping, cleaning)
o Supporting someone to eat and maintaining fluids
o Keeping them company

o Taking them out or socialise
o Managing and taking to medical appointments
o Giving medicines and/or obtaining prescriptions
o Keeping a daily eye on them to see if they are all right
o Giving emotional support
o Managing addiction (e.g., gambling, alcohol, drug)
o Keeping someone safe (e.g., seizures, behaviours, learning disabilities, falls)
o Supporting religious/cultural needs
o Other help

9. What is the time impact of weekly 'administration' tasks?

10. Have you received enough training to support you in your caring role?
Yes No

If no, what would have been helpful? (e.g., information, IT skills, manual handling, medical information)

11. Does the person you care for also receive paid care?
12. If so, how is this funded? (Please tick one)

o Fully funded by Health or Social Care
o Self-funded
o A mixture of both

13. Do you feel this meet the needs of you as the carer and the person who you care for?
Yes No

14. Have you had to give up paid employment or had to reduce hours of paid employment?
Yes No
If yes, how many weekly hours have you reduced?

Part 2 – Your wellbeing

15. If you have reached a point where you feel you can’t manage, how often does this occur?

16. What do you feel were the triggers? (Please tick all that are applicable)

o Tiredness/fatigue
o Anxiety about caring
o No respite
o Lack of sleep
o Behaviour of the person being cared for
o Linked issues e.g., continence, having to regularly strip beds/change clothes
o Other (please specify)

17. Were you aware of reaching this point beforehand?
Yes No

18. What do you feel would help you to avoid reaching a point where you feel you can’t manage or a deterioration in your own health and mental wellbeing?

19. Have you ever felt your own safety was at Risk?

Yes No

If so, how frequently does this occur?

20. Do you know where to go for support?

Yes No

If yes, what support were you aware of?

21. When you last felt unable to manage, did you reach out for support? (Including medical/mental health support)
Yes No

If yes, why?

22. Is there anything that did make a difference for you?

23. Do you use coping mechanisms?
Yes No

If yes, what works well?

24. Do you prioritise your own personal care?

Yes No

If no, what stops you?

25. Do you prioritise your own health and wellbeing? (e.g., medical/dental appointments.)

Yes No

If no, what stops you?

26. What would enable you to priortise your own health and wellbeing?

27. If you have had to give up paid employment or reduce hours, how has this impacted your wellbeing?

28. Have you been able to take a break or respite in the last 12 months?

Yes No

Part 3 – Feeling Isolated

29. If you live with the person that you care for, are you able to leave home regularly to be able to do activities for yourself? (e.g., meeting friends, personal tasks (not shopping) or social activities)

Yes No

If yes, what allows you to do this? (e.g., paid carers, family support)
If no, what impact does this have on your own physical and mental wellbeing?

30. What would have to change so you feel you could go out?

31. What would enable you to feel less isolated at home, if you could not go out?

32. Do you feel that the care you provide is affected by being unable to have regular personal time and space?

Yes No
If yes, how?

Thank you for taking the time to be part of this survey.

Would you be willing to take part in a follow up phone call to discuss further some of your responses to the wellbeing and isolation questions above

Yes No

The phone call will take around 45 minutes with one of our trained volunteers. On completion, we would like to thank you for your time with a £15 shopping voucher.
Would you like to be contacted by your local carer's organisation (Devon Carers, Torbay Carers, Caring for Carers Plymouth)?

Yes No

If yes to either (or both) question, could you please leave your:

Name
Email
Best contact phone number

Finally, to help Healthwatch to analyse the information you have provided could you please answer the following Demographic information.

What is the first part of your Post Code?

What is your Age Group? (please select)

Under 18 18-25 26-35 36-45 46-55
56-65 66-75 76-85 86 plus Prefer not to say

What is your Gender? (please select)

Female Male Prefer not to say
Prefer to self-describe

What is your ethnicity? (please select)

○ Arab
○ Asian Bangladeshi
○ Asian Chinese
○ Asian Indian
○ Asian Pakistani
○ Asian other background
○ Black African
○ Black Caribbean
○ Black other background
○ Mixed background
○ White British
○ White Irish
○ White other background
○ Other (please state)
○ Prefer not to say

Appendix 5

Additional selected comments in response to survey questions

Question 2: What is the length of time you have been a Carer?

"Perhaps 2-3 years; the situation has been incremental, not sudden."

"Officially 1 month. But have cared for my partner for a lot longer time over the years I have been with him."

"20 years full time. Part time before that."

"Since the 70's my learning-disabled daughter who though now in residential care comes home frequently, the last 6 years my husband."

"Difficult to quantify. The level of caring I now give is much more than a year ago. It seems to increase daily at the moment. You drift from "wife" to carer gradually!"

Question 9: What is the time impact of weekly 'administration' tasks?

"Most mornings, from about 9 till 11, during the weekdays are spent sorting out the weeks doctor, dentist, psychotherapist visits, form filling, other appointments, the afternoons discussing entertainment outings, shopping list (to be ordered online as it is a learning tool), trips to the gym to keep healthy, shopping."

"Several hours a day and I work full time."

"Time consuming, sometimes frustrating if dealing with PHB team. Gives me less time for myself."

"Too much to calculate."

"1-2 hours? Haven't taken much notice-just do it."

"Roughly 1 hour per week, another family member predominantly helps with the admin side of things."

"3 hours per day - this builds up due to lack of time and paperwork being a trigger to our cared for person and this becomes a real problem. Social services make us do reams of paperwork to evidence the already identified needs."

"It varies - but it is not made easier by legislation protecting data etc., especially when the person I care for has a communication disorder and doesn't like phone admin!!"

"Probably a 3hrs a week but it often varies. At times of crisis this is a much larger task."

"Constant I feel like a secretary or personal assistant without the pay scale!."

"Hard to say, it varies. Paperwork has taken up more time since my child turned 18 and especially dealing with the transition from school to adult services & SEN college.

"Dealing with different departments is never one phone call or email, it's always several, usually over days!"

"In everything, my cared-for comes first - everything else works around him. A lot of my time is taken up sorting out things for him, preparing, planning, contacting people. If I am right in what you refer to as 'administration' - that is every day, and the day works around it."

"Full time…. phone calls to services take hours of time as left on hold before being put through and then passed from pillar to post. Services are not joined up and you have to repeat yourself over and over."

"Constant - ensuring I 'find' letters for health appointments and bills. Constantly explaining to my mother about financial situation etc. It is a daily issue and is emotionally and physically draining."

"It's relentless, recently my days are taken up with daily phone calls to various professionals."

"As an average, an hour a day to cover financial, medical needs, admin and other correspondence."

"Administration is most days, always some one needing this filled in or that filled in Or I'm chasing some thing up. GPs or services what information .. it's endless. How do you measure those minutes and minutes spent on the phone, texts and emails."

"I have little time to do the endless admin for Dad so much, so I have almost no life of my own. I cannot keep up with all the admin."

Question 10. Have you received enough training to support you in your caring role?

Question 10a: If no, what would be helpful? *(e.g., information, IT skills, manual handling, medical information)*

"The best help I had was a self-referral to mental health who put me on a course to handle stress anxiety and sleeplessness."

"I am self taught and have lived experience. All of which has been mocked and deemed as inadequate LA and seen as if we can cope as a family and have children then the care and support that we provide cannot be so restrictive to us and maybe we are over egging it. We have never been offered any training and we only had our first carers assessment in 2019."

"Had to find out most of it by myself or Cit[izens] Advice."

"Have had to learn as need developed."

Question 10a (continued): If no, what would be helpful? *(e.g., information, IT skills, manual handling, medical information)*

"I have not received any training from anybody and support from whom, when I have reached out for support in despair, it happened for a few weeks and then like the person who started to offer support, just disappeared, with emails and contact ignored, which must be at least two years ago now. I need skills in how to manage and cope with the situation that I am in."

"I have only found out things from memory cafe for which I pay £33 per hour and other carers in the same position. It would be helpful if after diagnosis there was somewhere in hospital or who would visit to tell us how to care and what we were entitled to. I have only found out by my own efforts."

"Never had any training, been doing it so long, not much I don't know."

"The person I care for is my child and I (and his father) have learnt 'on the job'."

"No training, just day by day on the job unpaid with no carers allowance as now get state pension."

"Have only recently been referred to carers support and previous conversation with health professional on psychological consequences of stroke etc. would have been beneficial. There is no training per se, use of own intelligence and common sense is main requirement, but counselling regarding personal interaction etc. would have been appreciated."

"Information on how to get services to listen the first time and how to stop them asking the same questions over and over and still not getting the help you need . Just because you might look like you're managing then a lack of support is given but really, you're drowning!"

"We've learnt 'on the job' Helpful? More streamlined and coordinated support from agencies like County Council, DWP etc."

"How to manage and understand needs of who I'm caring for."

Question 15: If you have reached a point where you feel you can't manage, how often does this occur?

"Most days, but I snap out of it. No choice."

"Can be daily when things not working out, or not at all when doing better."

"Perhaps 2 x a month."

"Every day at various times in the day. This has been the case for many years. But when we tried to talk to someone about it and requested further support, we were threatened with safeguarding. We made a complaint, and everything got a lot worse and we lost the then funded support we had. This was later reinstated with the excuse there had been a miscommunication. We were then too scared to ask for any further support for many years. In that time, we reached many points where we could not manage. But somehow, we did."

"Usually at oncology review times but also as symptoms have worsened."

Question 16: What do you feel were the triggers that led you to feel unable to manage?

*“**Continual worry.”***

“Frustration at the situation.”

“I don't have enough help, end of.”

“Just everything in general.”

“Lack of any support.”

“Lack of support from local authority with eldest child education.”

“emotionally drained and on guard with no support.”

“Loneliness. Inability to meet my needs/ wishes.”

*“**My mental and physical decline in health.”***

“Relentlessness of caring for a severely learning-disabled person.”

“Seeing no end in sight.”

“Treatment of me by professionals.”

*“**Just too much on my plate.”***

Question 18: What do you feel would help you to avoid reaching a point where you feel like you cannot manage, or there is a deterioration in your own health and wellbeing?

“Being able to talk freely (i.e. on my own) with friends and respite esp. to address regularly having only 3-4 hours sleep per night over months.”

*“**A holiday or even a whole day out.”***

“Respite care - support with finding it (would be self funding).”

*“**Regular time away from the house to do something for myself (selfish I know).”***

“Time out and the freedom to do what I want to do.”

“Time out on my own without worrying about responsibilities.”

“Extra practical help such as someone to cover night duties enabling me to sleep.”

“To have a proper 2 days off once a month? But we don't have the money for this.”

“Better response to job adverts for carers.”

*“**Having a local community based meet up point for my mother to go to each week in her area.”***

“There is no need for specific services for my daughter just access to everyday services that readily available for the person we care for being able to live as he wishes in the community and lead a full life - with the right support.” public. Integration is the only way forward as acceptance and understanding will only come with the public being involved in everyday life of those who are so marginalised in society.”

*“**Somebody to possibly visit to assess the situation.”***

“Someone to take some of the load off me.”

“I need MORE support and more time to be with my husband and do the things in life that our friends take for granted.”

“Knowing who to ask for help.”

*“**Knowing what the next step would be to bring in outside care….is it Age UK assessment….or Social Services? Had to send for brother five hours journey away to support in the Summer.”***

“Talking honestly and openly to someone who can help look for the signs.

“An admiral nurse to guide us through the dementia pathway and give us information and morale support.”

“Having someone I can talk to and get proper advice/help from rather than being passed from pillar to post and getting nowhere.”

*“**Better benefits for carers so that I don't need to juggle work as well as caring for two people”***

“Better care agencies who could provide better motivated and trained staff. Some value put on the role of carers by health and social care sector.”

“Meeting other parents in similar situation. Being more confident about my child's future security.”

“We need support from the government. Unpaid carers outweigh paid carers. What happens if we go on strike? We get £307 a month to do a job that costs £1000 a week in a care home and we pay for our own breaks.”

“My son is in care, but I still have a lot of responsibility for him too. Them cutting my daughter's care package and hugely disrupting her life as they are currently doing has left me very low. They've strung it out for 6 months, causing us all huge anxiety and knocking the fight out of me.”

“Regular support from a qualified person. Somebody to see how my wife is, she can't help being like she is, she hates being like she is, but nobody seems to be interested in either of us at all.”

“The care organisation who provide the paid care doing what they should be doing. the funding is there just not the paid carers or the attitude of the paid carers. […] Several things happen at the same time; the other systems or organisation don't know this also happening but as the carer you are juggling it all. Multiple issues come at the same time. Systems and organisations speaking to each other. Improvement in quality of paid care.”

“Being believed and better supported by the local authority and complaint situations being averted as they do not help and only make matters worse and further escalate the nonbelievers of a person”

Question 19: Have you ever felt that your own safety was at risk?

“Less so now after change of medication.”

“Maybe weekly if having a violent meltdown.”

“When ever he is angry.”

“Daily during brief period medication and deterioration have reduced almost entirely.”

“Due to the nature of the care, we provide, there is an element of safety. But we are a very tight team and with other family and our older children there are around 8 carers a day involved in the care machine around the person we care for. We are all on the same page and can anticipate critical time and triggers. Safety and safety within the environment in house or out in the community is an issue all day long.”

“Occasionally outbursts of aggression and swearing which is somewhat startling.”

“Not so much now, but in the past frequently when their stress got too much for them.”

“I was informally "safeguarded" some years back and that resulted in measures to help both me and my cared-for that addressed the dangerous elements of the situation. I now feel 95% safer, which has had a huge impact on my own personal wellbeing and - equally importantly - my cared-for's wellbeing (who was also liable to put himself at risk as well as me.)”

“Very rarely now. Before I had counselling it would be a couple times a week.”

“I am aware of own age creep imposing some limitation as husband (patient) ages further.”

“about every 4-6 weeks. This is only me being tired - and down - not my cared-for. I just can't be bothered to look after myself - you just have to keep going on the tread mill.”

“Only that the equipment is heavy & not easy to manhandle. If anything happens to me there will be no-one to do the care.”

“Frequently, at least once a week. My own health is poor and worsening due to my caring commitments.”

Not very often, maybe annually but it’s the fact I get to the point I have fleeting thoughts I can’t carry on.”

Question 20: Do you know where to go for support?

Question 20a: If yes, what support are you aware of?

“I have had to say yes, because we know where to go but when we have gone, we have not had any outcome. We support each other in house now as a family.”

“Devon Carers, but just not got the energy to reach out, so just have a good weep in the corner instead!”

“What is the point they don't help anyway.”

“No professional has ever signposted us to any support. But I came across Mencap Torbay in 2017 and prob saved us from going under. They simply listened without judgment.”

“I have support from Caring for Carers - although my mentor missed my yearly review this year.”

“I have been supported by receiving funding to clean the house, which is great. My mental health has suffered because of the constancy of my caring role. There are no PAs in my locality.”

Question 21: When you last felt unable to manage, did you reach out for support?

Question 21A: If yes, why?

“Anxiety triggered by circumstances were debilitating and feeling burnt-out as a lone parent with no other adult available to assist.”

“Because I did not know which way to turn. I could not function. The IBS became unbearable. I seemed to be facing a never-ending nightmare.”

“Because I’d have internally exploded otherwise.”

“Started having panic attacks.”

“Having that overwhelming feeling of not being able to cope and things getting too much.”

“Physical breakdown of health needing blue lighting to hospital.”

“I reached out to my employer because I was struggling to hold my job down.”

“Because I was overwhelmed with what I had to cope, my husband had to have a heart bypass and I knew I would not manage that extra caring which would be required.”

“Because if I'm not well they cannot manage and its more for me to pick up going down there.”

“For some respite to regain my sense of self.”

“I knew that I was close to breaking point.”

“I wanted help to get some paid carers to assist me with my caring role.”

“I was ready to kill us both.”

“It was a culmination of several things happening at once - fire wouldn't start, no hot water, car problems.”

“Sent for my brother five hours journey away. He came for three days. He said I must call in any outside help I need. Mum resists until next emergency occurs. At least she now has a private cleaning lady an hour a week.”

“So that I could continue to be a good carer.”

“To enable me to cope and carry on with role.”

“Mum was hospitalised, suggestions were made but nothing came of them.”

“Due to the general stigma, and the fact it was the lack of understanding from the LA that had caused everything to break down in the first place along with the confidentiality and bias within services which was constantly breached and the locality of the social workers homes to ours, all just seemingly waiting for us to mess up I felt unable to reach out. I was offered counselling sessions on my last 2 carers assessments, but I have yet to feel I can trust anyone re how I feel other than my family.”

Question 22: Is there anything that did make a difference to you?

“My 2 sisters give me help and a break every now and then.”

“My brother did more when I felt exhausted.”

“My friends surprised me by booking a weekend away in a caravan in my own which was just what the Dr ordered.”

“Asking family for more help - 2 live away so asked them to call mum more frequently which was fairly short lived and is now occasional.”

“Being able to talk to someone not connected.”

“Speaking about things and to get reassurance.”

“Talking and sharing with other carers.”

“Connecting with others in similar situation.”

“Able to talk to other people who have been in a similar situation.”

“If someone can't help me and they point me in a better direction or offer an alternative view, I will run with that.”

“I ended up in tears to an answer phone ringing my daughter’s epilepsy team out of desperation, although the issue didn't directly involve them, they actually spoke to the hospital department concerned and got me an answer after I'd sent 4 months trying to get one.”

“I have a very supportive husband and some good friends I can talk to. I also have a work colleague in a similar situation, so we discuss the issues and pressures.”

Question 23: Do you use coping mechanisms?

Question 23a: If yes, what do you find works well?

“Being aware of my triggers, exercise, talking to family.”

“Going for a walk by the sea or in the countryside and swimming.”

“DPT Talk works techniques- a variety. Devon Carers.”

“I do comfort eat when I get stressed out or stuck with a situation and that is not a helpful thing! But I also try and mark out me-time these days - a chance to take myself off and unwind a bit for an hour or two.”

“I have friends I talk to and use humour to lift my spirits, or I contract myself into myself and a book to block everything out for a while.”

“Talking/messaging friends and family; being very firm and insisting for important things; leaving the room; a good cry.”

“Chocolate! Cup of tea. See an understanding friend and explode.”

“Deep breaths. Going for fresh air out in the garden for 2 mins.”

“Trying to get through the next minute, 5 minutes and so on. Or comfort eating but that's not helping long term.”

“Attacking the garden, chatting to/phoning friends and family having a good old sing/holler to music.”

“Telling myself I must be strong as worse to come in the future.”

“Retreating to my own quiet space when things get too stressful and overwhelming.”

“Keeping a happy face and not dwelling on negativity.”

“I talk to my husband and vice versa. We laugh. Sounds strange given how low we are but we do. We laugh at our day. Because our day is so bananas so crazy and so unexplainable to others. So, we take time to laugh at the irony of not being able to get anyone who actually ‘gets it’.”

“I find reading helps me takes my mind off the reality of being a Carer.”

Question 24: Do you prioritise your own personal care?

Question 24a: If no, what stops you?

"My love (and caring for) my wife first."

"Making sure that my husband is clean, well dressed etc."

"61 years married this month so love for husband keeps me going while my own physical health is reasonable."

"Time. Being totally filled up with looking after others. Lack of headspace to think clearly and rationally."

"Only because I am not good at self-care anyway. Although I have got better over these past three or four years and do take some time for myself when I can and try and follow up on medical appointments, for example, when I can. But, in general, everything does still revolve around my cared-for's needs."

"Lack of time. Lack of enthusiasm. Feeling that, in the scheme of things, I am not important."

Question 25: Do you prioritise your own health and wellbeing?

Question 25a: If no, what stops you?

"My husband comes first."

"Need to keep everyone else ok."

"Wanting to do everything I can to help them."

"We have limited resources his needs are greater than mine."

"Am so buried in my situation with caring- I'm afraid I'm 2nd down the list."

"I have to arrange support for my husband so that I can attend appointments if necessary. Its a case of hoping to be able to make appointments but not always being able to at the time. The care we provide is so unpredictable and he is 2:1 all day."

"Cannot be bother and too tired to even think about it."

"Time. Money. Being needed 24/7. GP surgery refusing to help, repeatedly."

"No time or someone to sit with husband."

"I don't have time to get appointment and get to GP."

"Exhaustion, lack of energy, time and money."

"Also to be frank - when you look after someone who is so ill - your needs seem secondary. You also can't be bothered to care about yourself - you have nothing left to give!"

"Worry, anxiety, lack of sleep and exhaustion from care roles. I noticed I missed my own appointments. I didn't have time/ head space to make them or re arrange them."

"Getting to see a GP these days is impossible. I don't have the energy to try. If I needed treatment, I couldn't take the time needed out of caring anyway."

"I arrange ALL appointments, such as dental, optical, Flu jabs, Covid jabs, so that we both attend appointments at the same time on the same day. I arrange medical appointments, for either of us, so that we both attend, doctors, hospitals etc. together and I explain to whoever we see that I am my wife's unpaid carer and I need to be in her appointments and if I have an appointment, I ask if she can come in with me."

"Don't have a dentist. Am relatively healthy and rarely see a GP - last time I saw a GP for myself was 8 years ago."

"Can't get dental treatment, have not seen GP for some time."

"My appointments are never prioritised, because they can't be really. However, I am actively fitting in appointments etc. as and when I can. I am no longer leaving things."

“Dental appointments - wow!! What a luxury that be- broken teeth a plenty and no NHS dentist. Private - too expensive by far.”

“Dentists and doctors are too hard to see!”

“I only go to doctors if I really have to and can't get a dentist.”

“Depression.”

“Low self esteem.”

“Have to get on with other things so just keep going.”

“No time or someone to sit with husband.”

Question 26: What would enable you to prioritise your own health and wellbeing?

“Proper respite (being allowed to use his Direct Payments to pay for respite at time that suits us (e.g. to be able to go away/attend a wedding/appointments etc. then I could pay friends/family rather than rely on favours (prefer to do without the help than be 'using people' when we can’t return the favour). They don't need our help in return. A bunch of flowers is not enough. For example, my husband and I have never had a holiday on our own for 36 years, not one.”

“Someone else to step in and give me a break.”

“Someone to take my caring role sometimes.”

“A break. Sleeping better. Opportunities to socialise. Regaining some self esteem.”

“More time and someone to sit with husband to allow for appointments.”

“Me time.”

“Mom to agree to carers going to shower her and someone to do the housework.”

“Having carers readily available to look after loved one.”

“I would appreciate assistance with getting a suitable wheel for my mum. I suffer with fibromyalgia and pushing her in a transfer chair is becoming increasingly difficult for both of us.”

“More information on services which could sit with mum which doesn't cost the earth as a self funding client.”

“Have good professional carers who are willing to learn the skills required to support my son.”

“Adequate education, health and care provision for my children so that I do not have to provide 24/7 care.”

“Easy access to doctors.”

“Being more organised and being able to put myself first.”

“For my own health to improve, to have more time to do so.”

“I do prioritise my own health & wellbeing as I realise that I need to be well to be able to look after my dad.”

“I have to think of myself more, to look after my partner.”

“Putting myself first which is not going to happen, but I do attend all necessary health related appointments for myself.”

“I do much better than I did. I could do more however – I could probably be more proactive and actually take a bit of time out to address what should be coming up on the horizon for me wellbeing-wise and what I can actively do to enhance wellbeing in a more preventative way.”

“Greater resources esp. financial.”

“Having fund[ing] for an enabler.”

“Better resources. Financial and practical. Cheaper gyms, cheaper and healthier food availability.”

“Better benefits for those of us who need to work!”

“A little time for me or help financially.”

Question 29b: If you are not able to leave the house, what impact does this have on your own physical and mental wellbeing?

"When I have to cancel everything, I do miss the good nurturing aspects of being with someone different and hearing their views and seeing their personalities. I do like going to a cafe alone too and watching the world go by - it sort of feeds me and I miss that. I do have some massage once a month - when I have to cancel that, I really do miss that space."

"Limits my social life, stops me doing many things I enjoy including volunteer."

"I get out once every six weeks to go to the barbers for a haircut. I worry from the minute I leave the house, until the minute I get home again. I am normally only out for 45 minutes. I need this small break to be able to have a conversation with somebody, that responds to me, about all and everything. I can no longer have a sensible discussion with my wife about anything as she really is unable to do so, which is awful to say, but it is the reality. I say to her that I have nobody to talk to and have a discussion with."

"I have no friends because my caring role takes up all my time and it's the same for my husband too. The social invites dried up years ago. I feel very lonely at times. I need to get out more I know that, but I have very little confidence and I avoid people I know incase I start crying or something daft when they ask how we all are."

"My isolation is from lack of energy after caring and work. I find it hard to pick up my phone and even message someone. I don't want to be negative, or even honest about what we as a family have going on with others socially."

*"**Depression, Isolation, mild agoraphobia."***

"I'm getting afraid to leave the house."

*"**Always tired, muscle aches and pains due to lack of exercise."***

"Drained and my health is suffering."

"Feel tired, fed up."

"I struggle, I get angry and snappy with the person with dementia."

Question 30: What would need to change for you to take a break or go out?

"Carers in the home so I could go out! Cinema is a thing of the past, Theatre visit is a luxury, a meal out without taking who I care for doesn't happen."

"Easy access to help who will sit with husband."

"More cover for caring for partner while away."

"Some respite care but my son will not agree to it."

"Availability of good quality paid carers."

"Be able to find a suitable paid carer."

"Previously the CFP would attend a day centre, Mon-Fri, but this was cut by DCC after 2020."

*"**Have support available with someone who understands and committed."***

"Help for mum to be left alone."

*"**Lack of guilt? On a few occasions when I have been out for 3-4 hours my husband has had a fall or has felt unable to get food for himself."***

"FREEDOM AND LACK OF GUILT."

"My son to feel safe and happy."

"That my partner is ok and well."

"In a perfect world, a bit of normality and stability."

"More money to pay carers"

"Self funding is so expensive for someone to sit with mum for 2-3 hours twice a week."

Question 31: What would enable you to feel less isolated at home if you could not go out?

"I just want to get out. I feel trapped by staying at home."

Question 32: Do you feel that the care you provide is affected by being unable to have regular personal time and space?

Question 32a: If yes, how is this affecting you?

"I would be a better giver of care if I felt better about myself and my life as it is at present."

"Get fed up not chatting and laughing."

"Feeling so drained on a daily basis left me with no energy to think about some space for myself."

"Well, if I'm tired and stressed and depressed, that definitely reduces my effectiveness and my ability to be proactive and creative in how I do things.

"I get grumpy and irritable, less caring."

"No time to recharge, do my own thing."

"Constantly on call from my dad."

"I am desperate to have a holiday but cannot, due to circumstances."

"I have to share a bedroom with mum now as I'm up with her during the night. I have no time physically on my own."

"I never seem to have the time to do anything for me. If I'm not working, then I'm doing something for my dad or looking after my grandchild so my daughter can work."

"All they see is a bitter old woman. I will likely die young which will leave them without care."

"I'm exhausted! Sometimes I'm just so sick of her, I love her to bits but oh lord she is wearing!"

"I get ratty and impatient and take it out on hubby then feel a bitch."

"Can't leave my loved one to take a shower without them shouting for me constantly."

"I am short tempered on occasion, and I feel this is felt by my sons and sister."

"Cancelling often any arrangements I have made to meet friends because there is always some crisis or other with my parents."

"I get very run down, tired and impatient at times, I get frustrated and feel like I can't get anything done during the day, or sensible times of the day. I sometimes lose my patience with my wife and have to just walk out the room after I have moaned at her, then feel really guilty about it, as I know that she can't help it. I never get up before 11.00 am now as I am going to bed so late to get some personal time and wind down. My wife would stay in bed all day if I let her, as she feels at her worst during the day and at her best, if you can call it that, after 10.00pm, she goes to bed about 1.00 am every night."

"Occasionally resentful/wish we could join in an event we are invited to but can't go to because we have to stay at home with our son or just one of us go. Sometimes we take him with us, but only if it is something he can cope with/be appropriate at/be welcome at. We all perform better after a break/night out or holiday. Unpaid carers would perform better too if they could still have normal life."

"Find it very difficult to maintain calm and reasonable attitude with partner especially when she refuses to take safety measures (walking aids), eat or tries to access stairs unaided."

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