

Torbay Carers' Strategy 2024 - 2027 Consultation Report

January 2024



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Introduction

According to the 2021 Census there are over 15,000 people in Torbay who provide unpaid care for a friend or relative. Every three years, Torbay Carers' Strategy is updated and coproduced by Torbay and South Devon NHS Foundation Trust, Torbay Council, voluntary and community sector partners and most importantly in consultation with Carers across the Bay. The strategy, or plan, aims to meet the needs of Carers in Torbay.

To help shape Torbay Carers' Strategy, Torbay Carers' Service, with input from Carers, devised a survey to find out how support could be improved for Carers in Torbay. They commissioned Engaging Communities South West, working in partnership with Healthwatch Torbay, to independently analyse the survey data and produce this report.

About Us

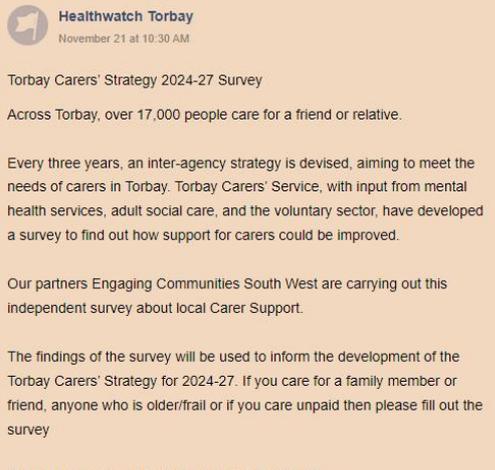
Engaging Communities South West (ECSW) is a not-for-profit organisation offering a range of services, including community voice, facilitation of engagement events, data capture and analysis, report writing, communications support, training and service/project evaluation and review. We provide these services to advance three key areas: Community Voice, Access & Empowerment, and Strategic Support. We also manage the contract for local independent health and social care champion Healthwatch Torbay.

Methodology

The survey consisted of 22 multiple-choice questions and 11 open-ended questions. 6 of the multiple choice questions included a free text option for additional comments and some questions had 2 or 3 parts. Hard copies of the survey were posted out to all Carers registered with Torbay Carers' Service and a link to an online version of the survey was emailed to all registered Carers who had provided an email address.

The online version of the survey was produced by Engaging Communities South West and shared through social media and through partner projects, including Healthwatch Torbay, Paignton Community Hub, Torbay Carers' Service and voluntary sector partners of the Torbay Carers' Service. Healthwatch shared via their social media accounts, website, email newsletter and through their community networks. There is an example social media post pictured on the right.

The survey ran from 30th October 2023 to 11th December 2023 (6 weeks) and 377 Carers responded to the survey during that time.



Healthwatch Torbay
November 21 at 10:30 AM

Torbay Carers' Strategy 2024-27 Survey

Across Torbay, over 17,000 people care for a friend or relative.

Every three years, an inter-agency strategy is devised, aiming to meet the needs of carers in Torbay. Torbay Carers' Service, with input from mental health services, adult social care, and the voluntary sector, have developed a survey to find out how support for carers could be improved.

Our partners Engaging Communities South West are carrying out this independent survey about local Carer Support.

The findings of the survey will be used to inform the development of the Torbay Carers' Strategy for 2024-27. If you care for a family member or friend, anyone who is older/frail or if you care unpaid then please fill out the survey

Complete the survey here: <https://loom.ly/N5jUFFs>



Key Findings

This section shows a summary of the key themes gathered from carers' in this consultation.

1. The top three things that Carers said would make the biggest difference to improve their caring situation were:
 - Improved communication with Carers – checking in, responding to need, providing clear advice and information.
 - Quicker and easier access to healthcare services.
 - More support for the person they care for and themselves so that they feel able to cope in their caring role, both mentally and physically.
2. The most common issues identified by Carers were:
 - Help and support,
 - Communication with health and social care professionals, and
 - Someone to check in / talk to them.
3. Nearly two thirds of Carers (63%) who responded to the survey selected their GP/ Doctors' Practice as the place where they felt they could have been identified as a Carer sooner and the place where most Carers said efforts to identify Carers sooner should be focused.
4. There is a lack of awareness and recognition of the role of unpaid Carers amongst Carers themselves. Carers suggested that more needs to be done to raise awareness of the role of unpaid Carers, using real life experiences of the day-to-day situations that people are faced with, to help unidentified Carers to recognise themselves in that role and to seek registration or access support where necessary.
5. The services that Carers find most useful are the Signposts Newsletter and the Signposts Information Service. However, the results also show that many Carers are unaware of the services available to them and some suggested that health and social care professionals also need to be more aware, so that they can signpost Carers to the right support. Carers also suggested that Torbay Carers' Services could be more proactive in providing information to Carers to make them aware of the support available to them.
6. Many Carers had high praise for the quality of service they had received from Torbay Carers' Services. Where comments were negative, this mostly related to a lack of awareness around what services are available to Carers and difficulties accessing Carers' support services. For example, Carers who work, Carers who are unable to leave the house and Carers who live outside Torbay but care for someone who lives in Torbay.
7. Almost half of the Carers who responded to the survey (49%) are caring for someone who is experiencing mental health issues. Of those, more than two thirds (68%) said they felt either 'not at all' or 'not very' supported, compared to less than a third (32%) who felt either 'slightly', 'well' or 'very well' supported.
8. More than a third (37%) of the total number of Carers who responded to the survey said they had either sought help or would be seeking help with their finances.
9. Suggestions as to how Carers' Services could be improved include:
 - More peer support / face to face support groups.
 - More information and contact with Carers about what support is available to them.
 - Better signposting to support and advocacy, particularly for Carers who feel isolated and overwhelmed.

Detailed Survey Results

This section collates all the feedback gathered from Carers responding to the survey questions. During the analysis of this feedback, some question responses were segmented by age, locality, type of carer, and type of condition. Where significantly notable differences to responses occurred after this segmentation, these were included in the corresponding question summary.

Please Note: All commentary is included as verbatim as said by Carers to illustrate the themes identified from the data analysis. Not all comments are included and some relate to more than one theme.

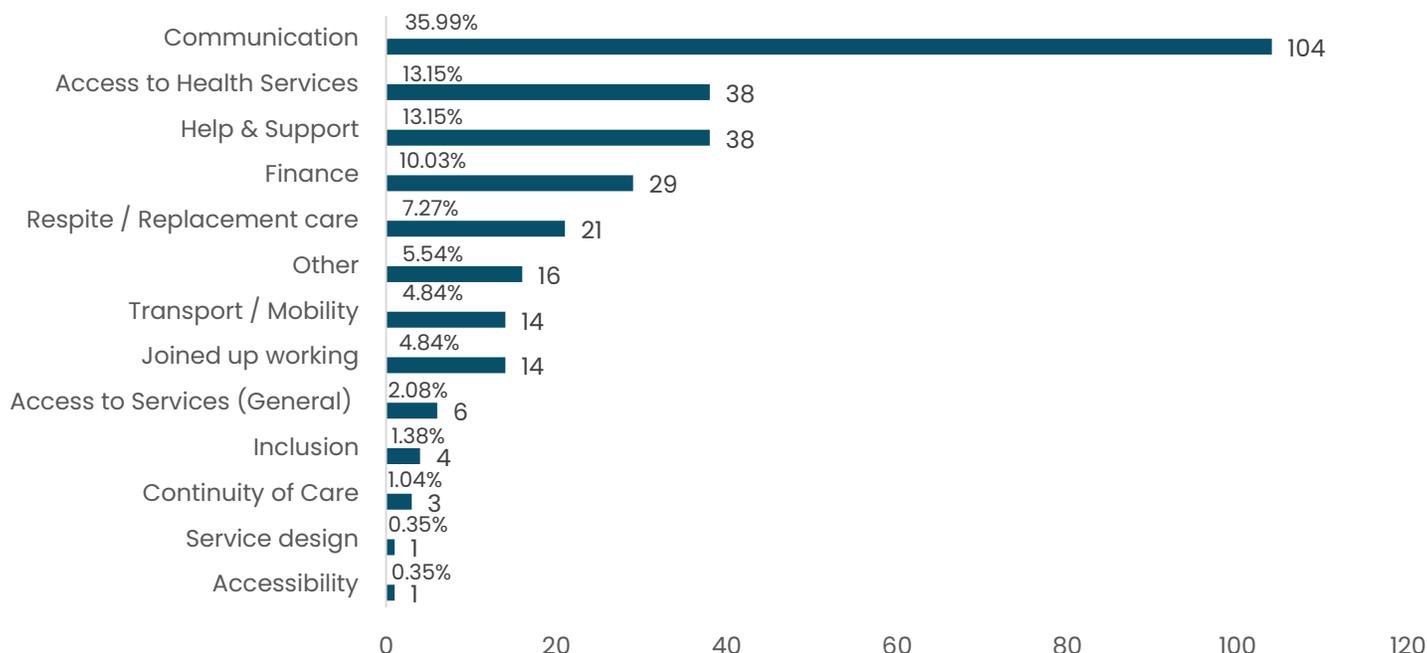
Question 1: In brief, what could Health, Social Care or Community Services do to make the biggest difference to improve your caring situation?

320 Carers responded to this question. 285 Carers (89%) provided a suggestion as to what would make the biggest to improve their caring situation. The suggestions were split into themes and the most common themes identified from the responses include:

- Communication – 104 Carers (36%)
- Access to Health Services 38 Carers (13%)
- Help and Support 38 Carers (13%)
- Finance 29 Carers (10%)
- Respite / Replacement Care 21 Carers (7%)

Fig 1 provides a full breakdown of the themes relating to the comments:

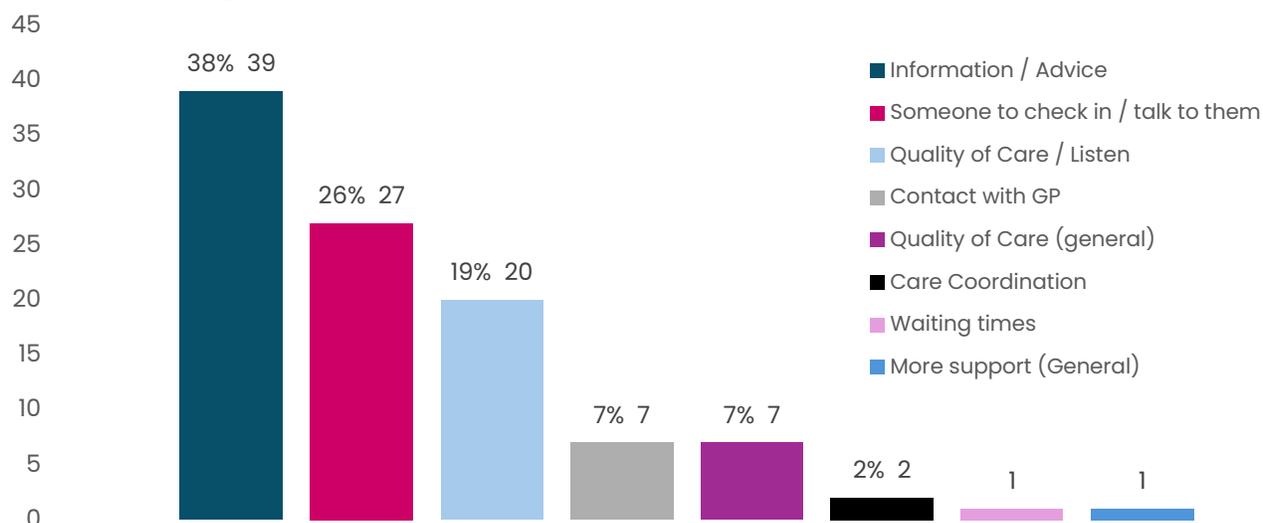
Fig 1: Themes that capture what Carers said would make the biggest difference to improve their caring experience



Where possible, the top themes were split into subthemes and a breakdown of the subthemes relating to Communication is provided in Fig 1.1.

Communication

Fig 1.1 Breakdown of theme and sub theme: Communication



Of the 104 suggestions made relating to Communication:

- 39 comments (38%) related to the provision of information or advice and the most common suggestion was a main point of contact.
- 27 comments (26%) related to improving communication with Carers by listening to their needs, recognising and acting on their concerns and keeping them informed.
- 20 comments (19%) related to Carers wanting someone to keep in contact with them so that they feel less isolated and alone and to be kept informed of what support is available to them.

Comments relating to Communication:

Information and Advice:

"Having an emergency number 24 hours that can respond to a significant need without being transferred to a number of other contacts, either practical support or appropriate guidance/advice in the moment."

"Non-emergency contact to be able to check information, guidance on other occurring situations."

"Having just one or two points of contact for all social care/community services. There are too many people/agencies involved, so that messages left and requests made are lost or misunderstood, time is wasted and so often nothing gets done."

"Help me navigate how to access support for my mum - health, wellbeing etc. give advice and information so that I don't have to spend hours researching things. I don't know what I don't know!"

"I think one of our issues is not always knowing who to go to if there is a problem, e.g. if his catheter leaks who do we call or if he falls (not always wanting to bother 999) and we get our neighbour in to help, we do have some telephone numbers, but it can get a little confusing."

"Just be there in case of need / advice and support."

"Knowing where to go for support and advice. A one-point of contact."

"Make help information more easily found. I am a listed carer but have no idea how to access the different departments. Do not say it is on the website! because of age we don't do websites or computers of any kind."

"Make it clear what help and support is available if any, especially for people like me who do not live in Torbay but the person they care for does."

"Make people generally more aware of the services you provide - I didn't know there was a Carers Service, nor did I consider myself to be a Carer!"

"Make themselves known, in a clear and precise format, both online and in paper format, as many carers are older and do not use or have internet access, of currently, can't even afford to have it. By producing a directory of the available services complete with accurate and precise descriptions of what each contact / department of the above offers and when, perhaps with a; If you need help with, contact guide. This would ensure that the correct people would be contacted, about the issues that the Carer needs help with."

Quality of Care / Listen:

"Make me feel valued! Being a carer is lonely, hard work and stressful so a regular phone call would be appreciated to say you are doing a good job."

"In short, listen more to the carer. On technical and clinical issues, the services will probably know best — and so they should. But if a carer is making a point or a recommendation, it needs taking into consideration. Services don't stand a chance of knowing the person under care as well as the carer."

"Listen more and be more accessible for people especially as sometimes one phone call is not enough also to check in with people to see that they are doing ok."

"Listen more to what we have to say."

"Listen to me as a Carer and see me as a Carer - both in respect of me but also importantly as part of the situation for my cared for person. it is not easy caring and whilst I lovingly choose to do this it does have an impact - so the smoother my interactions with services in relation to my cared for person, the easier things become."

"Someone to check in / talk to them."

"Check in more often with carers to see how they are and remind them of where then can get help and support when they need it."

"Keep in contact more with carers."

"A voice on the end of the phone when you've had a bad day but don't need an intervention just someone who understands to listen. Sometimes you don't want to bother friends again."

"Ask if the carer needs any support, as I find myself not being able to keep up with day-to-day tasks."

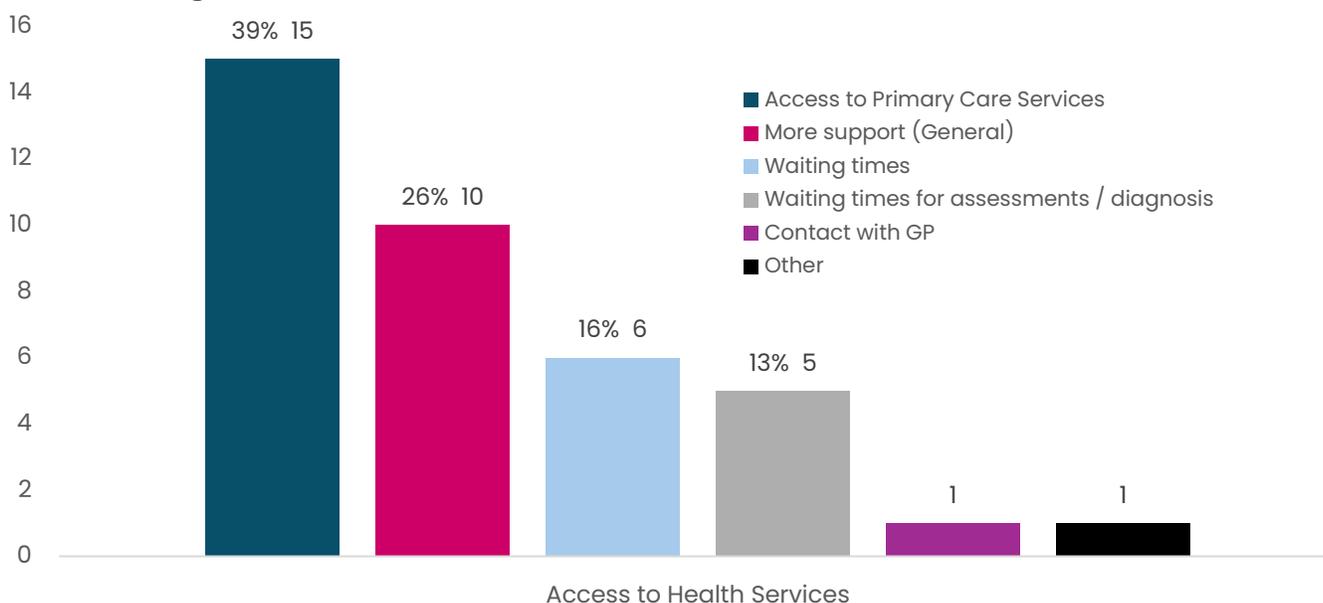
“Reach out more to carers. Once I became my husband’s Carer I felt very isolated. It felt like I was drowning, and it took me a long time to ask for help or even to know where to look for help. I had to actively seek out information when I felt I could cope with it, which was several months after my husband’s stroke. Maybe if a person is identified as needing a carer it might be possible for GPs to contact the next of kin to offer support?”

“Regular contact with somebody who can offer support to the carer and the person you are caring for knowing where you can get help when needed.”

Access to Health Services

Fig 1.2 provides a breakdown of the subthemes of the comments relating to Access to Health Services.

Fig 1.2: Breakdown of theme and sub theme: Access to Health Services



Of the 38 comments relating to Access to Services:

- 15 comments (39%) related to Access to Primary Care Services – mainly GPs.
- 11 comments (29%) related to waiting times for services, assessments, and diagnosis.
- 10 comments (26%) related to access to services and support in general.

Comments relating to Access to Health Services:

“Easier way to get G.P appointment!”

“Easy access to doctors’ appointments for myself and the 2 people I care for Enable easier doctors face to face appointments.”

“Timely response to requests for GP appointments, referrals and support requests.

“GP appointments can take over 1 week after an online submission before contact and over 2 weeks before a telephone consultation for a non-urgent call.”

“Being able to get a doctor's appointment without jumping through hoops.”

“Lobby GPs to make getting appointments easier and more face to face for the permanently & chronically disabled.”

“Have more support from doctors’ surgeries like being able to arrange doctor’s appointments in advance.”

“Prompt appointments for carers and the cared for. Better management and review of medication and general health of cared for, monitoring of their long-term diagnosis and changes to medication to be made.”

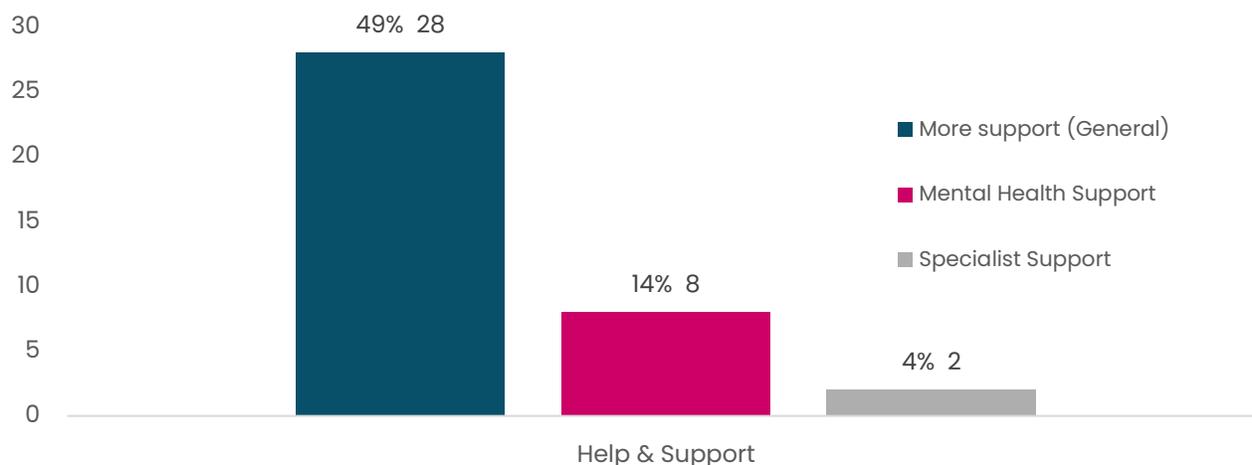
“Provide access to regular check-ups for person cared for.”

“For GP Online form can only be completed between 8 - 4:30. Can only help complete over phone between that time. Even when told to book appointment by GP must re complete form. Tell me important to look after my own health so I can support person I care for but actually no common sense or access to do so. What magically happens at 4:31 which means I can’t complete an online request form at a time that fits around my caring responsibilities. Services referred to support weight loss not accessible to Torbay residents. I feel totally devalued as a human. Told it’s really tough being a carer but no support. Must make sure I am doing everything right for the person I care for despite my own health getting worse.”

Help and Support

Fig 1.3 provides a breakdown of the subthemes of the comments relating to Help and Support.

Fig 1.3 Breakdown of theme and sub theme: Help and Support



Of the 38 comments relating to Help and Support:

- 28 comments (49%) related to a need for more support in general to help them in their caring role.
- 8 comments (14%) related to more support for mental health (mainly for the cared for)
- 2 comments (4%) related to specialist support for the cared for person (administering meds and taking bloods)

Comments relating to Help and Support:

More support in general:

“Support old carers better.”

“Support such as carers and day centres.”

“The biggest support that we get is from Torbay Stroke Survivors, they offer a sense of purpose and peer support.”

“Attend my wife 4 x a day.”

“More hands-on help.”

“More help.”

“Take my grandmother to appointments and out shopping.”

“Would like regular coffee chats with people with autistic adults to relax and maybe get ideas for the future.”

Mental Health Support:

“Help me to feel less lonely.”

“Help with person’s loneliness.”

“Mental health services to be more proactive, ongoing support for people with a mental health condition and continuity.”

“Mental health therapy should be made easier and quicker to access.”

“More mental health support.”

“Waiting lists are so long!!!! More support around mental health is needed and around autism.”

“Easier access to emotional support when required.”

Other responses to Question 1 that did not include a suggestion:

There were 35 Carers (11%) who provided a response to Question 1 but they did not include a suggestion. Their comments either indicated that they were satisfied with the services they received or were not sure what to suggest.

Question 1A: Can you summarise the main issue in 1-3 words?

301 Carers (80%) responded to this question. Of those who responded to this question 244 Carers (81%) chose an option from the drop-down list. 57 Carers (19%) provided another response. Where the ‘other’ response did not fit with any of the existing themes listed, these were categorised as ‘other’ as seen in the chart at Fig 1A. The results in full are presented in Fig 1A and Fig 1A.1. The most common issues identified by Carers were:

- Help and support
- Communication with health and social care professionals
- Someone to check in / talk to them.

Fig 1A: A summary of the main issues identified by carers

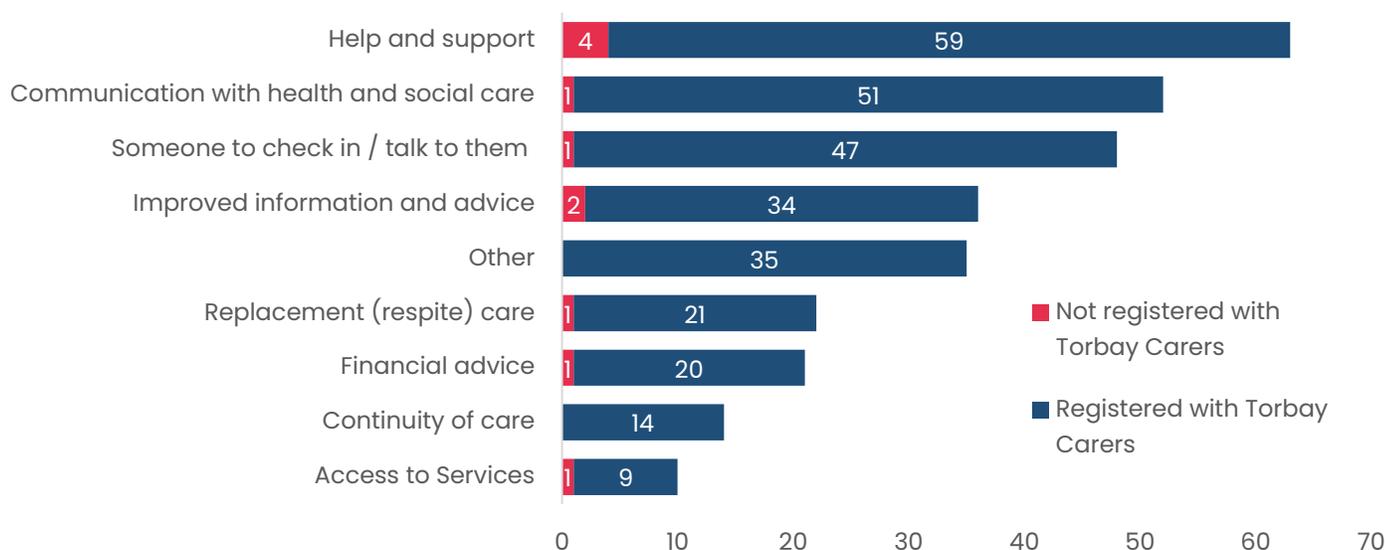


Fig 1A.1 Percentages table

Theme	Not registered with Torbay Carers	Registered with Torbay Carers	Total
Help and support	1.33%	19.67%	21.00%
Communication with health and social care	0.33%	17.00%	17.33%
Someone to check in / talk to them	0.33%	15.67%	16.00%
Improved information and advice	0.67%	11.33%	12.00%
Other	0.00%	11.33%	11.33%
Replacement (respite) care	0.33%	7.00%	7.33%
Financial advice	0.33%	6.67%	7.00%
Continuity of care	0.00%	4.67%	4.67%
Access to Services	0.33%	3.00%	3.33%
Total	3.67%	96.33%	100.00%

Other issues

Several themes are identified from the 'other' comments – Access to Services, Loneliness and isolation, Being Heard / Recognition for Carers, Finance, Mobility, Concerns about the future. Listed below are the comments that fit within these themes and any other comments.

Access to Services

"Easier access to healthcare."

"Find it very hard for my parents to 'see' a GP at present. They do not have mobiles to do E-consults, etc."

"It needs to more available."

"Weekend access to help and support."

"Make access to help from Devon County Carers available for people who live in that area but the person they care for lives in Torbay."

Improved Information and Advice

"Communication and signposting."

"Centralised signposting and data capture & storage."

"Prominent help line."

Loneliness and Isolation

"Feeling alone."

"Integration into locality."

"Isolation, stress, fatigue."

"Loneliness & isolation."

Being Heard / Carer Recognition

"No respect for carers."

"Listen to us."

"Listen, advice, emotional support."

"Recognition."

"The services don't seem to actually care or understand what we're dealing with."

Mobility

"Little effective disabled parking."

"Parking."

"Mobility."

"Local council to appreciate the difficulties when a person has mobility problems."

Finance

"Financial support and help with free/discounted help with gardening."

"More government funding."

"No income."

"Payment."

Concerns about the Future

"Worry about the future."

"Getting older slower weaker losing close friends lack of family support huge difficulties accessing medical care on interest."

"Can't leave the person I care for unattended, so we are both housebound."

Other Comments

"House living arrangements."

"Lack of innovation."

"Lack of staff."

"Not enough time for me"

"Notify courses quickly."

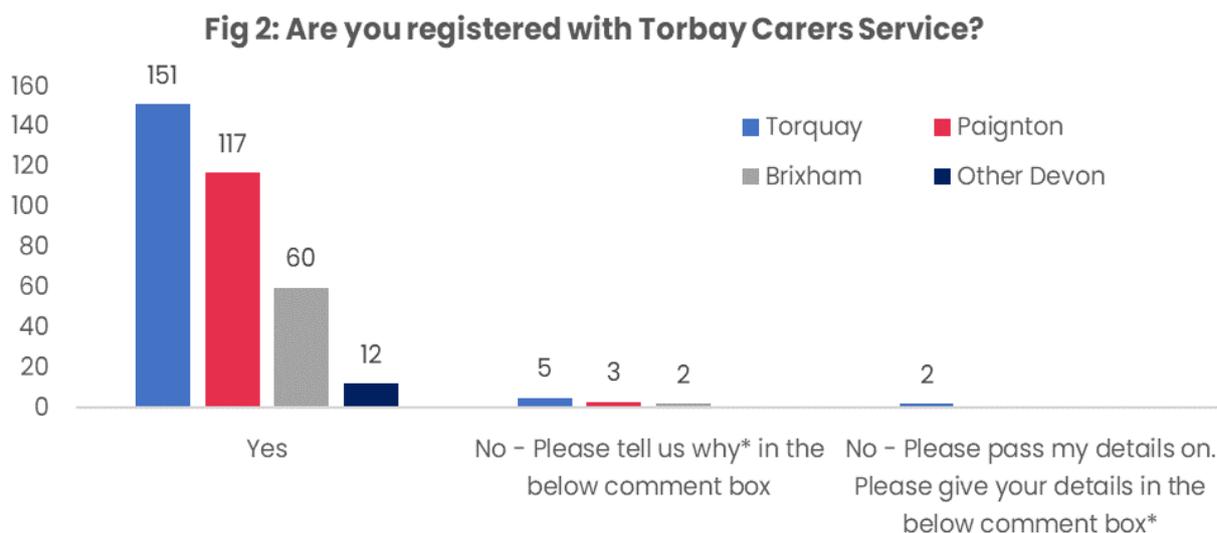
"Remove barriers to help - everything is a fight!"

"Waiting times."

Identification of Carers and Young Carers

Question 2: Are you registered with Torbay Carers?

363 Carers (96%) who responded to the survey are already registered with Torbay Carers Service. Fig 2 shows the responses to this question in a chart.



Of the 14 Carers who are not registered with Torbay Carers, 2 Carers requested their details to be passed on to Torbay Carers Service, 2 Carers intend to register to the service, 1 Carer is already registered with Devon Carers, 2 Carers were not sure of the benefits of registering with the service and 1 Carer has deregistered due to requiring care for themselves. There are no anomalies identified relating to age range or condition of the cared for person.

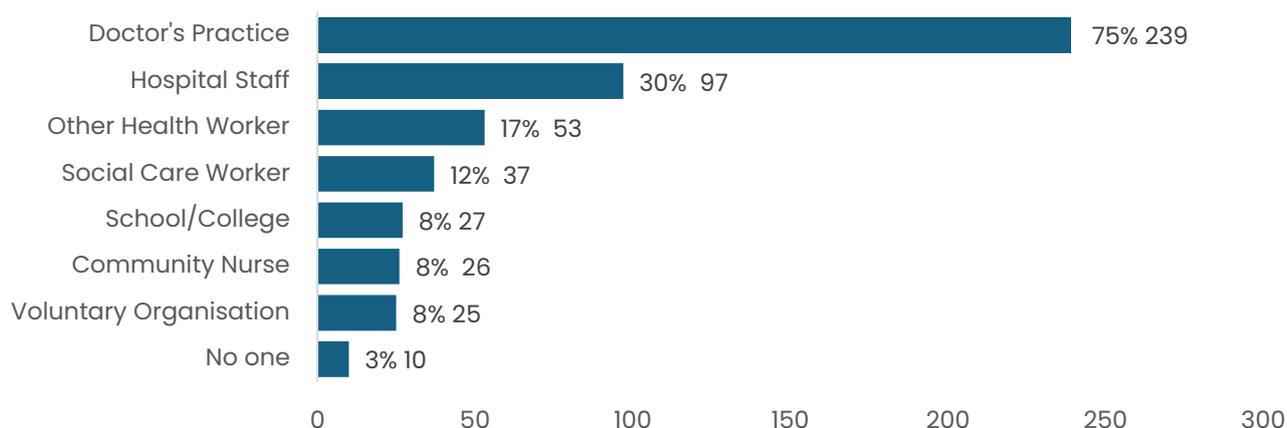
Question 3: If you could have been identified as a Carer sooner, who by?

319 Carers (85%) responded to this question. Many Carers selected more than one answer. Of those who responded to this question, the most common choices were:

- Doctor’s Practice: 239 Carers (75%)
- Hospital Staff: 97 Carers (30%)
- Other Health Worker: 53 Carers (17%)

Full results are presented in the chart in Fig 3 (overleaf).

Fig 3: Carers responses for where they could have been identified as a Carer sooner



Other suggestions included Police, employers, midwife, family, Diabetic Nurse, Local Authority, Mental Health Team.

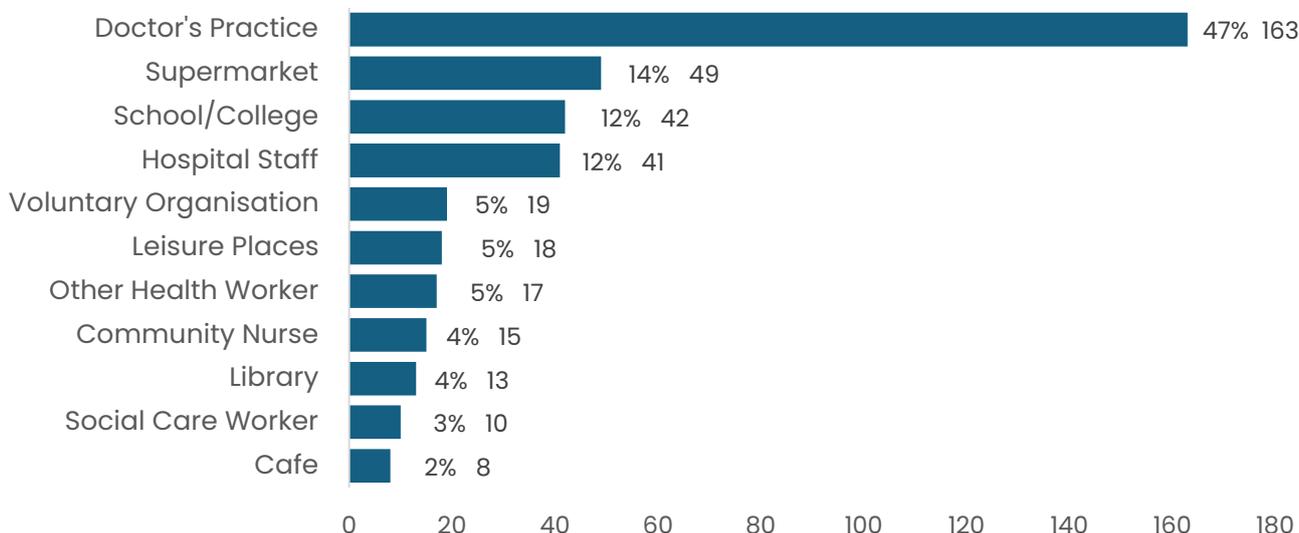
Question 4: To identify Carers / Young Carers sooner, where should we focus our efforts?

346 Carers (92%) responded to this question. Some Carers selected more than one option. The most common choices were:

- Doctor's Practice: 163 Carers (47%)
- Supermarket: 49 Carers (14%)
- School/College: 42 Carers (12%)
- Hospital Staff: 41 Carers (12%)

Fig 4 provides a breakdown of the responses as to where Carers suggest that Torbay Carers should focus their efforts to identify Carers:

Fig 4: Breakdown of Carers responses for where Torbay Carers should focus their efforts in order to identify Carers



27 Carers (7%) made ‘other’ suggestions in response to this question. 7 Carers suggested an online social media campaign, with use of video suggested by 1 Carer. A wider awareness-raising campaign was suggested by 4 Carers, to include leaflet drops, buses, churches, supermarkets, pharmacies, the local news and local radio stations.

For young Carers or parent Carers, comments included:

“Anywhere people witness struggling families should be automatically sign posted to/or representatives in early years/primary school to chat with young children about siblings etc.”

“Carers of children and young people through their child’s school”

“Clearly for young carers School/College is the obvious answer!”

“When a child is a carer should get treble child benefit for themselves.”

Comments relating to doctors or medical staff include:

“People don’t often class themselves as carers. Sadly, the Dr’s surgeries etc. are not what they were.”

“Doctors’ practice might seem the obvious choice, but it’s almost impossible to get seen these days. We were “lucky” a few years ago & were invited to a meeting by a member of our church, held in Brixham.”

“My doctor’s surgery provided carers information to me as they were involved in my parents’ care needs.”

“I was only told about it from taking my dad to his appointments.”

“I’m not sure, the hospital and GP surgery have both been wonderful and picked up that I was to become a carer straight away.”

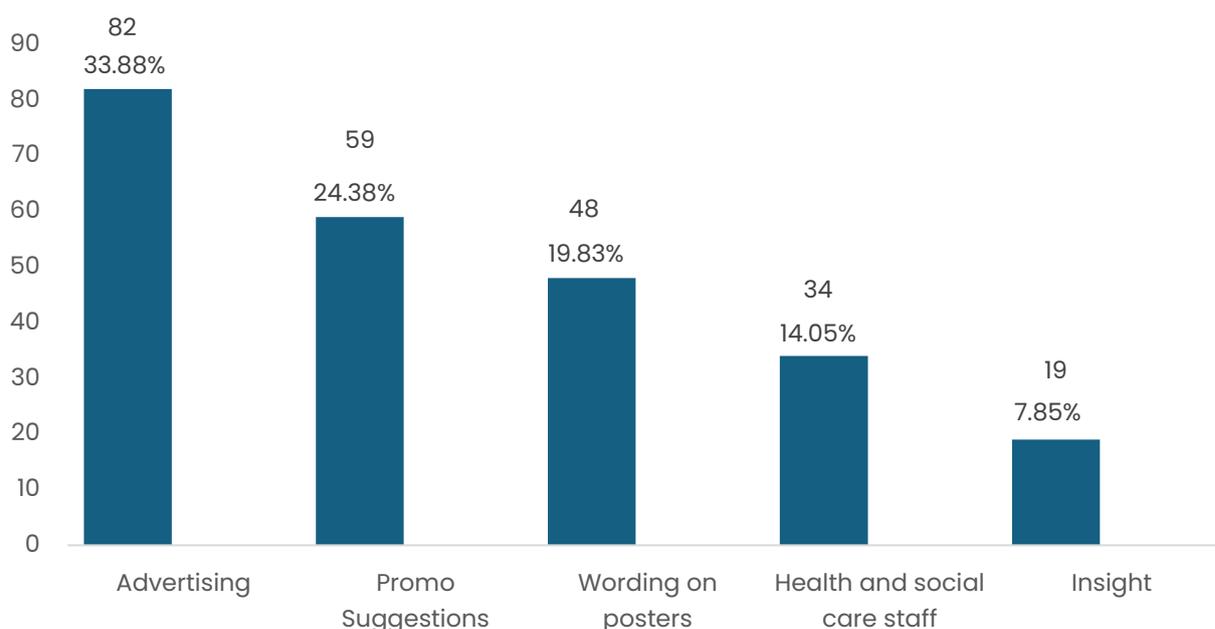
Question 5: How can Carers Services make it easier for people to identify themselves as a Carer or Young Carer? (e.g., wording on posters / advertising / promoting services somewhere different)

242 Carers (64%) responded to this question. 82 responses (34%) referred to advertising, with some suggestions as to where the role needs to be advertised more, e.g. in schools, in supermarkets, on buses, in the library, on TV, social media and on the radio. 59 Carers (24%) provided suggestions for promotional materials, including Carers cards and lanyards, which would help to raise awareness in the community. (Detailed below)

Many Carers responding to this question suggested that information needs to be clear and when promoting the role of unpaid Carers to raise awareness it is important to include a definition of what a Carer is and does. 48 Carers (20%) shared their suggestions for wording on posters and how to get the message across to raise awareness of the caring role to enable people to identify their situation as such.

34 Carers (14%) suggested that more can be done by health and social care staff to alert Carers to the fact that they are a Carer and to be recognised and registered / referred / assessed as one. 19 Carers (8%) provided valuable insight into their own experience of identifying themselves as an unpaid Carer.

Fig 5: Breakdown of what would help people to identify themselves as a Carer



Advertising

A selection of comments relating to advertising include:

"Advertising in surgeries, hospitals, supermarkets, backs of toilet doors."

"Advertising. I find advertising in public toilets effective. Especially if they are on the cubicle door or above wash hand basins and dryers."

"Don't just aim it at people caring for the elderly."

"Education schools, libraries leisure places."

"Advertising is good if it reaches people in places they go frequently. Needs to be clear and perhaps with a QR code for people to scan on their mobile phones (esp. younger people who are carers)."

"Give information to employers in the area."

"Hospital Radio."

"I never know I could get help for 11yrs then I saw it advertised in library. "

"I think the services are fairly well advertised but not sure about schools?" "Maybe social media would be a good idea for young carers."

"In outpatient clinics, GP surgeries, places where carers are often waiting with the person they support."

"More advertising, including posters in doctors' surgeries, in town, add leaflets to Council letters, post on Facebook, posters in public toilets (they do get read!) etc."

"Perhaps more tv advertising... people see but don't look, read but don't take it in... Tv is probably the best way...?"

"Promote more in schools and GPs, and the wording can sometimes put people off as some young people (me included) don't trust adults due to bad experiences."

"Spotlight 6.30 BBC by doing a programme showing how to get help as dementia is so common in communities."

"Supermarket cafes, leisure places, library where people go day to day."

"TV / radio / advertising billboards. Online / podcasts. "

"Via school and social media for the younger ones."

Promotional materials

The most popular suggestions from those responding to this question were posters, leaflets, lanyards, and badges. Other suggestions included identity cards, car stickers and table toppers in cafes. Selected comments relating to promotional materials include:

"Give them a card that has their name and maybe a photo on to prove they care for someone."

"A lanyard would be good with any special needs registered clearly printed. With carers logo."

"A small but recognisable badge /or similar issued to all carers."

"Table toppers at cafes so people can read whilst waiting their order."

"Posters in workplaces might help employers to keep it in focus. My employer has a carers policy but so far in my case have failed to act on it."

"Show the card logo or something similar to advertise acceptance or welcome etc."

"The current card is good."

"I think you are doing a great job I carry a card now which makes a great difference."

"Clear definition in plain language-message spread as widely as possible- with letters from hospitals/diagnosis etc. for carers of children."

"Coloured lanyards."

"We're still using old methods- leaflets, newspapers, radio, NHS websites - to reach out. We need a social media campaign to inform communities of what a Carer is and inform residents of how we can support them. Go to where people are now, rather than where they used to be. Admittedly, not all Carers- particularly older Carers - access social media, but their friends, neighbours and family do. So perhaps we target them using short, professional videos."

"When your loved one becomes dependent on you (and perhaps additional care) for care, the hospital or GP service should provide you with a standard document (similar to a fit note) which then triggers access to various services."

Wording on Posters

A selection of comments relating to wording on posters include:

"Identifying clearly what a carer is simply - a lot do not realise they are carers."

"Make it clear that 'if your life is being altered by caring for someone else' you are a carer and there is support on offer."

"Caring for someone close to you? Don't want to be doing it? Call us today for help!"

"Describing specialist activities a carer might do e.g. food shopping, help with medication."

"Describing the role of a carer with details of who to contact for support."

"Do you feel isolated...unheard...ignored..."

"Do you help someone else."

"Does caring for a person adversely impact the way your life. "does caring have a financial impact?"

"Don't overwhelm the poster, easy to read and straightforward."

"Emphasise that carers don't have to live with the person or do everything for a person."

"Explaining what a carer does, so that the individual can identify themselves as a Carer."

"Informative posters about carers service, eligibility info (less wording is best to get attention) so in bullet point form with website/contact number on surgery wall, and links on surgery websites."

"Large letters on poster with phone number and website, keep poster very simple."

"Make it very clear. More bold wording in big letters to make it stand out."

"Making it clearer how to go about it."

"Maybe a poster with questions e.g. do you help someone daily with etc."

"Perhaps by using a statement. People underestimate themselves in a question. Instead of 'do you care for' It might be better to use 'if you do this then you ARE a carer'."

Health and Social Care Staff

A selection of comments Carers made that highlight the role that health and social care professionals play in helping Carers to be identified include:

"All the above would work, but the social care system or doctors should be aware of carers situations when they ask for help with their family members."

"Most carers, in my experience, are speaking/acting on behalf of someone, or accompanying that person. The GP is often the first port of call and a brief question and note about who cares for the person can be a valuable identifier."

"Care providers i.e. medical staff to make people aware."

"Doctors and other staff within their practice see people who are in need of care first and should be able to identify those who are likely to provide ongoing support."

"Educating Health Care Workers & Employers what a registered carer is, and all that this responsibility carries with it."

"Encourage GPs to recommend Carer's services to patients."

"Everyone is registered with a doctor, so maybe it could be a requisite question for all that register or attend a GP, or local A&E hospital."

"Get GPs, their receptionists, their nurses to discuss it."

"Get medical professionals to inform people when speaking to them."

"Give prompt questions to GP practice so when someone joins or when someone becomes unwell, they ask who is looking after them. Also, as a parent to a child with a chronic condition I was never asked how much care I was providing."

"GP practices need to detect patients who are struggling."

"I think if social services were doing their jobs properly and sufficiently, they'd have suggested this to us a long, long time ago, especially with how much involvement we've had and how much stress they've seen us under. It was a hospital discharge coordinator that signed us up personally for it."

"Make Dr's more aware of these services. These are the primary points of contact."

"Making it easier to contact GP surgery by email would help once registered."

"Maybe where a friend or relative has permission to be given information or talk to a nurse or doctor on a patients behalf those people could be contacted directly, maybe by post, and given information about Carers' Services in that way."

"Members of staff at doctors/hospitals/supermarkets could have leaflets with them or available to pass on to people who don't know anything about being classed as a Carer."

"My experience is with caring for my elderly parents, so I'd say it starts at Doctors Surgeries, since in this scenario you're often having to sort appointments, prescriptions, etc. Seeing a poster at the surgery, or if there had been a conversation when I had asked for the surgery to note me as main point of contact for my parents, I would have been more aware."

Carers insight into their own experience of recognising themselves as a Carer

Carers who shared their insight and experience of being a Carer in response to this question, describe the impact their caring role has had on their life. Use of personal experiences such as those shared overleaf could help those who may not already recognise themselves as a carer to see similarities in their own situations.

“A lot of people just assume that it’s normal for them to be caring for a person when if you haven’t trained to be in that sector of work it isn’t. Every day people shouldn’t have to care for loved ones without a professional’s help as it’s an extremely stressful situation to be in if you haven’t got the right support, but you can’t access the support if you don’t realise you’re a Carer.”

“The whole profile of being an unpaid caregiver needs raising, as well as understanding and recognition of the importance and emotional and physical demands of the various roles it can take. There is very little real understanding of how being a caregiver can take over your whole life and it can be very isolating and hard to even know where to go for help.”

“Populate all areas that Carers visit or come into contact with, especially within health services and health service third parties, e.g.: voluntary counselling, health workers, community services etc., with relevant data and description of how to identify if you may be a Carer for somebody, for example. If you do this and that for someone, you are defined as a Carer, but may not realise it. In my case, I was caring for my wife for over two years, before I was made aware that I was a Carer and that was made aware to me during a phone call with Talkworks. My doctors offered no advice and did not make me aware of anything, which has led to my anxiety, which I have never had before, building up, with caring and worrying about my wife, who despite, getting worse, we both get no support from anybody with regards to the ongoing, four-year situation. We have been appalled at the way we have been just left to decline in today’s society.”

“Maybe explain how parenting is different to being a carer as well? Many see looking after their loved ones as part of their commitment/duty/role and do not realise when the lines start to blur and they become a carer as well as a mother/father/husband/partner etc.”

“I didn’t realise I was a Carer, because he’s my dad, I thought it was just accepted that’s what you do, at the expense of my own mental health.”

Information, Advice and Support

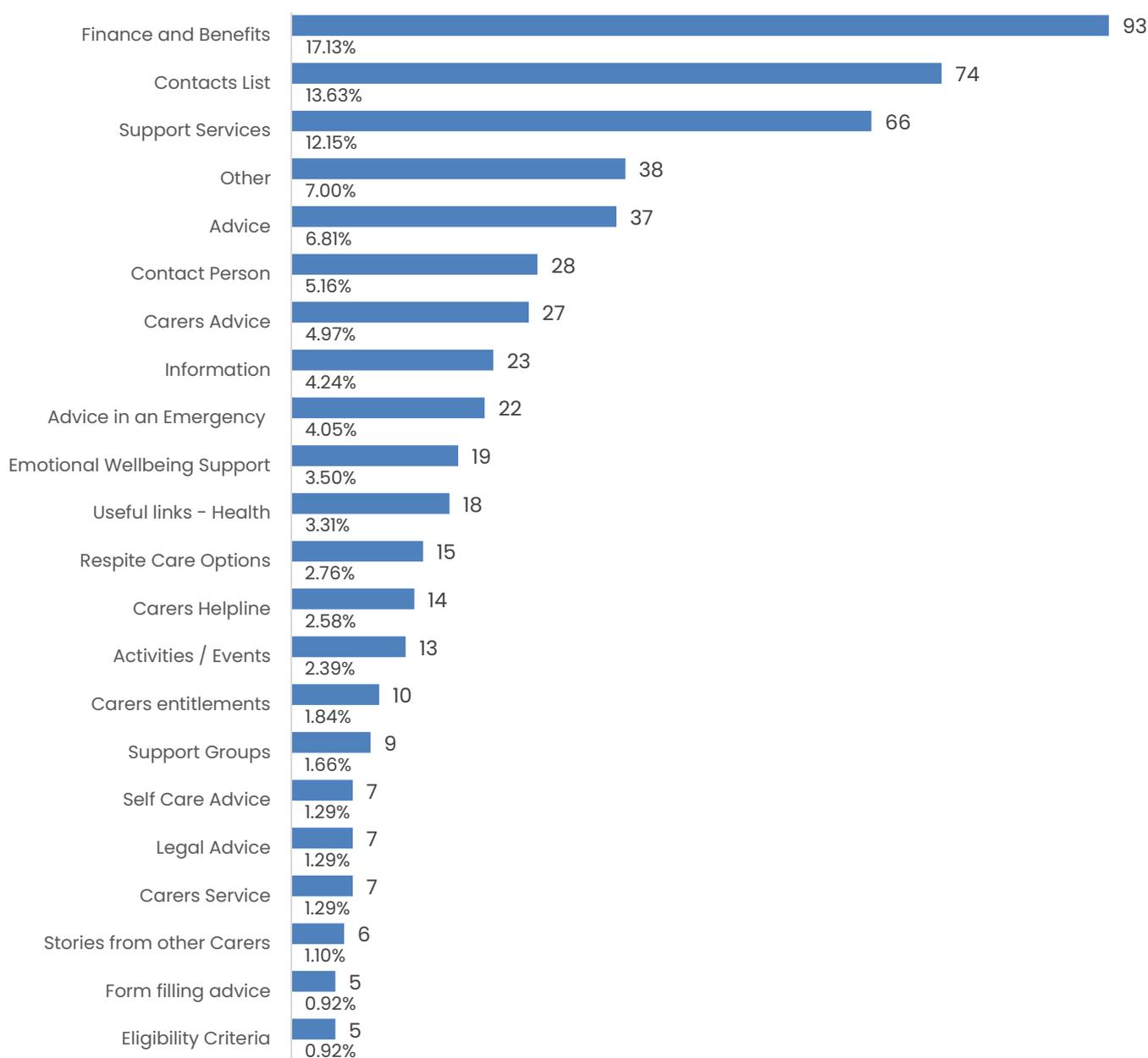
Question 6: What are the top 3 things that that you would want to find on our website?

263 Carers listed up to 3 suggestions for what they would want to find on the Torbay Carers Service website. In total 542 suggestions were recorded. Fig 6 (overleaf) provides a summary of what Carers wanted to find on the Torbay Carers Service website.

The top 5 things Carers said they wanted to find on the website are:

1. Finance and benefits information – advice and links to information
2. A list of main points of contact – signposting information
3. A list / links to support services available to Carers
4. Advice in general (FAQs how to... etc.)
5. A point of contact and details of when Torbay Carers will be available (including out of hours information).

Fig 6: Information Carers want to find on the Torbay Carers Service website



Suggestions from just 4 or fewer respondents to this question are shown as 'other' in Fig 6, which includes the following:

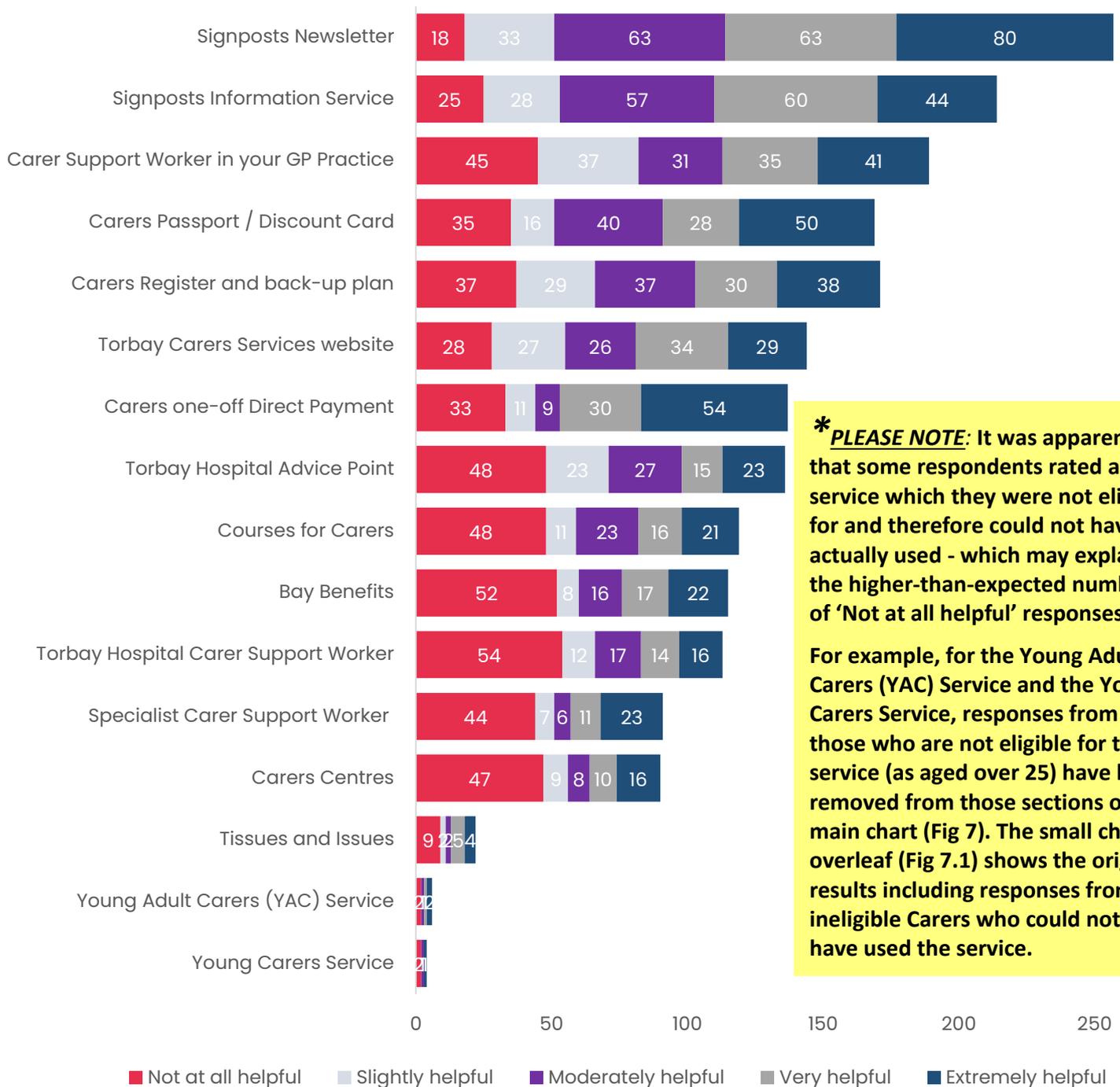
- Checklist for Carers when the person they care for is newly diagnosed
- Peer support options
- Links to out of hours support
- News / updates
- Advocacy information
- Disability friendly venues
- Online group / chat
- How to guides
- Housing advice
- Volunteering
- Healthwatch

Question 7: Of Carers Services you have used, please score how helpful they were.
 (Score 1-5. 1 is not helpful, 2 slightly..., 3 moderately..., 4 very..., 5 extremely helpful.)

321 Carers (85%) responded to this question with their ratings.

Not all services are applicable to all Carers, some are specific to younger age groups - hence lower numbers for The Young Adult Carers Service, Young Carers Service and Tissues and Issues in Fig 7 (below) which shows the results of the ratings Carers provided for each service they said they had used, filtered by the most frequently used services. Those who responded with not applicable or 'N/A – not used' have been removed for easier analysis.

Fig 7: How Carers rated the services they had used*



*** PLEASE NOTE:** It was apparent that some respondents rated a service which they were not eligible for and therefore could not have actually used - which may explain the higher-than-expected number of 'Not at all helpful' responses. For example, for the Young Adult Carers (YAC) Service and the Young Carers Service, responses from those who are not eligible for the service (as aged over 25) have been removed from those sections of the main chart (Fig 7). The small chart overleaf (Fig 7.1) shows the original results including responses from ineligible Carers who could not have used the service.

Fig 7.1: Selected Ratings including those ineligible to actually use the service (see disclaimer in yellow box on previous page for further explanation)



Of those who responded to this question by rating the services they had used, the ten most frequently used services that Carers found either slightly, moderately, very or extremely helpful overall were:

- Signposts Newsletter – 239 Carers (93% helpful*)
- Signposts Information Service – 189 Carers (88% helpful*)
- Carers Support Workers – 144 Carers (76% helpful*)
- Carers Passport / Discount Card – 134 Carers (79% helpful*)
- Carers Register and backup plan – 134 Carers (78% helpful*)
- Torbay Carers Service Website – 116 Carers (81% helpful*)
- Carers One off Direct Payment – 104 Carers (76% helpful*)
- Torbay Hospital Advice Point – 88 Carers (65% helpful*)
- Courses for Carers – 71 Carers (60% helpful*)
- Bay Benefits – 63 Carers (55% helpful*)

**Percentage of those who said they had used this particularly service and found it either slightly, moderately, very or extremely helpful overall - please also note the disclaimer on page 21.*

Question 7A: Have you any comments about any of these Carers Services?

171 Carers (45% of all Carers who responded to the survey) provided a comment in response to this question, which helps to illustrate the reasons why Carers may have rated the services as they did for Question 7.

Responses to this question were either positive, negative, neutral or was a suggestion for improvement. 7 Carers provided responses that contained 2 or 3 separate points within one response. The responses were categorised by topic, theme and sentiment.

Many Carers had high praise for the quality of service provided by services they had used. Where comments were negative, this mostly related to a lack of awareness around what services are available to Carers and difficulties accessing Carers support services. Several comments related to Carers not being contacted by anyone to provide support.

176 comments in total were analysed and the results are shown in Fig 7A (overleaf).

Fig 7A: Breakdown of comments by theme and sentiment

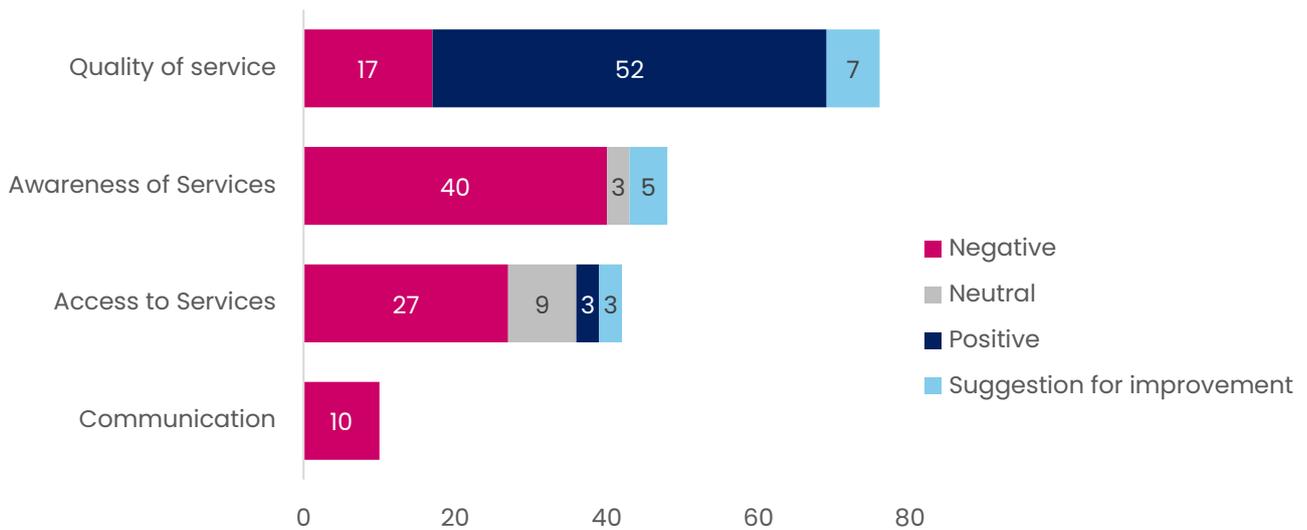


Fig 7A.1 Percentages table

Row Labels	Negative	Neutral	Positive	Suggestion for improvement	Total
Quality of service	9.66%	0.00%	29.55%	3.98%	43.18%
Awareness of Services	22.73%	1.70%	0.00%	2.84%	27.27%
Access to Services	15.34%	5.11%	1.70%	1.70%	23.86%
Communication	5.68%	0.00%	0.00%	0.00%	5.68%
Grand Total	53.41%	6.82%	31.25%	8.52%	100.00%

Where Carers specified more detail in their comment this was further broken down into categories.

Quality of Service

Many Carers value the support they have received and comments that were positive in sentiment and include:

"Pennie's support has been invaluable. Even as an ear to listen to frustrations."

"She listened when I really did need to just let out my thoughts and was never judgemental."

"Thank you we don't use you much but it's comforting to know you are there, if required."

"The initial and regular contact by phone with a support worker was very good and reassuring."

"The most helpful, honest and consistent person we as a family had the support of was Tracy Thomas. She went over and above to help us."

"The ones I have used have been fantastic."

"The ones we have used are very. Helpful"

"They are supported on the phone and the olive centre are amazing."

"Torbay Carers have been very kind."

"GP Support Worker has been invaluable but I understand we are lucky to have her for a year."

"I am very grateful for their support. The GP support worker contacted me over 6 years ago."

"Please value your support workers, without them so many carers would not get the support they need. Support workers are greatly undervalued especially by management."

"Rated 3 for all special carer support worker services."

"If it was not for Mencap Torbay (Emma Young and Team) I would not have a clue what was going on."

"Lots of useful info from Torbay Carers / Mencap."

Negative comments include:

"Not very positive feedback from Carer support in GP practices"

"No of these have helped or not offered at all!!"

"None of it is applicable or it just doesn't work. It's mainly for people dealing with dementia and therefore it's easier to put all mental health and trauma into the dementia box, everything else is too complex and no one wants to know."

"Over 65 MH support - not at all useful."

"The one-off payment is a joke."

"I found the Signposts service unhelpful and felt unsupported and unimportant as a Carer. Carers services in Torbay are disjointed and confusing and most of the time I'm too stressed and exhausted by my caring role to then try and navigate the various carers organisations. We need a joined-up service that works to make everything easier for the carer. The £200 carers one-off direct payment is better than nothing but needs to be much higher if it is to be of real benefit. It also needs to be made much easier to "justify" - I was advised to say I would use the money for a break, as this would be easier to cost - but in reality, it hasn't been possible for me to go anywhere and certainly not with £200. This payment should be completely unconditional and if the carer wants to use the money for a course of massage, why shouldn't they?"

"Consultation with Carers is good but not sure it always listens to the real needs of carers as it always seems heavily budget orientated and old school mentality. I.e. they work within their own strategy box and only make small changes which, only moves forward the Carer service slightly. Rather than following a whole plan through. This gives the feeling of carers not having their voices heard as the small steps only affect a minority of carers personally."

Awareness of Services

Almost all Carers who responded to the survey are registered with Torbay Carers Services, yet most comments relating to awareness of which services are available to support Carers are negative in sentiment.

Many Carers commented that they were not aware of some of the services listed which may indicate the need for more direct contact with Carers to inform them of what help is available and a wider promotion of the range of support that Carers can access so that they are not missing out on opportunities for support that can help them in their caring role.

Comments include:

"Don't hear enough about them."

"Don't know anything about them."

"Everyone is always very helpful and supportive once they've been in touch, but there is often a long delay in knowing about and accessing these services."

"Have not had a career discount card but would love to have one please."

"Have not heard of some of the things listed."

"Haven't used half of them because I am not sure what they do?"

"I didn't know about some of them."

"I didn't know a lot of them existed."

"I didn't know about half the things listed above. I did contact my doctor's carer support worker and she was the one who told me that because my daughter was under 16 at the time, there was NO support for me!"

"I hadn't even heard of most of those above!"

"I haven't actually heard of many of them."

"I haven't heard of Bay Benefits."

"I haven't heard of most of these??"

"I think I need to make myself more aware of what's available."

"I wasn't aware of the one-off payment. I had to take my dad to RD&E hospital from Paignton, 22 times last year on a weekly basis to get his leg dressed following a clot that had burst on his lower limb, maybe I could have got support with petrol?"

"Most of the above I haven't heard about."

"Not advertising enough."

"There are some there that I haven't even heard of."

"Young carers could do with more funding and have never heard of the carers one off payment."

"Didn't know most of them existed."

One comment related to staff awareness of the Carers Card for parking:

"Parking on hospital sites always seems to raise discussion as admin / hospital staff do not seem to be aware of what to do when presenting your carers card and requesting free parking. On one occasion I received a £70 fine notice as the reception staff had not acted on me presenting my card."

Access to Services

Most of the comments relating to access to Carers Services are negative and many refer to the fact that it is difficult to access support due to working hours.

Comments relating to inabilities to access services for working age Carers include:

"Difficult to access when you work full time."

"I don't use most of the services available to carers due to work commitments."

"I feel most are tailored to full time carers. I am a single parent. I still care full time but must work part time, so I don't lose my house. I haven't been able to attend sessions or courses etc due to my work commitments. It feels like I'm forgotten."

"I cannot access support groups because I work 9 to 5."

"I've looked at the signposts newsletter and the groups are on days I work or the day I spend with my mother."

"There is not much in place for parent carers, everything is focused on the care of the elderly."

Experiences of access to mental health support are mentioned and are mixed in sentiment: Examples include:

"As for counselling I was so, so desperate for face-to-face counselling but couldn't get it. I went in Torbay advice point to cry in there."

"I needed counselling, but it was very hard to make contact. That need has now gone."

"I was only made aware recently of the Mental Health Carers support worker and have since made contact and found him very helpful."

"Please note I am a newly registered carer so have not yet had the opportunity to use some services. I have been given access to 6 sessions of Emotional Support counselling which is excellent, and I now feel more supported in this respect."

"Centrepeace, were excellent for my wife, but after this counselling stopped, she soon declined back to how she was, they even extended the number of weeks they offered her, as they and only they realised that she was and still remains desperate for help and counselling."

Communication

Comments relating to communication were negative and include:

"I was ignored for 10 years while I cared for my son. It was just assumed I was doing what a normal parent does no one helped until he became an adult."

"Have advised my GP surgery I am a carer but have heard nothing since, except that I now am invited for flu jabs."

"I've had no contact/ check from support worker for some time. Support 2 people across 2 GP practice."

"Had one direct payment 3 years ago."

"I've been ignored and no one has talked to me."

"When they are good they are very good but sometimes they don't keep in touch."

"I was offered psychological support in preparation for bereavement, but I've not been contacted since regarding an appointment."

"My GP CSW has not been very communicative."

"My daughter was a registered young carer and then a young adult carer but she was never contacted, no-one ever called/visited to introduce etc and she is not the type to attend random meetings or meet strangers (she has CPTSD and mental health issues herself) so she just got on with it on her own with no support apart from occasional discussions with a school counsellor that she saw fortnightly."

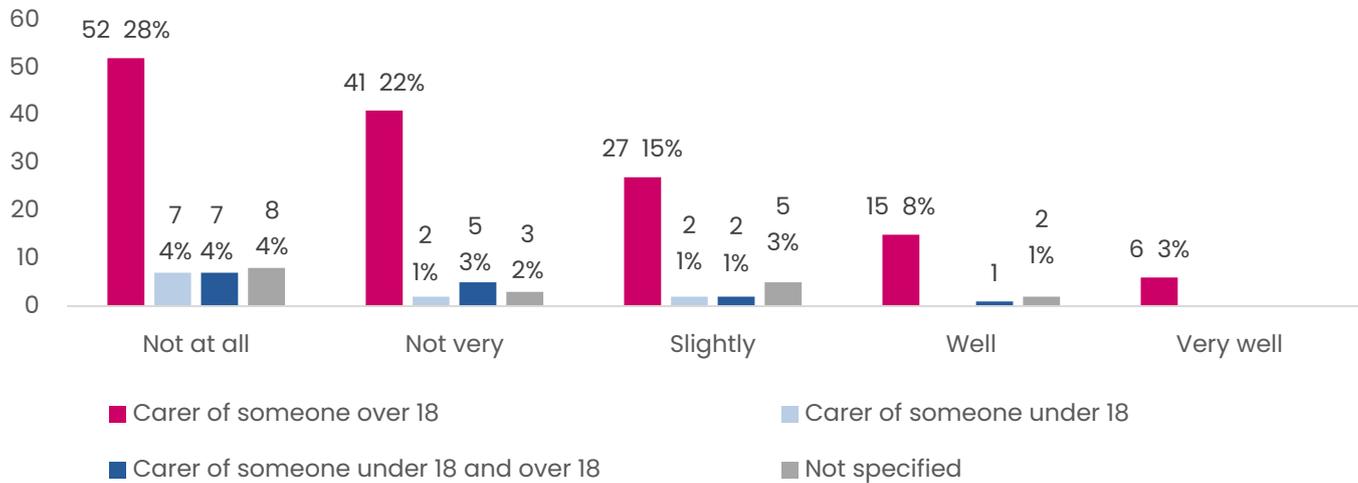
Question 8: If the person you care for has mental health issues, how supported do you feel as their Carer?

338 Carers (90%) responded to this question. Of those, 153 Carers (45%) responded 'Not applicable'. Of the 185 Carers who said they care for someone with mental health issues, 125 Carers (68%) said they felt either 'not at all' or 'not very' supported, compared to 60 Carers (32%) who felt either 'slightly', 'well' or 'very well' supported.

The figures of those responding to this question suggest that Carers caring for someone under the age of 18 feel proportionately slightly less supported than those caring for

someone over 18. This is illustrated in the results in Fig 8 below, with those who responded 'Not applicable' removed for easier analysis:

Fig 8: If you care for someone with mental health issues – how well do you feel supported as a Carer?



Question 8A: Do you have any comments?

149 Carers (44% of those who responded to Question 8) provided a comment about their experience of supporting someone with mental health issues.

- 108 comments (72%) are negative in sentiment.
- 20 comments (13%) are positive in sentiment.
- 12 (8%) comments are mixed in sentiment and
- 9 (6%) comments are neutral.

The comments were themed and a breakdown of the themes that the comment relates to, with the sentiment of the response, is provided in Fig 8A. (overleaf)

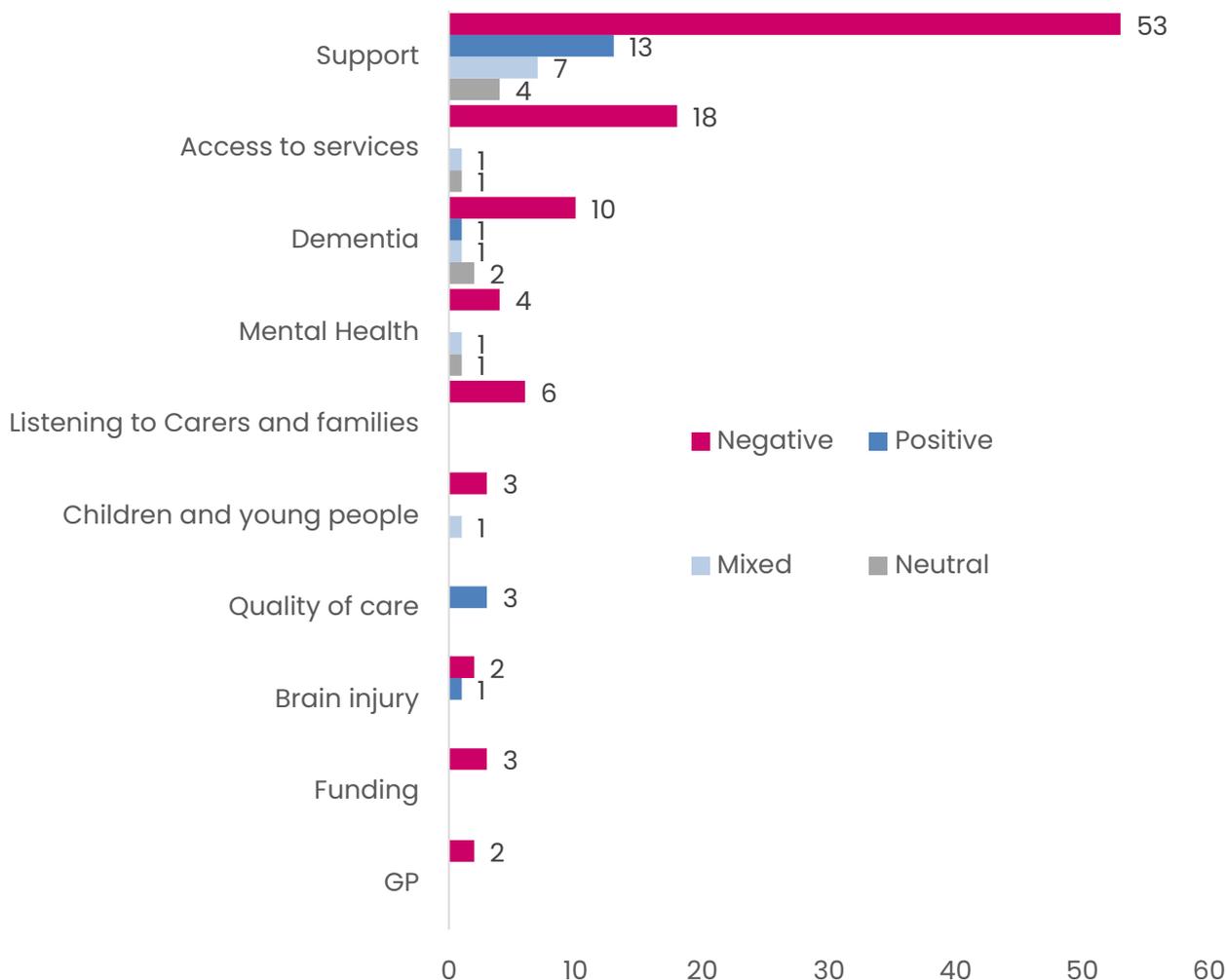
The overall feeling from the comments is that Carers who responded feel overwhelmed and unsupported. Many of these Carers are struggling to access support for the person they care for which is having an impact on their own mental health and wellbeing. Those who are seeking support themselves are experiencing difficulties in accessing the right information and support.

Some Carers who responded commented on the support relating to the condition of the person they care for, therefore comments relating to specific conditions are listed after Fig 8A. Apart from 'mental health conditions' affecting the cared for person, Dementia was the most common condition mentioned by Carers.

Other themes not included in Fig 8A, with only 1 comment per theme include:

- Peer support
- Respite
- Parkinson's
- Carer crisis
- Anxiety
- Stroke

Fig 8A: Comment themes in relation to support for Carer supporting someone experiencing mental health issues



Selected responses to question 8A relating to specific conditions include:

Dementia

“Friends stop phoning once had dementia at my age its very tiring to look after her. A regular health visitor would help as a friend to keep pointing you in the right direction.”

“I don't know who to talk to. I'm just learning how to care for my mum as her dementia has accelerated quickly. This form is now prompting me to ask for advice or help.”

“It is very stressful caring for someone with dementia and having to keep working full time, coordinate careers, medication, vaccinations, household admin for two households. What to do when we need to go away for a few days.”

“Mum has early dementia. I have had not advice or support for this at all.”

“My mother has dementia. Although dementia is common and always in the news, I don't feel that services in general have taken this on board enough yet. For all the meetings, discussions and policies there must be every day about dementia, the end result so far for us is pretty much zero.”

“My wife has been diagnosed with Mild Cognitive Impairment Alzheimer’s. I have been referred from GP to Older Person Adult Mental Care and back to GP several times. Support from both entities is sparse although it is appreciated that the lack of staff and high number support requests are the main reason.”

“No physical support available. Left to me to look after my dad who is 93 and has a dementia. I live 130 miles away.”

“Dementia is a big disease, but there is lack of information out there regarding finance issues I.e. POA, wills, etc.”

“Mum has recently got diagnosed with Dementia. Our interaction with the OPMHS has been positive.”

Children and Young People’s Mental Health

“As a carer for a young person at 12-16 years the support for them was not as effective as when they became a little older, then the approach, dynamics and conversations were different and helpful, if this approach had been available sooner our life could have been different. At 18 the service provision was noticeable different and better. There should be a MH service for 17–21-year-olds.”

“Every time I phone CAMHS I feel like a nuisance and like I'm making a fuss.”

“No MH support for teenagers. Fobbed off constantly by CAMHS.”

“Have been prevented from assessment and support for years no respite or social worker at all until over 18 when YP had complete crisis. completely failed by all services now with ombudsman who agrees as did paediatric consultants. Tragically we know we’re not the only ones. So, we’re doing this to try to prevent another suicide of a YP in Torbay.”

“When my daughter was having difficulties at her secondary school, I was told by sendiass to get a doctor's note for her and keep her home. My doctors (Pembroke House) told me they did not provide doctors notes for adolescents! My poor daughter nearly had a nervous breakdown at the age of 13 years because KEVICCs could not provide the support she needed every day but wouldn't admit this to the local government. She is now 17 so hopefully the doctors would take it more seriously now, but I doubt it.”

“I have an autistic and adhd son and a partner who has attempted suicide. I am still waiting for counselling myself. I do not feel at all supported.”

“My son is struggling, school blame it on health, Paediatrician says its the school responsibility, because he's clever we don't get any help or support. People are getting very little help and support, and expected to just get on with it.”

Adult Mental Health

“Because my son is aged 42 lives on his own and can make his own decisions it is more than difficult for me to get him to agree to see a mental health worker.”

“Being terminally ill my wife has suffered from bouts of deep depression, apart from 'pills' offered by GP access to talking therapies is woeful, and being put on a waiting whilst dying, is not helpful.”

“In emergencies as times were extreme I needed help. I used the police, although I did meet with an olive centre care worker that helped. But a crisis line or ongoing support is needed as we are getting old and both anxious.”

“Do not have a support worker the one he did have was not very good. Been out of work for 10 years due to MH issue no real help to get him back to work.”

“Hard to find OAPS help of a telephone line or a group to use.”

“No local services will commit to a long-term support plan for someone with mental health issues that affect their ability to travel. If the patient can't get to therapy, therapy isn't available.”

“I find that the support for brain injuries is very lacking so we have had to fight for any little support we can get.”

“Adult mental health services disregard carer input if they feel the adult in their service has capacity. They don't see the home picture or recognise that the carer is managing the situation all the time. It is very frustrating advocating for the adult with mental health needs if you are not recognised in your role.”

“No support from mental health team for me apart from carers voucher scheme, GP medication and self-referral to Talkworks. I was considered too complex for Talkworks! I did not meet criteria for help under mental health team.”

“It's very difficult as my I care for my partner who has very severe mental health issues, we have been waiting over 2 years for a care coordinator by Chadwell Health and Wellbeing Clinic and there has been 0 support from them at all. No one can communicate. I got told last month that someone would call me back “the next day” and I have been waiting a month for the call. Every time I call up as the carer no one wants to talk to me they want to speak to my partner but one of my partners issues is that they can't talk over the phone as it causes extreme stress and anxiety (they are autistic and agoraphobic) they were supposed to write this in the notes, but this happens nearly every time I call up. It causes so much distress for me and my partner.”

“There isn't even any help for the person with mental health issue let alone their carer.”

“Trying to get support or clear answers from services have been almost impossible. Husband has PTSD and must wait months for appointments in a crisis leaving me to help him alone. No one from any health agency checks in to see how we are in this time. Not even an email.”

“The mental health service in Torbay is not fit for purpose, nearly every interaction my wife has with them triggers her mental health to get worse. The Torbay mental health service does not provide caring support, it is inconsistent, waiting times are ridiculous, staff are rude regularly and often dismissive.”

Selected themed responses to question 8A not relating to a specific care area, include:

Access to Services

“I've been trying to get help since July. It is now nearly the end of October. For example, getting prescriptions correct and medication available at the same time so only one visit to the pharmacy is required, and getting a GP to make a home visit. This might be resolved now, since changing pharmacies.”

“My cared for does not regard himself as having any issues, so it is difficult to get him to engage with help that may be available.”

“The person I care for did not eat a meal for over 3 years and nothing was done about it even though I tried everyone. Not one person helped.”

“There is no care or support for 2 vulnerable adults with long term trauma. Doesn't work for me or my mother.”

Listening to Carers and Families

“Dr does not understand. Neither does the hospital.”

“I couldn't complain about the hours of respite I had, but when asking questions there never seemed to be many answers.”

"I feel unprepared to deal with the emotions and questions that I am asked by my partner (the Patient). She's often confused and upset by her illness and I lack to knowledge to reassure and calm her."

"As a young carer Adult often does not listen especially cared for."

"Difficult to be heard as adult who's cared for can refuse information about them being shared yet concerns still arise."

Positive comments

"Julie has been really helpful with my confidence."

"My brother supports me my mum has good and bad days and on bad days I need help."

"My son's Gastroenterology Consultant recognised that he had PTSD relating to a previous hospital experience which causes him anxiety. She referred him to the Adult Clinical Health Psychology Service, and within a few weeks we began therapy sessions. I have tried to get this support in the past with little success. My son is fully engaging with his therapist and the sessions help me to understand how to help him."

"Only Carer Support Worker at surgery had any idea what is involved."

"The almost magic answer has been to employ an independent Home Help for 8 hours a week. She takes some of the mental strain away from me and is also very good at dealing with my Partner when he is very frustrated or being difficult. We only thought of this after the one month in hospital and we are using the Attendance Allowance to pay her."

"The IATT team have been helpful to me the most."

"The Macmillan Nurses always remind me to look after myself too."

"Was carer for Mum who had dementia. She has passed and I'm now listed as carer for Dad. (I was doing both). Had regular support for Mum."

"I have had to access well-being service through my doctors and they have been invaluable."

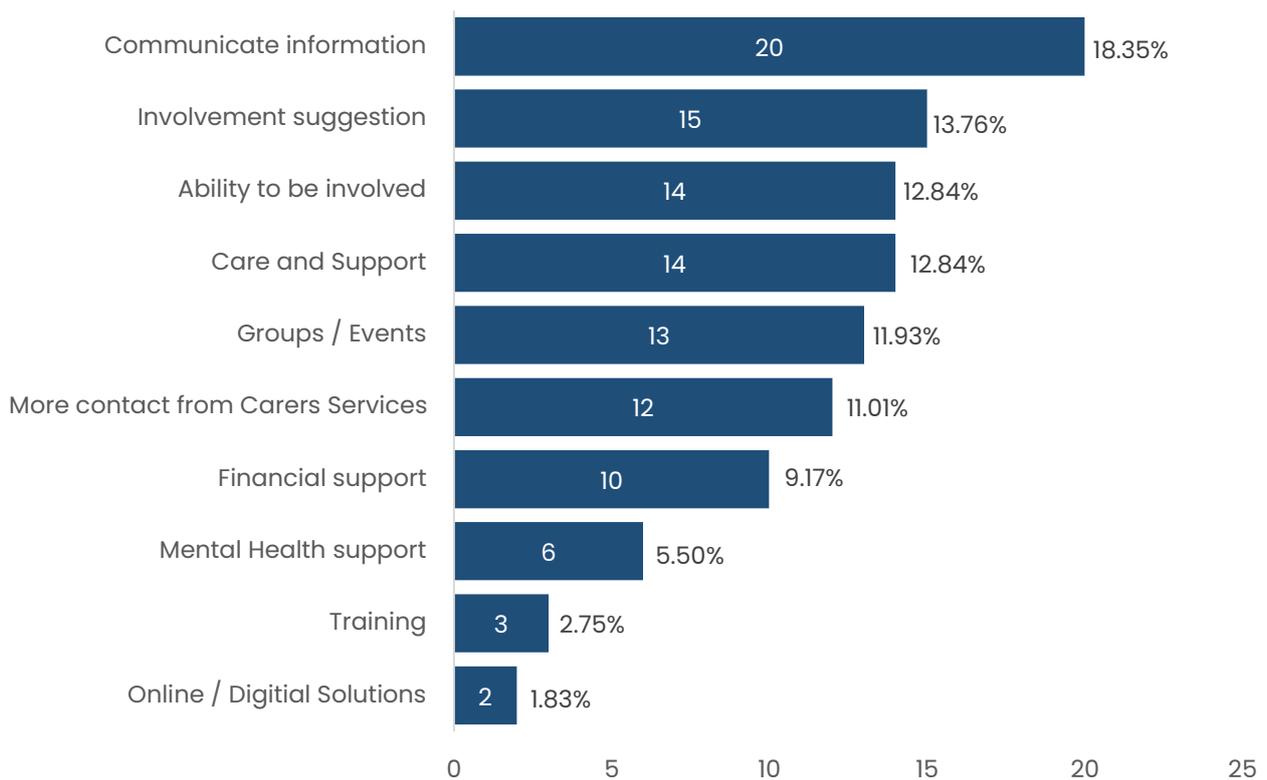
Involvement

Question 9: Are there any areas of Carers Services where you think we could improve involvement of Carers? If so, what?

119 Carers (29% of those surveyed) provided a suggestion for how Carers Services could improve involvement of Carers. The most common suggestion was to provide more information to Carers to inform them about what opportunities there are for involvement and to engage with services and to widen opportunities for involvement to include Parent Carers, Carers who work and Carers who support people with conditions such as brain injury or Diabetes.

Fig 9 (overleaf) provides a summary of the themes that Carers comments related to.

Fig 9: Suggestion themes for how Carers involvement could be improved



Selected comments within each theme include:

Communicate Information

- “Direct communication with carers.”*
- “Do we have a staff group that I have missed reading or hearing about?”*
- “Get the health services to promote it more.”*
- “I am not aware of any area of Carers services (apart from the Mencap older carers service) that involve carers in any way.”*
- “More info on what the carers service can offer.”*
- “Making help clear to carers especially new to carers. Having a directory offered to carers so they know what help is available. Enabling those who live outside Torbay to access courses.”*
- “How to help someone with dementia step by step guide also how this changes how to adapt.”*

Involvement suggestions

Ability to be involved

This theme captures Carers comments that relate to factors that impact on the Carers ability to take part in activities for Carers, whether that be because they are housebound, or they work or for another reason.

Selected comments include:

- “In my case, I can't go to anything reference carers, unless it is on in the afternoon, due to how we must manage my wife's life at the moment, so I see things that I would like to go to and can't go to them as they are mainly AM events, so that eliminates me from them.”*

“Some weekend or Out of Hours involvement. After working all day want to chill out, having a way for Carers to link to areas Carers Services want to know more. Having a portal or designated site for this.”

“Support for those living in isolation and who are unable to attend meetings and events. Video links, perhaps?”

“I think this is very individual. When I look back over the 30 years, I know there were periods where I was just surviving. Trying my best to care for my daughter and work. Maybe if I had not worked, I could have got more involved with Carers services.”

“I work full time and cannot take time off for coffee mornings etc. would be nice to have the occasional weekend or evening meets.”

“A sitting service. I can’t always get to meetings.”

“By giving Carers registered in Torquay access to events, courses etc. run by Devon Carers if like me they don't live in Torbay.”

“Evening events for carers who work full time.”

“Help with having time out of your caring role more help to look after yourself.”

“I can't attend anything in person - when my mum became housebound, I became housebound too.”

Care and Support

Comments within this theme relate to care that Carers have specified they need for the person they care for and are not specific to Carers involvement. Selected comments include:

“24 hr. help care please other than to be directed to the Samaritans when I am in so much distress. Availability, action, help, solutions.”

“Counselling.”

“Early Help & Portage - as a competent and proactive cater and parent, they were behind in our needs and not helpful at all. But if you do nothing for your children you get all the attention. It's not a fair distribution of resources.”

“Free respite for unpaid carers who are also pensioners.”

Groups / Events

Selected comments include:

“Events/ courses different times.”

“Conferences to include parents. Free legal advice.”

“Might be helpful if volunteers who represent the carers had more pop-up events to promote the sort of things you do.”

“Group sessions for Carers and Patients on Mental Health (Depression and Anxiety).”

“Groups for middle aged/younger carers.”

“Meeting other Carers.”

“More meetings to be able to give out views with our experience we have learnt.”

“Possibly more access to people in similar situations.”

“Regular meets.”

“We used to have a coffee morning for carers but that doesn't seem to happen anymore and now I am gardening.”

More contact from Carers Services

Selected comments, again not specific to Carers involvement, but in response to this question include:

“Follow up check by Carer Support Worker to ask how I was managing.”

“More regular contact with support worker and to feel they can do something to help.”

“On going support to check on a Carer.”

“Persons self-helping and asking for help to stop addiction to alcohol etc., could benefit from ongoing support after a course etc., even just the odd phone call can be a helping hand on days when they struggle with their demons.”

“Regular check ins with carers so they feel supported. Ask if there’s anything they need any advice or help with.”

Financial Support, Mental Health Support, Training, and online solutions were suggested as other ways that would enable Carers to be more involved.

Support to the person that you care for

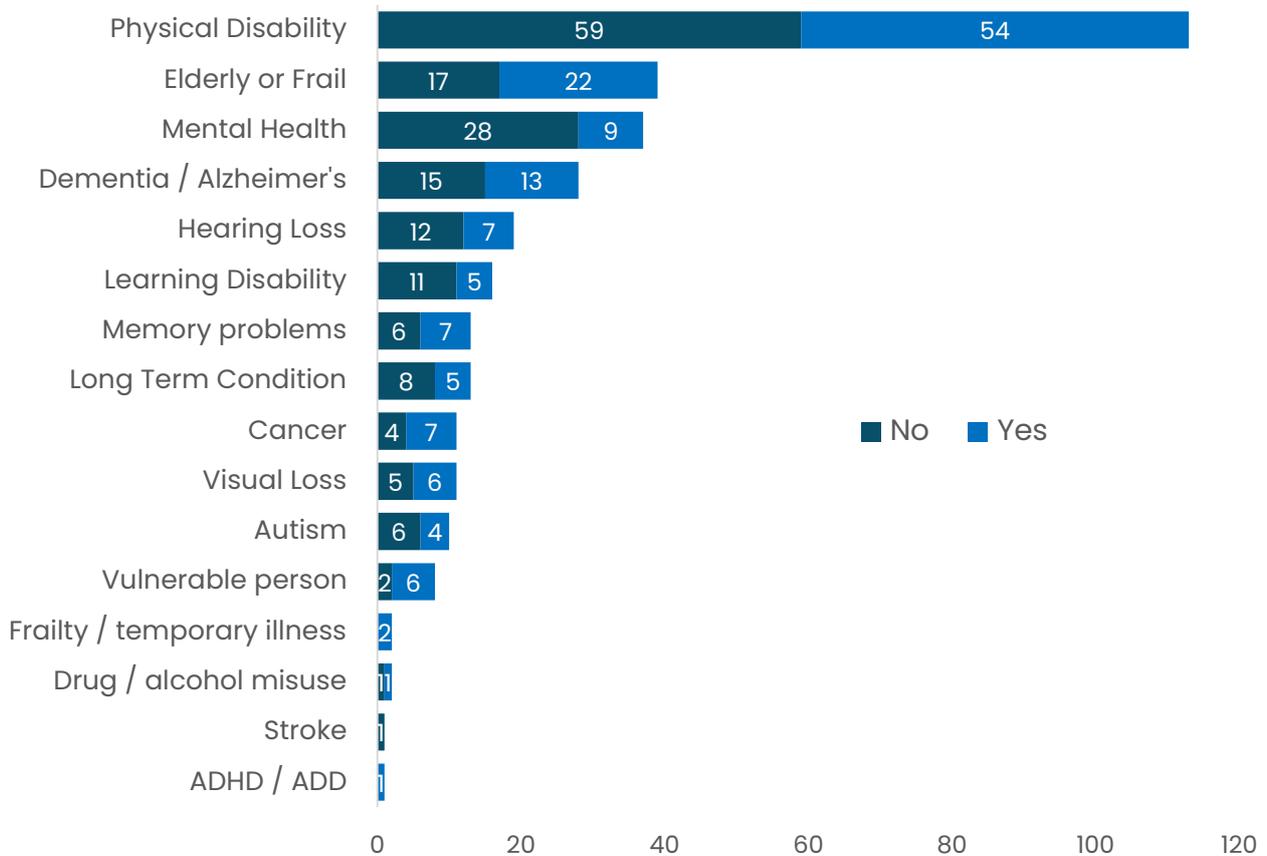
Question 10: Are you happy with any plans you have in place for a deterioration in your health or the health of the person / people that you care for?

342 Carers (91%) responded to this question. Of those who responded, 182 Carers (53%) selected ‘No’ they were not happy with the plans in place and 160 Carers (47%) selected ‘yes’ they were happy with the plans in place if their health or the health of the person they care for deteriorated.

324 Carers (95%) who responded to this question had provided details of the condition that affects the person they care for. The responses were analysed by the condition of the Person that the Carer cares for and the results show that the responses were generally even across the conditions, except for ‘mental health’ and ‘learning disability’ where results indicate that more people were unhappy as opposed to happy with the plan if one of them experienced a decline in their health.

The results in full are presented in Fig 10 (overleaf).

Fig 10: Breakdown whether happy 'Yes' or 'No' with plans if health of Carer or Cared for Person deteriorates



Question 10A: If not, what needs to be put in place?

146 Carers (43% of those who responded to Question 10) responded to this question. Of those:

- 70 Carers (48%) indicated that they had no plan in place.
- 23 Carers (16%) indicated that they needed to find someone to replace the care that they currently provide.
- 19 Carers (13%) indicated that they needed better access to a health service or professional if one of them experiences a deterioration in their health or wellbeing.
- 18 Carers (13%) indicated that they needed more help and support now rather than later.
- 10 Carers (7%) indicated that they needed advice to help them to develop a plan.
- 3 Carers indicated that they need to find alternative care that the person they care for is willing to accept.

A selection of comments include:

“My son needs extra support service and housing now and long-term there is an expectation that he/we can be signpost him to other services and that he has the ability to know what he needs and how to access services. He has a learning disability extremely poor mental health and physical mobility issues. His support workers are not skilled in this area or familiar with supporting him to

access relevant community services he wants to and with the right support able to live semi-independently, however a lack of housing and specialist supports means he must remain dependant on me and because I am unwilling to throw him on the streets it is my choice to continue in this caring role. (NO CHOICE)."

"Whenever I've tried to get help, usually in an emergency no one can find any or I don't know where to go."

"We don't really have plans other than I have a registered that should something happen to me health and social care will need to get involved as we do not have family locally who could support."

"There appears to be very little / no resources / respite places available if anything were to happen to me and my husband (who is in his 50's and mentally aware of his situation) had to go into care other than elderly care homes. This makes respite difficult, and I worry about him (and our 16yr old son) should anything happen to me."

"I am not sure as I am my sons only living relative and I am aged 74. He will receive money from my estate after my death but if my health deteriorates and he needs help he will have to gain that from outside organisations somehow."

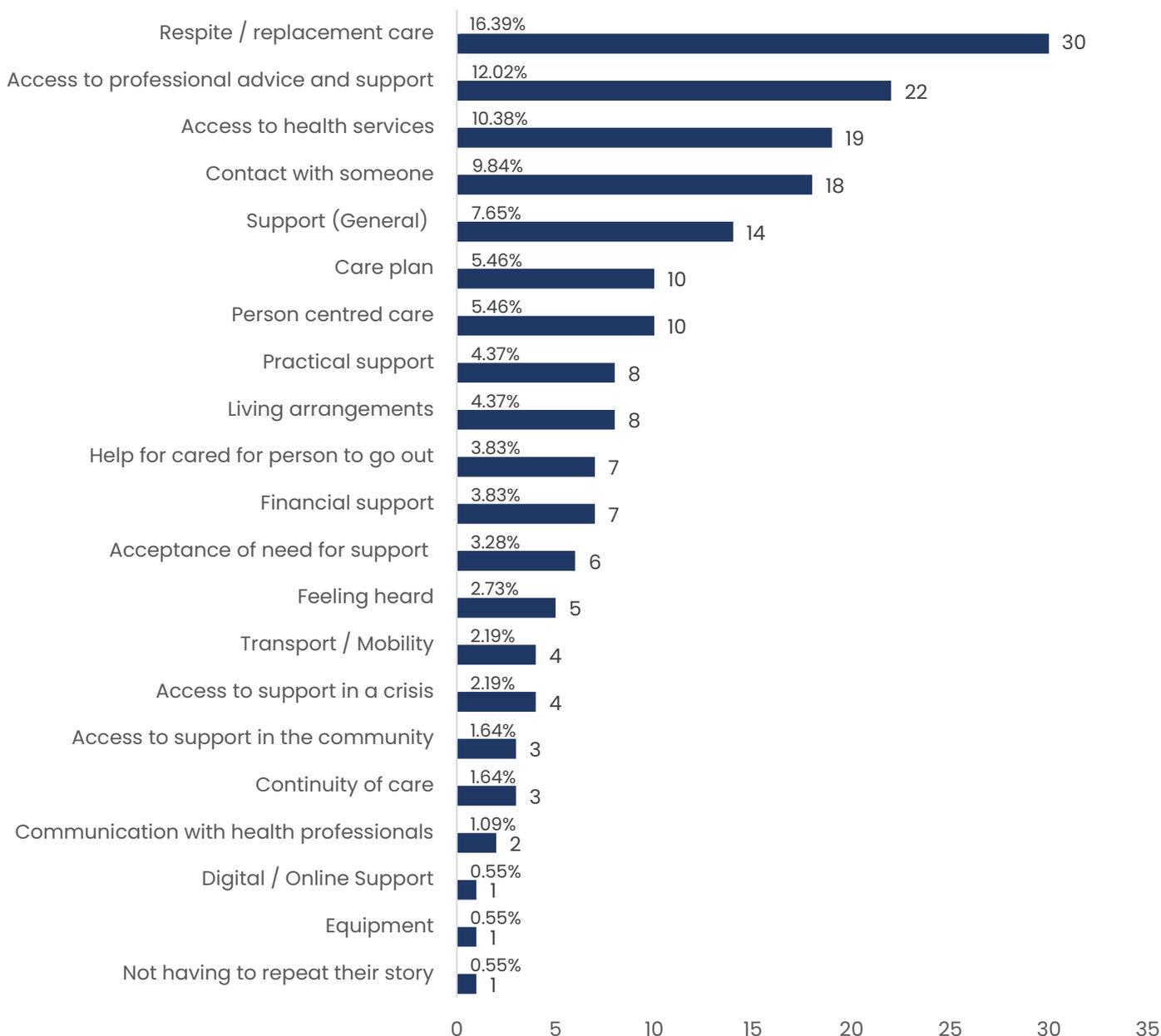
Question 11: What changes to the support to the person you care for would make most difference to you?

183 Carers (49%) provided a response to this question. Of those who responded, the suggestions were split into themes and the top 5 themes identified from Carers responses are:

- Respite / replacement care 30 Carers (16%)
- Access to professional advice and support (12%)
- Access to health services (10%)
- Contact with someone (10%)
- Support (general) (8%)

The results in full are presented in Fig 11 (overleaf).

Fig 11: Themes relating to changes to support that would make a difference



177 Carers (97%) out of the 183 Carers who responded to this question provided details of the condition that the person they care for is affected by. The top 5 themes are consistent across the range of conditions that Carers said relate to the person they care for.

Fig 11A, which can be found in the appendix, shows the numbers in relation to each comment theme broken down by the condition that the cared for person has.

The only notable anomaly was that slightly more Carers of those with Dementia commented that their living arrangements would make a difference to them, such as if the person they care for was in residential care.

Respite / replacement care

Respite (or replacement) care to enable the Carer to take a break from their caring role was the most common change that Carers said would make a difference to them.

Of those 30 who said respite (or replacement care) would make the biggest difference to them, 5 were carers of someone under 18 (13% of the total number of carers of someone under 18), and 25 were carers of someone over 18 (8% of the total number of carers of someone over 18).

The most common condition in the 25 adults (over 18) being cared for was a physical disability (31%), followed by Dementia /Alzheimer's (16%) and elderly/ frail (16%). The most common condition in the 5 under 18s was Autism (80%).

A selection of comments include:

"Having someone (male) to sit with him so I can have an outing with a friend for a couple of hours."

"Having voluntary sector support for someone to be with them during times when carers are not there. I say voluntary sector support because there is no NHS-funded system in place for people to sit and comfort people who are lonely, like my mum - who has early dementia and gets very sad and confused. There should be far more support for elderly people who get lonely, without the family having to pay privately for it, which is what I am having to do."

"Holiday scheme suitable for autistic children at a reasonable price to enable respite in holidays and social opportunities."

"Somone to take over when we want a break. But this is difficult with the autism and changes."

"Sitting service respite."

"Respite available would make the most difference."

Other comments relating to the top 5 themes include:

Access to professional advice and support

"Have a phone number he can call to receive support when he's stressed and anxious."

"Time for someone to talk to. Explanation of end of life care available."

"Understanding of her condition which seems to be lacking as there is no known cure and medication."

"Information to support care, great whilst being tested, etc., but nothing afterwards."

"Knowing what we are dealing with."

Access to health services

"A chiropodist for diabetic foot care."

"A GP can be seen or listens."

"An NHS dentist."

"Any support with my son's mental health would be welcome."

"Doctors to be accessible and see person."

"Getting an appointment and course of treatment via therapy for my husband's mental health."

"Getting her on the right medication to help her - that would help me."

"Hospital appointments as he's legs are getting worse; doctors and physios are useless."

"Knowing I can get support from mental health services when I notice a deterioration rather than waiting for a crisis."

"Next stage of treatment for diagnosis."

"Proper mental health support."

“Quicker diagnosis and treatment to prevent further deterioration.

“Regular GP contact and specialist cardiac care, IN PERSON. Much more contact from the Carer Support Worker.”

Contact with someone

In relation to the Carer themselves:

“A regular “how are things?” call from a support professional.”

“Having a named support worker to contact with needs/questions.”

“Having a personalised social worker.”

“Having a regular check in with their social worker.”

“Having a support worker, and one that is consistent. I’m dealing with this alone other than occasionally family assistance.”

“Having access to speak to someone when you need it, not just 9-5.”

“Just having someone to ‘sound off’ to (in the nicest possible way).” “Someone who understands the frustration and isolation of caring.”

In relation to the cared for person:

“Someone regularly popping in to see my dad as I live 140 miles away.”

“Someone to help them feel less lonely and convince them to trust someone other than me solely.”

Person centred care

“Better funding, more creativity, more innovation, fewer blanket rules and ‘we don’t dos’.

“He is highly intelligent and interested in things; most befriending or activity opportunities provide too little stimulation.”

“Provision of supported activities tailored to her unique difficulties.”

“The opportunity to build a rapport with people or organisations who could provide support. My daughter does not trust adults and needs time to build relationships with them. A sudden change in the person looking after her to a stranger would be extremely traumatic.”

“To get the help and support he needs in school, he needs a 1:1 yet will never get one.”

Support at Home

Question 12: Torbay’s Community Helpline links people to community-based support. If you have used this service, did they pick up any issues you had as a Carer?

355 Carers responded to this question. Of those who responded, the majority (87%) had not accessed the service. Of the 47 Carers (13%) who had used the service, around three quarters (72%) said Torbay Community Helpline did not pick up on any issues relating to the caring role and around a quarter (28%) said the Helpline did pick up issues they had as a Carer. This is illustrated in the table overleaf:

Response	Total sum	% Total
No	34	72%
Yes	13	28%
Total	47	100%

9 comments were made by Carers in relation to this question. 1 Carer who had not used the service said, "Didn't know it existed." 4 Carers commented who had used the service said:

"Care worker at my GP surgery applied for a grant so that I could have a break."

"Carer support at surgery."

"I have used 01803 446022 but not since becoming a registered carer."

"I was guided to the right person to ask for help. Thank you."

"I left message after message for a named individual who did not get back to me. It took me a few months before I finally got a call from a Wellbeing Coordinator who has been very helpful."

Comments that were negative in sentiment include:

"I contacted the hub by email if I recall, but no one came back to me."

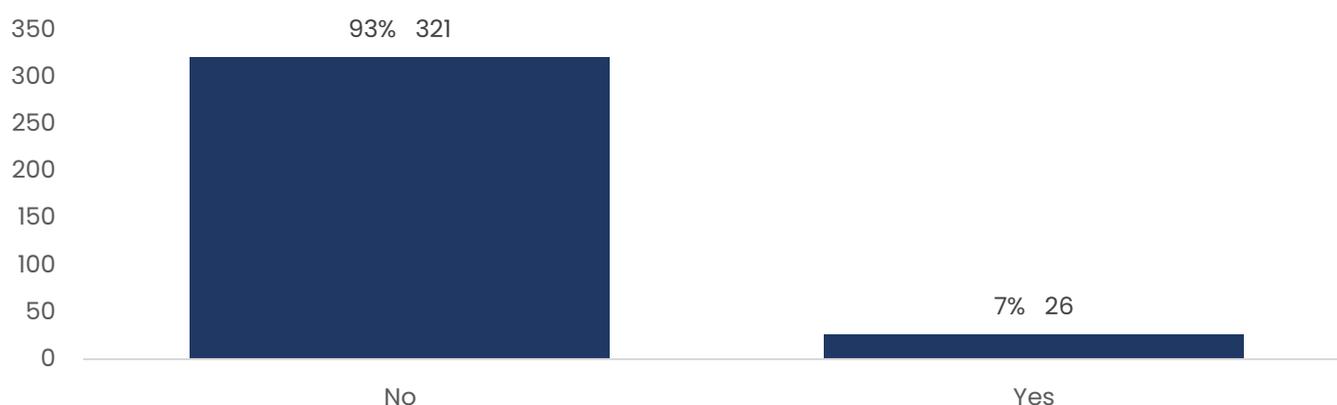
"I was told I would have a financial review and still haven't had the phone call."

"Most community things that begin with Torbay are unlikely to actually do anything useful."

Question 13: Would you like support to improve your basic IT skills or confidence?

347 Carers (92%) responded to this question. Of those who provided a response, 321 Carers (93%) responded 'No' and 26 Carers (7%) responded 'Yes'. The results are illustrated in Fig 13.

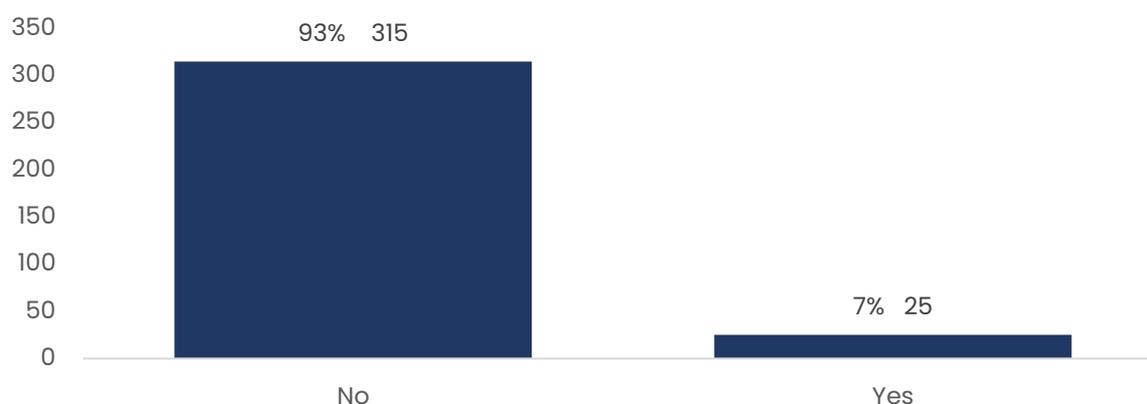
Fig 13: Would you like support to improve your basic IT skills or confidence?



Question 14: If you are confident with IT, would you be interested in supporting other Carers to improve their skills?

340 Carers (90%) responded to this question. Of those who provided a response, 315 Carers (93%) responded 'No' and 25 Carers (7%) responded 'Yes'. The results of are illustrated in Fig 14. (overleaf)

Fig 14: Would you be interested in supporting other Carers to improve their IT skills?



Question 15: Is there any online support that you find useful as a Carer, that we could share with other Carers? If so, please give detail.

56 Carers (15%) responded to this question. Of those who responded, 32 Carers (57%) made suggestions for online resources which are listed below in full as verbatim:

"Age Concern" x 2

"Alzheimer's Society Talking Point Forum"

"Alzheimer's society but they closed down in our area"

"Autism U.K. website"

"Bay Benefits need to be more widely recognised"

"Contact" charity to support families"

"Because my partner has huge anxiety about his many health issues and about life in general, I referred him to Talkworks but they said they only do short term therapy. However, they told us that since he has prostate cancer, he could have 6 free online counselling from Macmillan. This has helped him- having someone independent to talk to and she has not restricted it to cancer worries. You can book this online and then they do a telephone assessment to see if it would be beneficial."

"Benefits and work website"

"Carefree gives you a 1- or 2-nights hotel for £25.00"

"Cerebra"

"condition specific websites; for me head injury and brain tumour charities"

"dementia talking point, Alzheimer's website"

"Education with how to pay bills, insurance, even things as simple as cars. Young people usually ask parents for help, but when they are the cared for person it can make us feel alone and like we have to learn everything by ourselves. A live chat would be useful to ask these questions."

"Encourage people to use organisations' websites, like Down Syndrome Association, Cerebra, Alzheimer's Society etc which are very useful and normally provide a telephone service for advice and just listening."

"Housing help and support"

"<https://understandingdementia.co.uk/>"

"I have found the distance learning courses helpful they are provided by South Devon College"

"I think Pinpoint Devon is good idea for finding carers."

"Ipsa, Sossen, LGO Health, LGO Education & Social Services, Advocates services"

"Macmillan and Myloma UK"

"memory clinic Saturday at Baptist church very good"

"Mrsmindfulness.com"

"NHS Web page for symptoms etc"

"Parkinson"

"partners of those with Parkinson's. Zoom meetings very good, based in Exeter who invites efforts etc to discuss issues, trials, exercise, drugs etc."

"Social media online forums."

"The Stroke Association"

"Tissues and Issues, QWELL"

"Use the gov.uk website and occasionally age UK"

"Video and telephone calls."

"Yes 01803 210371 [SENDIASS]"

"Yes, let them know that the financial assessment team in Torbay IHCT are helpful."

Other comments in relation to online resources

24 Carers (43%) did not provide information about an online service they found useful, many because they do not wish to access online resources or support. These comments are listed below:

"Ability to email mental health staff when advice is needed."

"Apps on my smart phone are very useful. Ringo for parking for example."

"As a carer I prefer contact with real people not online services, being a carer can be very isolating."

"Don't like anything online you need to speak to a human being."

"Face to face of telephone is essential for over 70 carers."

"I did try online dementia support group meetings which were good but sadly I was unable to continue due to caring demands."

"I don't use online support."

"I just access your website for any information that I need, and I have always found it easy to navigate."

"I'm sorry no - I'm learning how to care and cope myself."

"It would like support face to face not online."

"No because mum doesn't know how to use the internet."

"No this is what I desperately need."

"No too busy to access support if I am honest due to full time work!"

"Online support does not work in our circumstances at all, as my anxiety stops me from concentrating and reading stuff as it won't let the information in anymore."

"My wife needs face to face contact."

"Not online but I learnt to use it through a book called computers for dummies and passed in the book to other people who are now good at IT skills."

"Not sure yet and although I am fairly confident with basic skills it is not enough to be able to assist others."

"Not that I am aware of. When I felt suicidal and wanted to drive both of us over a cliff, I felt there was no one I could reach out to."

"Like face to face why do you think everyone uses online?"

"Quite newly registered so not yet identified this."

"Systems expect us carers to have computers that we want to use!!!"

"Too much on-line and not enough face to face contact. Too many blanket e-mails from NHS and surgery urging you to do things without any consideration of the individual's circumstances."

"We both dislike doing anything online & avoid where possible. We use email & some other services when absolutely necessary, but it is not our first choice of contact."

"When in doubt 'Google'"

"Have just used Google for any queries sometimes quicker than calling, email etc."

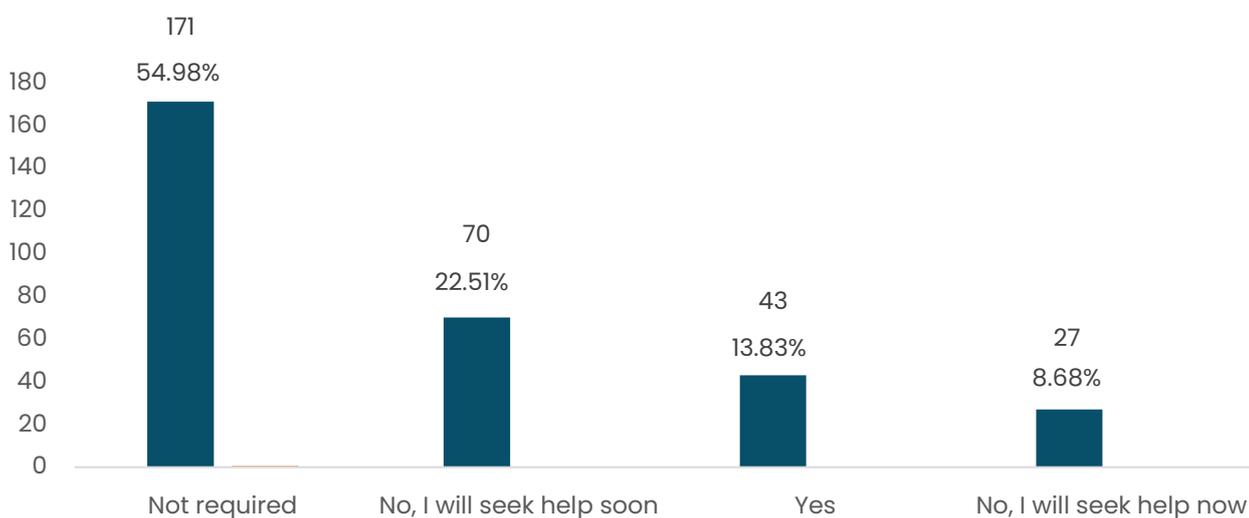
Question 16: Have you had any help that you need with your finances?

311 Carers (82%) responded to this question. Of those who responded, 171 Carers (55%) did not require any help. However, 43 Carers (14%) had already sought help for their finances, 70 Carers (23%) said they would be seeking help soon and 27 (9%) Carers said they would seek help now.

In summary, just under half (45%) of Carers who responded to this question said they had either sought help or would be seeking help with their finances. That is more than a third (37%) of the total number of Carers who responded to the survey.

Where Carers have provided their age there are no noticeable differences within the age ranges. Where Carers have provided their postcode, there is a slightly higher number of Carers who have already sought financial help in Torquay - 27 Carers out of the 43 (63%), however this is in line with the slightly higher number of Carers who responded to the survey who live in Torquay. Fig 16 shows the breakdown of the responses to this question.

Fig 16: Carers responses to seeking help with their finances



Commentary

Carers were also asked to provide comments in response to this question. 106 Carers provided further details in relation to their response. The table below provides a breakdown of the number and percentage of comments in relation to each theme.

Comment Theme	Total	% of respondents who provided a comment
Benefits entitlement	31	29%
General observation of their circumstances	29	27%
Uncertainty or a question about financial support	23	22%
Effect on mental health	13	12%
Eligibility for a funded service	7	7%
Suggestion	3	3%
Total	106	100%

General observations mainly indicated that Carers are coping within the finances they have. A sample of comments that differ slightly include:

"We have a debt plan, but I have blankets ready for winter as I can't afford heating on all the time, I even have candles mostly in lounge to cut costs on electric too."

"Often finances are based on the income of the household, but people don't realise that most of that money will go to services for the cared for person."

"Was referred to have a financial review with GP support but it hasn't happened yet."

Comments relating to benefits are set out below and split into categories where the respondent has specified the type of benefit in their comment.

Comments relating to Personal Independence Payment (PIP)

"Applied for PIP a year ago - no response."

"Because I work, I don't qualify for any carers financial support we have to just rely on his PIP."

"My son I care for was rejected twice for PIP; I am the sole earner in the household with no financial support/ benefit."

"We battled with DWP and now receive PIP/DLA. The one thing I will add is upon my 65th birthday and receipt of pension my carers benefit ceased."

Comments relating to Carers Allowance

"Carers allowance for a self-employed basis is very difficult. They require more detail than the Tax office. It's ridiculous the amount of information they want and every few weeks they want more form filled in."

"I care for 5 members of my family. All disabled to some extent or another. I get carers allowance for one of those people. One. Please change that."

"I don't claim as I know it will affect the person that I care for which I don't feel is right. I CAN get carers allowance, but it will influence the person I care for regarding their benefits."

"I think it's awful that to be paid a carer allowance you have to be a carer for 30 hours or more a week, which we most definitely do alongside a full-time job. But then you'd have to be earning a pittance to be eligible for £70 odd a week. If we are doing the jobs of people paid to do the jobs, families should be given money to subsidise lost hours when they're having to leave work early constantly to take someone shopping, pick up food, deliver food, fuel costs, help with bills of the person they care for, transporting them to hospital/GP appointments. Me and my sister do all of that, but because we work full time also, we get nothing. Yet we can't afford not to work, because a carers allowance isn't even equivalent to full-time week's pay."

"I would like my caring role to be recognised as a full-time job and receive an income. It seems unfair that because I care for my parents in my own home that my only benefit is the carers allowance which doesn't even cover the cost of one shop a week let alone the bills!"

"The limits on qualifying for carer's allowance make finding a part time job nigh on impossible. I had 12 hours a week job with Wilko which fitted in with my caring duties. Having been made redundant I cannot find a suitable job."

"The government should help carers get back into work not penalise them by taking away the carers allowance just because I earn over a certain amount, which is ridiculous when I'm providing the same level of support to my daughter regardless of working or not as I fit work around her!! It's crazy, it stops people from bothering."

Comments relating to Attendance Allowance

"I didn't realise for a long time that Epileptic fits can qualify for Attendance Allowance, often at the Higher Rate, on the grounds of Safety and Security. This money has been a massive help."

"If the person you care for has dementia - it would not occur to them that their attendance allowance could be used for outings etc. which you pay for."

"We have qualified for attendance allowance and winter fuel allowance but nothing else."

General comments relating to benefits

"My husband is unlikely to work again and I have lost my job because of his care needs. We will eventually have to live off our savings, supporting our son through college etc., before we are entitled to financial help. What was the point of working and saving all our lives when others appear to get help and have never worked."

"We are not earning enough to support ourselves but too much to receive any support. If I gave up work to claimed benefits my child would be eligible for free school meals and I could access a holiday fund. My family are more vulnerable than some families that currently access due to the large mental strain the situation has on us. We have no family or friends locally capable of supporting us."

"I fall in a hole as earn too much for any benefit I believe, but am the only person with income to pay the bills that keeps a house and food etc. So I have to ask my adult children to contribute most of their benefits towards household expenses and they are left with very little for themselves which I feel is unfair."

"Apart from carers allowance wasn't aware there was any other financial support available?"

"As she receives no benefits, it means, neither do I."

"Govt schemes and current entitlements so difficult to know if you've got what you are entitled to."

"I work and feel unable to receive any benefit other than yearly £200 from carers support which is fantastic. I don't qualify for anything else."

"I would assume anything that my person was entitled to would be given - winter fuel payment for example- rather than needed to be applied for."

"I'm not entitled to Carer support as I earn more than £132 per week. This isn't enough to live on."

"There seems to be no financial support for unpaid carers as far as I'm aware."

2 Carers commented on the service they received from Bay Benefits:

"Bay benefits are very good."

"Kyla at Bay Benefits has been key, so helpful and thorough. We need much more financial support from the government."

2 Carers commented on how they had used financial support:

"Had help to purchase a laptop which was great."

"Towards buying mobility scooter for my husband."

Carers responses indicate that there is a level of uncertainty around finance and benefits entitlements. Several Carers either asked a question or indicated that they were not sure about something in relation to finances and required support. Some of these comments are listed below:

"How do I claim the fund for carers?"

"As an unpaid carer am I able to claim one off payment and how often can it be claimed?"

"I am on a visa with no recourse to public funds. I would hope that due to this need to keep working that additional support could be available in practical rather than financial ways, to compensate for need to maintain my financial independence without support."

"I am on maternity leave and not sure what I am eligible for caring for 2 family members."

"I don't know what will happen when my son turns 18, I lose my tax credits but will still be expected to care for my son full time. He will never leave home. I have no idea how I will negotiate the future financially."

"I don't think there is financial support for my current need to alter my home."

"I would like to know whether Torbay Council offers financial support for Dementia."

"It could be clearer what financial support there is available and how to access help if needed."

"It would be good to know if my dad is entitled to any benefits and if I can have a disabled parking badge to park closer to places if I have my dad with me."

"More clarity on what is available including support would be helpful. Possible courses on finances and managing it would be good."

"The person I care for will soon turn 16 and is unable to manage their own finances. I have had no support and do not know what I should do at this stage."

"Where can we find help for financial advice?"

"Why do we only receive help every 2 years and only if you know to ask for it, I've lost out several years payment only found out by accident."

"Would be helpful to have a piece on website explaining all help available for carers. I.e. Water sure, social tariff phone broad band etc."

Mental Health

Some Carers provided comments relating to how their financial situation was impacting on their mental health. All comments of this nature were negative in sentiment and a selection are listed below:

"Always worry that benefits will stop."

"I find finding the time stressful."

"I have severe financial worries."

"It's really hard because my partner will only eat certain brands and with the cost-of-living crisis, I'm running out of money much more quickly and it causes extra stress that I don't really need."

"It's a very fine balance trying to keep head above water, financially-speaking."

"Life is now difficult to manage financially."

"Looking at having to give up work to support my wife, worried how we will cope financially and is causing stress and anxiety."

Comments that relate specifically to an adult social service funded by the Local Authority are listed below:

"Although not eligible for funded care, I wish there was some funding in exceptional circumstances."

"As written earlier, it was a battle to get the care at home for mum and the money through. Thankfully sorted now."

"Now we are above the financial threshold, so we are self-funding. I'm worried about support when we go below that threshold."

"The discount giving by the Council caused me a problem this year. Having had a discount for a number of years it was stopped as they said I had not filled in a form!"

"The formula used to ascertain what expenditure is allowed and income to determine the self-payment figure."

"The funding for a respite break for me as a carer was much appreciated."

"We get nothing from anybody, apart from £200 towards a holiday break from arranged by the GP carer support, before she disappeared."

Suggestions for improvement

Some suggestions that Carers made in relation to finances included:

"Love the tips given in Signposts Magazine, maybe a reminder of current financial issues and which Signpost Magazine issue mentioned in maybe helpful for carers."

"I believe more help should be given for general expenses for transport costs regardless of income status."

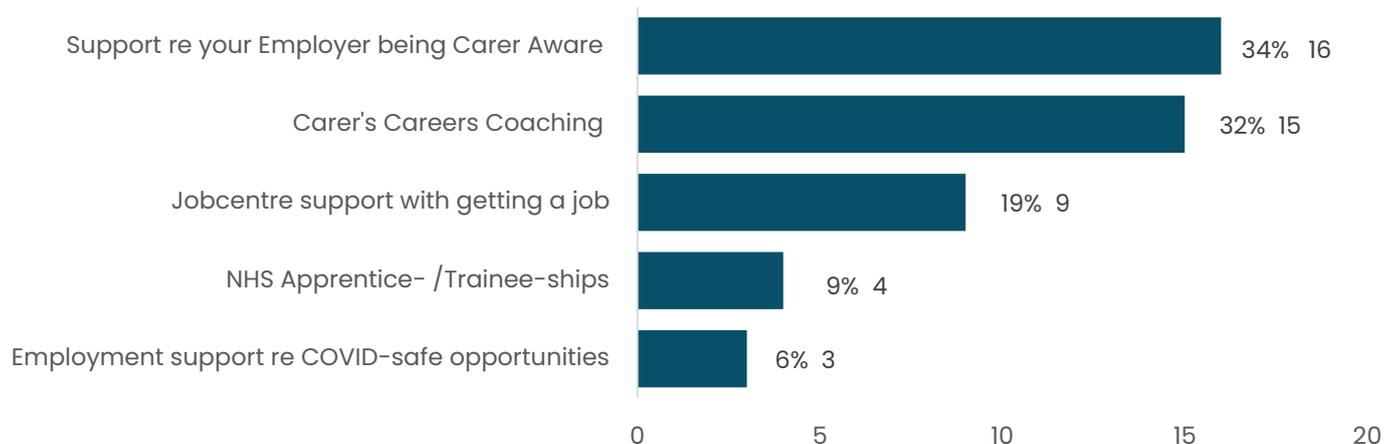
"Change the government."

Other Support

Question 17: If you want support with employment, which of the following services would be useful to help you to either stay in or to go back to employment / training?

47 Carers ticked one of the options available. Fig 17 (overleaf) provides a breakdown of the responses for each option.

Fig 17: A breakdown of support that Carers would find helpful in relation to employment or training



21 Carers provided further comments in response to this question. 3 Carers described what other support they would like in relation to employment or training:

“A network of local firms who offer flexible working to carers.”

“Advice on working from home.”

“Sewing and alterations.”

Other Comments included:

“Looking after my mum and sister means that I cannot work.”

“My struggle is that I work in the NHS, have no family support and struggle to find care for my disabled child. There is a massive shortage of enablers, and the stress really takes a toll. I love my job. But have already had to reduce my hours because of childcare and I can see that I will have reduced my hours further in time to come.”

“I can't work because of my caring responsibilities and my husband working shifts.”

“I had to give up full time job as the caring overwhelmed me. I've gone back to 2 days a week.”

“I had to give up my job as my employer wouldn't give me set hours.”

“Employers want flexibility. The financial rules don't allow this.”

“As my husband has officially retired, they stopped his EESA, we had to go onto universal credit, as he gets a pension, we get nothing, hate it.”

“Completely not on the web even have trouble trying to read screen due to macula problems.”

“From my own experience, I have not found my employer to be understanding of what it means to be a Carer. Employers can say they are supportive and flexible, but sadly saying it is different to providing that support and understanding. Education & Legislation maybe.”

“I need to be able to take phone calls and take time out to take mum to doctor's appointments.”

“I think at 69 I worked long enough and caring is now taking up all my time.”

“I would welcome the opportunity to work part time, I have always worked but it has been really challenging to find work that fits around my caring role and, I have serious back problems which restricts the type of work I can do.”

“My Employer has been very understanding but they aren't familiar with my rights and don't have a policy for carers.”

“My employer ignores carers policy other than to offer an unpaid week off which is established in law and doesn't cost them anything. All other adjustments I request are rejected - and this is an NHS [...]trust!”

“My employer is supposedly Carer Aware but things still difficult when need to take time off work for caring responsibilities.”

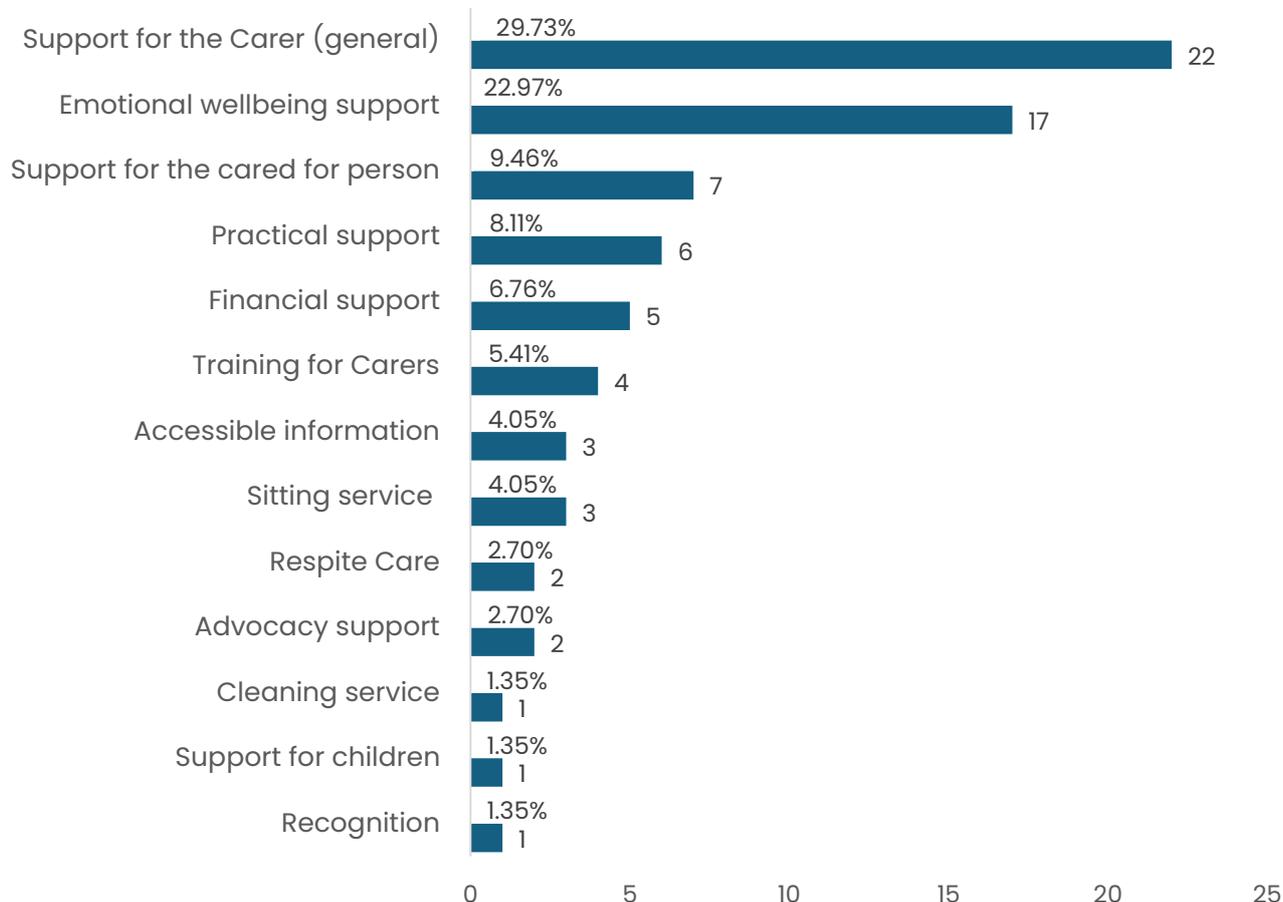
Question 18: As a Carer, is there any support you need that is not provided?

360 Carers responded to this question. 275 Carers (76%) responded to this question with ‘no’ and 85 Carers (24%) responded with ‘yes’. Of those who ticked ‘Yes’:

- 37 Carers (44%) live in Torquay.
- 29 Carers (34%) live in Paignton.
- 14 Carers (16%) live in Brixham.
- The remaining 5% of Carers lives outside Torbay.

The results are consistent with the locality breakdown of the respondents to the survey and do not indicate that there is a need for more support in either Torquay, Paignton or Brixham. Of those who responded ‘yes’, 74 Carers (88%) provided details as to what support they felt they needed that is not currently being provided. The results are set out in Fig 18.

Fig 18: Support Carers need that is not provided



Comments suggest that more support is needed for people who may have an additional need themselves, e.g. a disabled Carer and / or parent Carers of children or adults with a learning disability. A selection of comments that specify what support would be helpful is included as follows:

Support for the Carer (general)

"I have fibromyalgia so maybe a support group for carers who have disabilities?"

"Single parent carers who are either caring or are at work - how are we meant to access everything available? It's not equitable."

"Specialist support for carers who care for an adult who was born with a profound, lifelong learning disability."

"Support for carers of post-16 children."

"Co-Carers (the very elderly) will be an increasing cohort; a service for ex-Carers living alone in large houses to enable them to downsize would be a good self-funding investment, releasing large properties for residents."

"Formal support for carers of children and young people."

"Help supporting people with mental illnesses and Bereavement."

"I think there's a gap for adult carers between 25-35. Support with managing work and caring, deciding on having a family and partner and how caring may affect this."

"Support for carers working full time, that also have primary school aged children."

"Support for people caring for someone with sensory loss."

"There's no support with carers who now have long covid."

"We ALL need support, not just minority groups!"

"I am a carer who has autism and C-PTSD. support for neurodivergent parents of neurodivergent children."

"Carers with SEND needs are overlooked. Any support towards SEND needs would help."

"I care for my partner and the only other carers I know care for their children."

Emotional Wellbeing Support

Several Carers comments relate to the need for timely access to mental health support. A selection of comments include:

"Carer counsellor service would be nice, free mental health support."

"Emotional support I never have a break it is 24/7 care."

"Help and advice quickly for people with mental health problems so they don't have to wait months or even years."

"I suffer with anxiety and struggle asking for help or advice and going to groups."

"Not now but in a crisis. Mental Health- I was very stressed."

Someone to talk to as things get worse."

"Something that fixes burn-out and depression. It can be hard sometimes, but you don't get to stop."

"To be able to integrate in community or confident when visiting hospital. I have lost my self-esteem/confidence."

Support for the Cared for Person

"I feel I get no help and have been left to sort things out myself. My problems are 1. sometimes being overwhelmed or needing short term help and today 2. when I'm ill or sent to hospital there is no backup to look after him."

"Perhaps accessibility to care - discharge coordination at TBH when pt is ready to leave as my father was sent home without a care package (without anyone - (discharge coordinators)) contacting me etc then having another hospital admission."

"Short-term, urgent care situation caring for a parent who is terminally ill.

as stated above about GP services or maybe occupational health help or a physio to keep the elderly at home active."

"We are unpaid carers in our 80s and worry that our daughter would get help and advice on her own."

Other comments relating to specific types of support that Carers said they need include:

Practical Support

"A source of contact who knows my situation and can coordinated other services."

"Even when paying for services, would be helpful to access help e.g. what care homes available today."

"Help for carers to find a hobby."

"Help with filling forms out."

I'd welcome an IT course."

"IT Skills."

Training for Carers

"Being able to access some of the courses provided out of working hours, which I can't access when at work."

"Most of the events, training etc is in Torbay so not very accessible for me, it would be useful to know if any events run by Devon Carers are run in Teignbridge that I could go to."

"Video links to events and training."

Accessible Information

"Access to British Sign Language support as I am profoundly deaf."

"You assume everyone is on the net."

"Carers whose English is not first language."

Question 19: Is there anything else you would like to add?

52 Carers provided a response to this question and the results are summarised in Fig 19 by theme and sentiment.

Comments relating to Carers Services

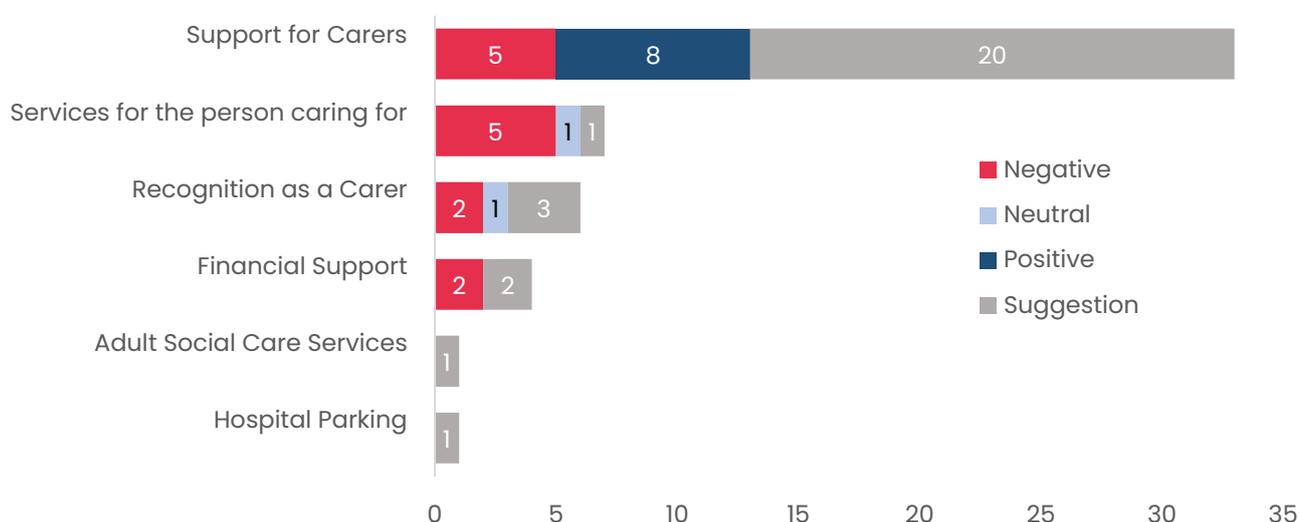
Most of the comments relate to Carers Services and more than half of them are suggestions for how support for them could be improved. All positive comments relate to Carers Services. The positive comments about Carers Services are:

- “Carers Aid are brilliant and try to support carers.”*
- “I feel that carer services are the only service that has helped me since my son returned home in April.”*
- “I feel Torbay carers service do really try to do a good job.”*
- “I like that you're available pretty much all the time, even if I don't use you. It's comforting.”*
- “Please just keep on keeping in touch with the newsletter.”*
- “The course are very friendly and a chance to meet new people.”*
- “Very happy with the support I get.”*
- “Torbay carers courses are great throughout the year. Looking after carers, enables carers to do their role better. Carers need to be cared for too.”*

Comments that are negative in sentiment (although not specific to Torbay Carers Services) include:

- “Even though I registered as a carer years ago - I only had my first actual carers assessment this year! Surely this should be automatically flagged as required on application?!”*
- “Not enough face to face support. Too much repeating of information over and over again. Lack of time to spend doing admin or chasing things up.”*
- “When I ask for local help, no one I approach is "appropriate" or able to provide support.”*

Fig 19: Breakdown of comments by theme and sentiment



Several Carers made suggestions for how support for them could be improved. Suggestions relate to peer support / support groups, more information about what support is available, better signposting to support and advocacy, particularly for Carers who feel isolated and overwhelmed. Selected comments and suggestions are listed as follows:

Comments about peer support / support groups

"Local support groups would be good - carers supporting each other."

"We need a space to come to relax, have time out, quiet space, alternative therapies, and dedicated counsellors. Preferably all under one roof."

"Before the pandemic there were monthly carer groups but now not anymore and that is a shame."

Comments about information and signposting Carers to relevant services

"I just wish it was more proactive. It sounds as though there is support out there, but I don't have the time to find it. If only someone could reach out and give me an introduction for an hour on what might be relevant in my situation."

"Lots of caregivers go under the radar. Really need to raise the standards of signposting. A little paper leaflet in the GP surgery doesn't cut it. The minute someone is awarded carers allowance they should be registered with local authority and sent relevant information. There is no macro view of the role, which is by its daily dynamics isolating. It seems very hit and miss whether you are identified or stumble on the relevant info."

"The Signposts magazine is excellent, but I think that as well as that and websites, I would appreciate a little handbook with everything Carers need to know in Torbay. Forgive me if this already exists but I am not aware of it."

"Could do with more support to help with my own health e.g. weight loss."

"Guidance on where to buy disability aids etc."

"Support with LPA, going to a solicitor is very expensive and feeling daunted doing one online."

Support and advocacy for Carers who are isolated and overwhelmed

"You do a great job for 'hobbyist' carers. These are the carers who can pop out for free cake, or do some training, or attend your carers celebrations, have time to fill in your surveys, sit on the LDPB etc. You need to be concentrating on us isolated, invisible, exhausted, on the brink of giving up, 24/7 carers of profoundly disabled people."

"Continuity of support."

"Please stand up to the local authorities for us as we are exhausted burnt out and that's what they bank on."

"Someone is needed to be our support to get the best outcomes in reviews - time parents had the opportunity to be paid in the direct payments - instead of just saying 'devoted' parent."

"All as written before to give the support and care. Following up on the person who you care for."

Other suggestions include:

"I would like to learn how to give the best care."

"Improve and free car parking arrangements."

"More health checks"

"On going grief counselling maybe."

"Please can you help carers who work as well as care."

"Please use the resources you are given better, so much money wasted." "Something for carers with Autism."

"Training on dealing with autism."

"Parking at Torbay Hospital is ridiculous and shows no signs of improving. We do not qualify for a blue badge, and as such parking is always a pressure no matter how early you turn up for an appointment. And if you can park, there is generally a fair distance to walk with an elderly relative to the appointment. A wholesale review and change to parking at Torbay Hospital is required, driven by Healthwatch, Carers organisations, and the Council, not just the Hospital."

Comments relating to Carer recognition

Negative comments include: *"it can be tough and relentless" and "sometimes feel like you are on your own."*

Comments and suggestions made that empower the Carer are:

"I believe the only people who can truly understand and support Carers are other Carers."

"Accept and appreciate the work we do especially as we need care ourselves."

"More publicity about how many unpaid carers there are might bring the lack of support due to lack of funds might raise awareness."

"Stop treating us as just 'family' and value that in fact, we are often doing jobs of those who should be doing it."

Comments and suggestions relating to financial support

"3x increase includes benefits, young carers should get treble child benefits and identified correctly through the government."

"Approach local council see if can get reduced council tax if you are an unpaid carer for over 35hrs per week? Give us a medal!! A free pizza?"

Comments and suggestions relating to services for the person caring for

"I don't mind assisting with these tasks, but I object to the assumption that the services can just leave me to get on with things. Little support or follow up."

"If a carer calls ASC they are phoning for a reason don't make them wait weeks before a return call is made adult social care is not fit for purpose."

"If my daughter could be treated with empathy and compassion and personal care on my daughter. Emotional and physically I am drained."

"I've been disappointed and help delayed due to confusion between NRS and the O. T's and between NRS and the Care Support Workers. This has been very frustrating causing delays in equipment my parents need. Professionals need to be informed if NRS does not have stock of an item, or NRS needs to have replacements readily available. We were sent in circles!"

"My wife can't/won't take Memantine. Another medicine could be appreciated but I told there is none. This is strange."

"At the moment my husband and I help each other but that's changing as his condition develops."

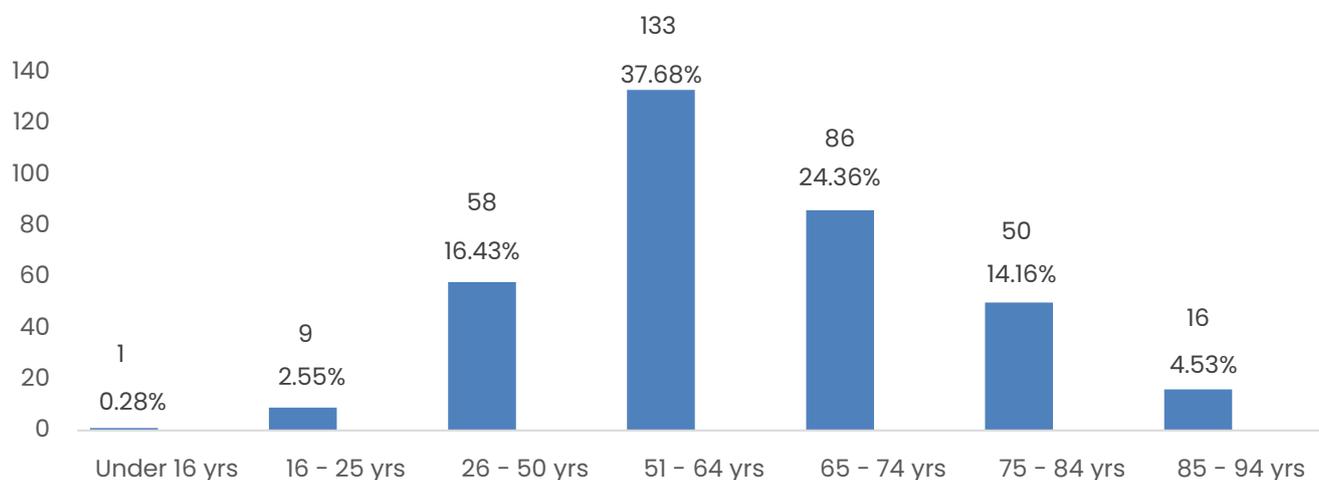
“Better advice and support could have been offered by GP some years back. Podiatry support and orthotic support special designed shoes for pain in foot. Now my husband has these shoes his foot pain has gone.”

Respondent demographics

Question 20: Please give your age range.

353 Carers (94%) responded to this question. The highest response rate was from Carers of working age, between 51 – 64 years (133 Carers / 37.68%) The lowest response rate was from Carers under 25 years (10 Carers / 2.82%). This is shown in Fig 20 below:

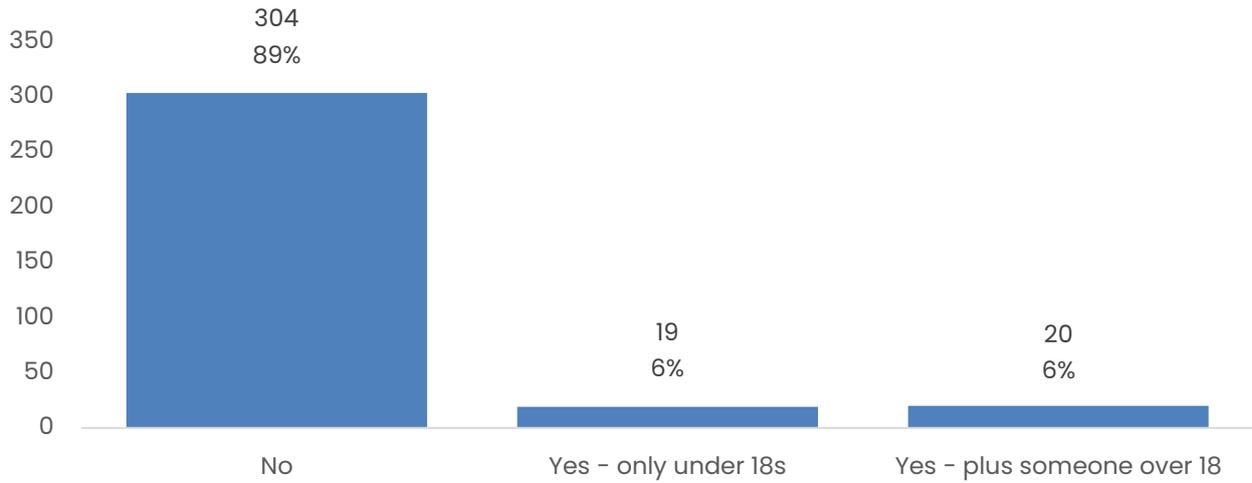
Fig 20: Age range of respondents



Question 21: Are you a parent Carer of someone under 18?

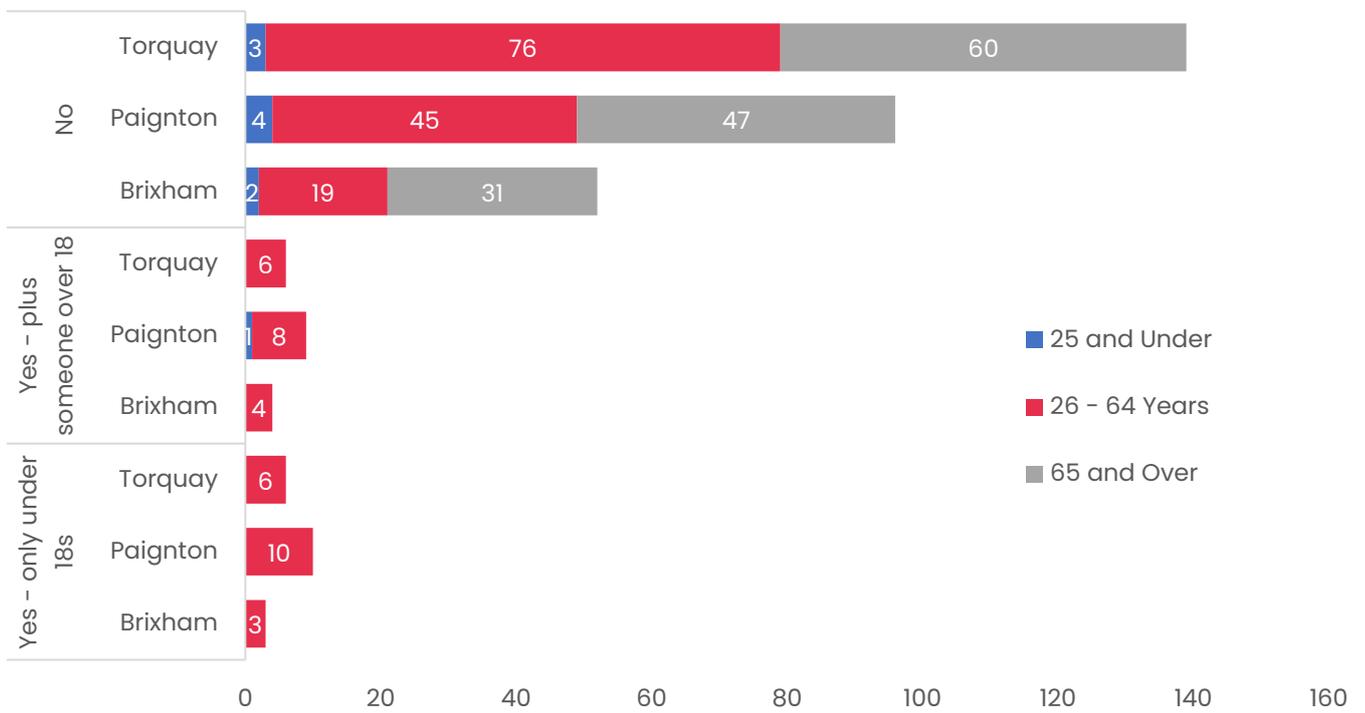
343 Carers (91%) responded to this question. 304 Carers (89%) do not care for someone under 18. 19 Carers (6%) do care for someone under 18 and 20 Carers (6%) care for someone under 18 as well as someone over 18. The results are shown in Fig 21 overleaf:

Fig 21: Are you a parent Carer of someone under 18?



Where Carers have provided their postcode and age range the results are shown in Fig 21A.

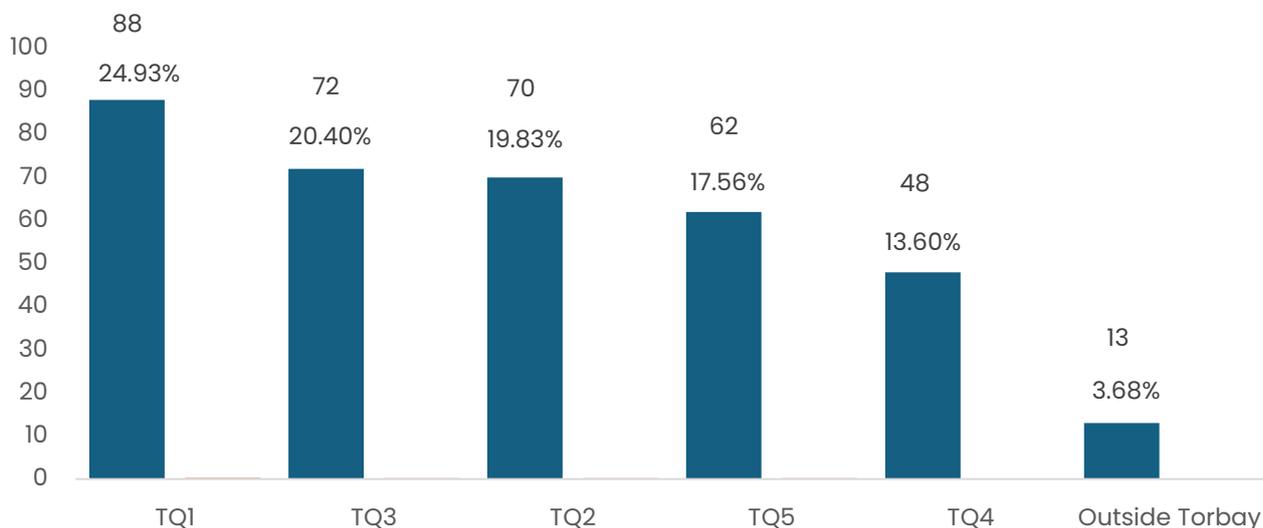
Fig 21A: Parent Carer breakdown by age and locality



Question 22: Please provide the first half of your postcode.

354 Carers (94%) provided their postcode prefix. 158 Carers (42%) live in Torquay, 120 Carers (32%) live in Paignton, 63 Carers (17%) live in Brixham and 13 (3%) live outside of Torbay. Fig 22 provides a breakdown of the postcode prefixes provided by Carers.

Fig 22: Postcode prefix of respondents



Question 23: What is the main difficulty / disability of the person / people that you care for that affect your caring role?

351 Carers (93%) provided details of the condition that the person they care for is affected by. Of those who responded to this question, 262 Carers (75%) provided details of a second condition and a further 188 Carers (54%) provided details of a third condition.

The results show that from those who responded to this question, in total:

- 313 Carers (89%) care for someone who is affected by a physical disability.
- 106 Carers (30%) care for someone who is elderly or frail and
- 82 Carers (23%) care for someone who is affected by a mental health condition.

Fig 23 and 23.1 (overleaf) provides a breakdown of the conditions that Carers selected for the person they care for. Carers were able to select up to 3 conditions if they impact them equally.

Fig 23: Condition of the Cared for Person 1

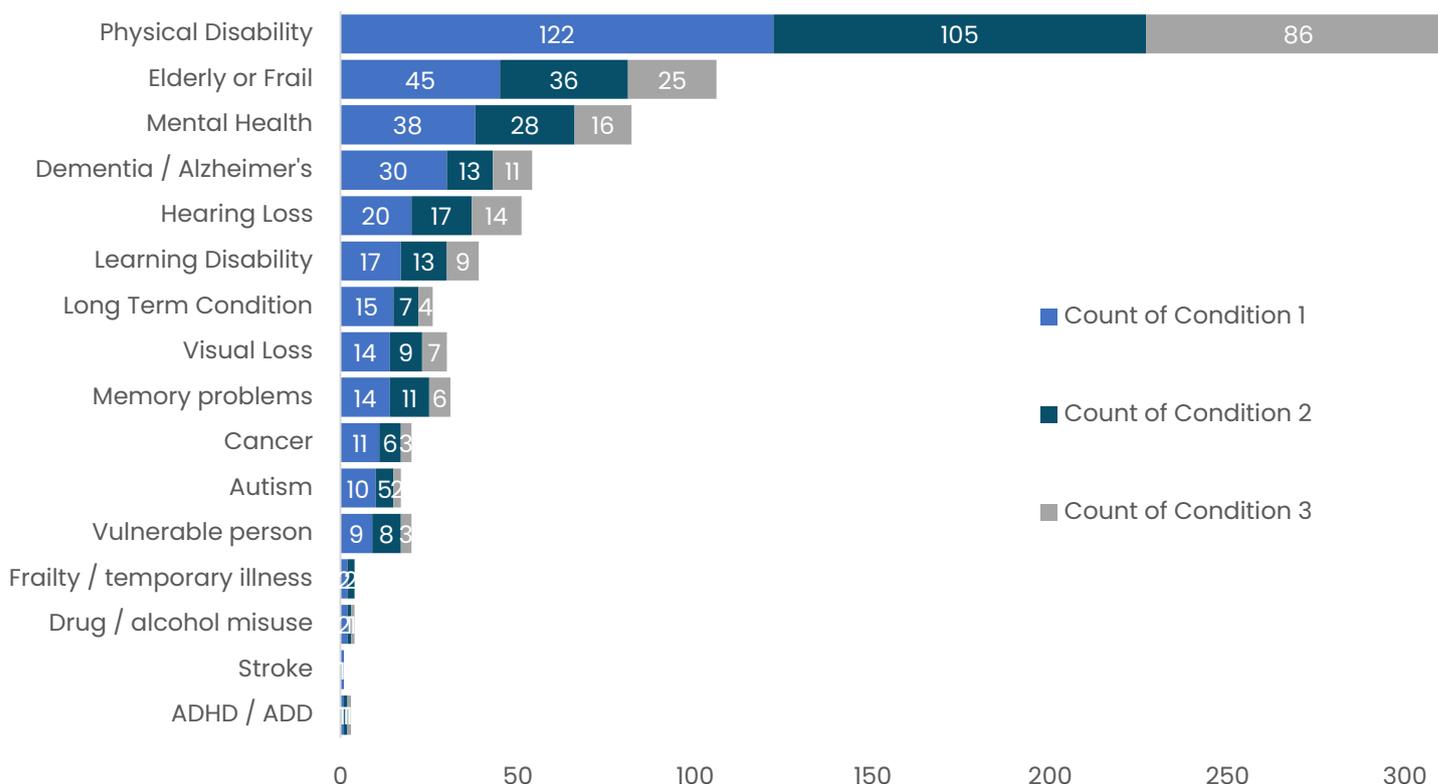
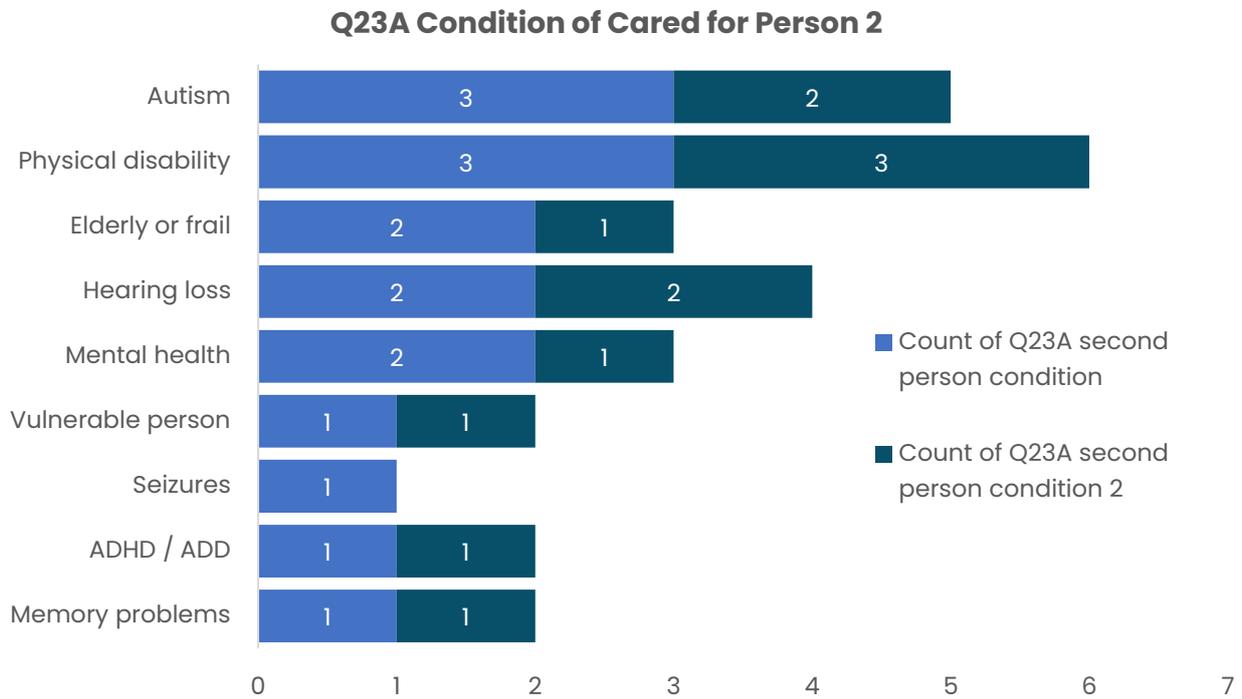


Fig 23.1 Percentage Table

Condition	Count of Condition 1	Count of Condition 2	Count of Condition 3	Total sum affected by condition	% of respondents to Q23
Physical Disability	122	105	86	313	89%
Elderly or Frail	45	36	25	106	30%
Mental Health	38	28	16	82	23%
Dementia / Alzheimer's	30	13	11	54	15%
Hearing Loss	20	17	14	51	15%
Learning Disability	17	13	9	39	11%
Memory problems	14	11	6	31	9%
Visual Loss	14	9	7	30	9%
Long Term Condition	15	7	4	26	7%
Cancer	11	6	3	20	6%
Vulnerable person	9	8	3	20	6%
Autism	10	5	2	17	5%
Frailty / temporary illness	2	2	0	4	1%
Drug / alcohol misuse	2	1	1	4	1%
Stroke	1	0	0	1	Less than 1%
ADHD / ADD	1	1	1	3	Less than 1%
Total	351	262	188		

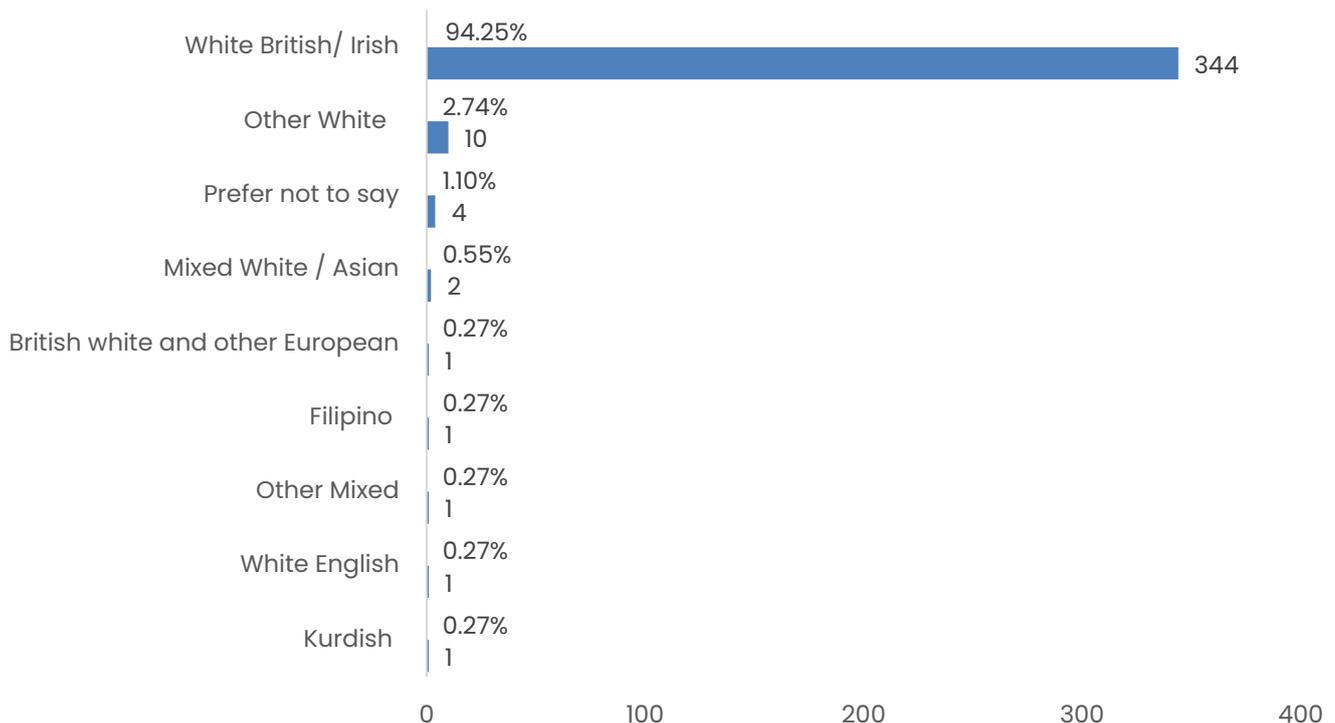
16 Carers also indicated that they care for a second person. Fig 23A provides a breakdown of the conditions that the Cared for person 2 is affected by.



Question 24: How do you describe your ethnic background?

365 Carers (97%) responded to this question. The results are presented in Fig 24:

Fig 24: Ethnicity of respondents



Question 25: What is your first language (spoken / signed) if not English?

7 Carers (2%) provided details of their first language as follows:

First Language	What is your first language (spoken / signed) if not English?
British Sign Language	1
Dutch	1
German	1
Kurdish	1
Shona	1
Spanish	1
Tagalog	1
Total	7

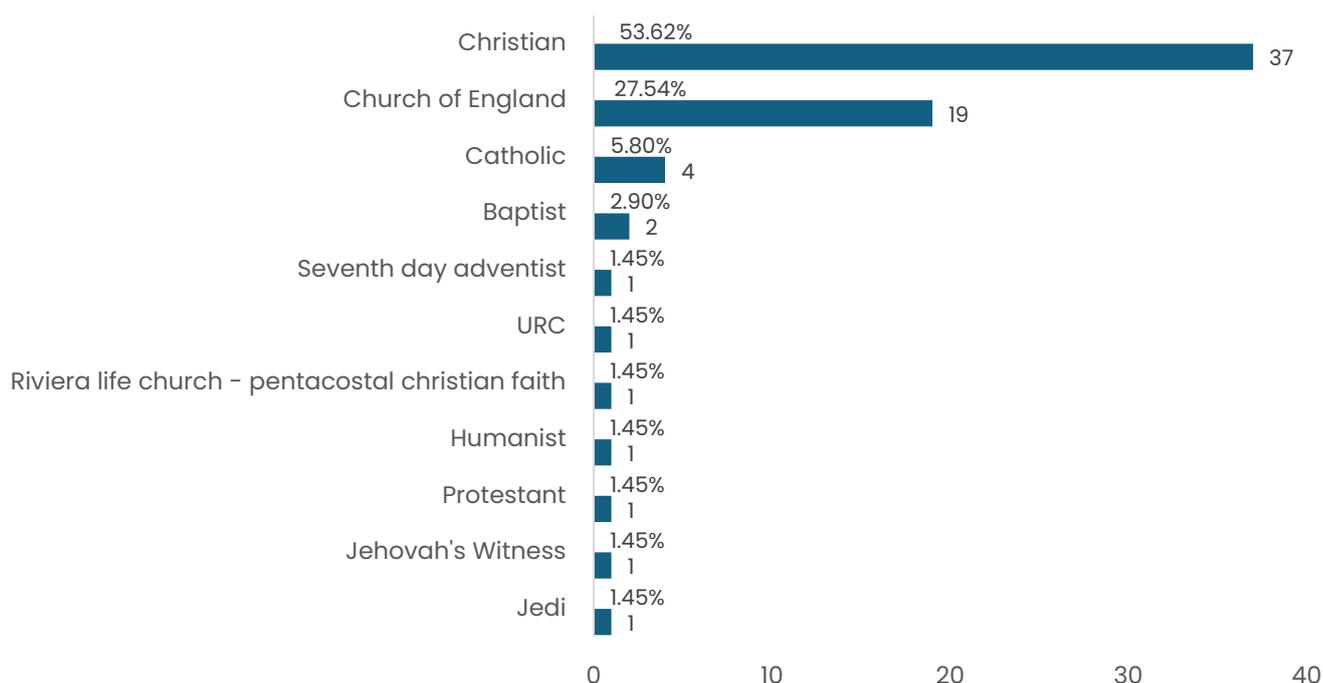
Question 26: What language do you prefer to read things in?

No other preferred languages were provided by Carers in response to this question.

Question 27: Do you belong to a faith / belief community?

273 Carers (72%) left this question blank. 104 Carers (28%) provided a response to this question, 35 Carers (9%) replied 'No' and 69 Carers (18%) named the faith that they belonged to. Fig 27 provides a breakdown of the faiths / belief communities that respondents provided:

Fig 27: Faith or belief community named by respondents who belong to one



Response from Torbay Carers' Service, Torbay and South Devon NHS Foundation Trust

"Firstly, I would want to thank ALL the Carers who took the time to complete this survey in their already busy lives. Please feel reassured that we have read and taken note of the findings of this detailed report.

Secondly, I would like to express my appreciation to the staff at Engaging Communities South West. Their work included not only inputting paper surveys but also a huge amount of work analysing all the information and making sense of it.

Since our last survey we had hoped to produce a booklet about Carer Support Services. This is still in draft form, and from your feedback it is clear that this is a real gap. I am therefore treating completing that as Carers' Services first priority.

Question 7 raised potential concerns about satisfaction with some of Carers' Services. However, as the comments are mainly positive, it is not clear how we can address concerns. In future, we will enable Carers to feed back very quickly using Healthwatch's Rate and Review Service. This should enable us to address any concerns as quickly as possible.

The early identification of Carers is obviously still such an issue that we will be working to make sure that Health and Social Care staff have the Carer awareness training needed so that this is done reliably and effectively.

Some of the issues raised are not about Carers' Services but other services that really impact upon Carers. They include replacement care ('respite') and mental health support for both adults and children. We have raised those issues with Torbay Council and Adult Social Care and will work with them to prioritise these.

There is a lot of detail in this report, and I will make sure that the key issues are translated into the Carers Strategy action plan which will be signed off in June. If you would like to work with Carers Services on the action plan, please ring Katy Heard on 07747 847 569."

For more information, visit Torbay Carers Service at:

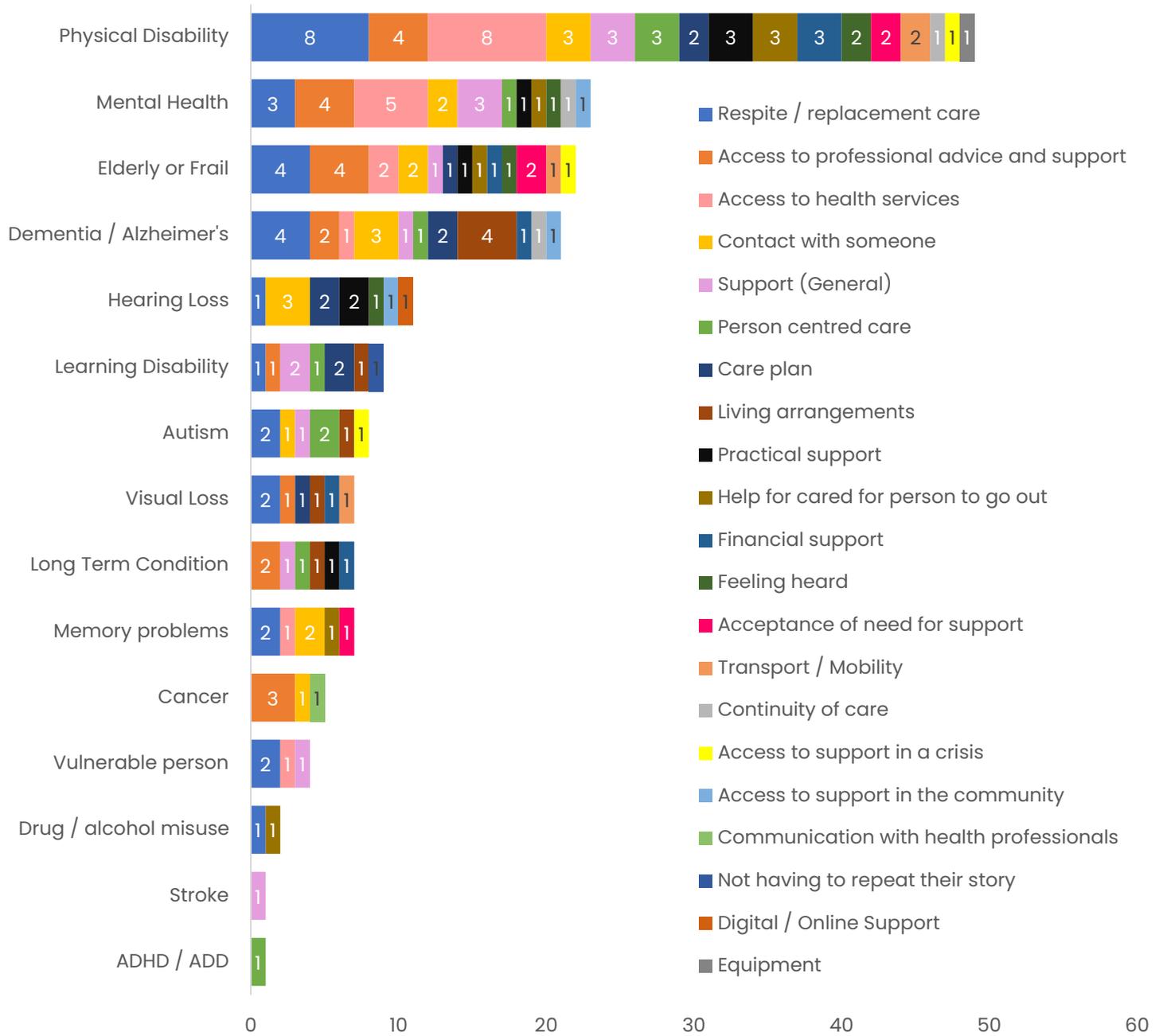
<https://www.torbayandsouthdevon.nhs.uk/services/carers-service/>

Recognition

Engaging Communities South West would like to thank everyone involved in the production of this report, particularly all the Carers in Torbay who shared their valuable feedback in this report and Torbay Carers' Services.

Appendix

Fig 11A: Breakdown of comment theme by condition of cared for person



Engaging Communities South West

“An inclusive, innovative and independent champion for the aspirations of local people.”

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