

Carers'
Consultation to
support the draft
2021-24 Torbay
Carers' Strategy







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### Introduction

Across Torbay, over 17,000 people care for a friend or relative (according to Torbay and South Devon NHS Foundation Trust). 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, developed a survey to find out how support for carers could be improved.

The findings of the survey will be used to inform the development of the Torbay Carers' Strategy for 2021-24. Healthwatch Torbay was asked to undertake the analysis of the survey findings in their role as the independent consumer champion for local health and care services.

## Methodology

An online version of the consultation survey was created on Healthwatch Torbay's secure website. It consisted of 27 multiple-choice questions and 15 open-ended questions. The survey opened on 2nd November 2020 and closed on 15th January 2021 and was emailed to all registered carers who provided an email address; a paper copy was also sent by post to those without an email address. The proportion of paper copies to email versions was higher. The views of younger carers will be sought in a separate consultation process, as we work towards a strategy for Carers aged under 25.

The survey was also publicised online by Healthwatch and the voluntary sector partners of the Torbay Carers' Service. Healthwatch shared a link on their website (visited over

18,000 times during the consultation) and regularly shared weekly links to both their 4,626 social media followers (1,542 Facebook, 3,084 Twitter) and the 750 subscribers to their weekly eBulletin. There is an example social media post pictured on the right.





### **Key Findings**

- 447 responses were received; 213 surveys were returned online and 234 surveys were returned on paper and inputted online by Healthwatch volunteers.
- Since the last survey three years ago, there has been a notable increase in the number of people being cared for who are 'vulnerable' or have mental health issues.
- Carers said their situation could be improved if they felt better supported; they would like accessible replacement (respite) care, a better relationship with health and social care services, and somebody who could check on their welfare, ideally a consistent worker.
- According to respondents in this consultation, identification of carers by Social Care staff
  has dropped since the previous survey, and although doctors' surgeries remain the largest
  identifier of carers, 63% of those identified as Carers since 2018 who said that they could
  have been identified sooner, said that it could have been by the GP surgeries.
- Throughout the survey, respondents expressed that they were not aware of the range of
  information, advice, and guidance available. Advice about finances and benefits and
  employment support may be particularly useful. Nearly 90% of respondents said they
  would value a booklet summarising Torbay's carer support.
- The majority of respondents to the Hospital-based support questions said they found services such as Hospital carer support worker, Family/carer supporter, Carers' Orange Lanyard, Advice point and free parking for carers either 'helpful' or 'extremely helpful'.
- Relatively few respondents had used the Torbay Community Helpline, but the majority of those who had found it helpful.
- Nearly half of respondents were struggling to some extent with the impact of the Covid-19
  pandemic, and over a third had concerns about finances or benefits. Respondents said that
  consistent communication from health and social care services, social support, and
  practical support would make a difference to them during the pandemic.
- More than half of respondents who used acute mental health services felt 'not at all' or 'not very' supported. Respondents with negative experiences described a poor attitude and lack of support from staff. Long waiting times for treatment was also a theme.



### **Detailed Results**

The survey consisted of 27 multiple-choice questions and 15 open-ended questions. 447 responses were received; 213 surveys were returned online and 234 surveys were returned on paper and input online by Healthwatch volunteers.

During the collation and analysis of the survey data, where respondents have given openended answers, the most common responses and suggestions have been organised into themes. These themes are summarised and listed in order of frequency, with the most frequently occurring themes appearing first. Examples of some responses have also been included.

Where relevant, statistics have been cross referenced with other survey questions and/or compared to the 2017 Torbay Carers' Consultation, with only percentages included here for accurate comparison (as there were significantly more responses in 2017).

#### **Section 1: Demographics**

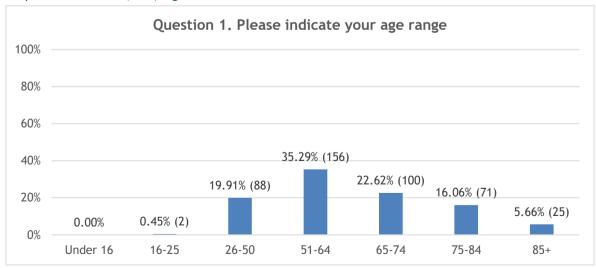
Question 1. Please indicate your age range.

442 respondents answered this question and 5 respondents did not answer it.

The majority of respondents (256, 58%) were aged between 51 and 74. The complete results are highlighted in the table below.

The 2018 Joint Strategic needs Assessment (JSNA) for Torbay states that approximately 36% of Torbay's 135,000 population falls between these age groups, with one in four adults aged over 65.

The 2017 Torbay Carers' Consultation gave similar results, with the majority of respondents then (57%) aged between 51 and 74.



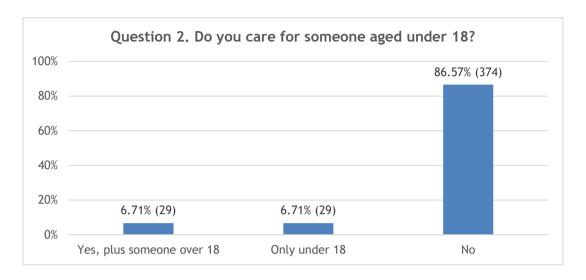


#### Question 2. Do you care for someone aged under 18?

432 respondents answered this question and 15 respondents did not answer it.

**374 respondents (87%) did not care for someone under 18**, the complete results are highlighted in the table below.

This is slightly lower than the figure from the 2017 Torbay Carers' Consultation (90%).

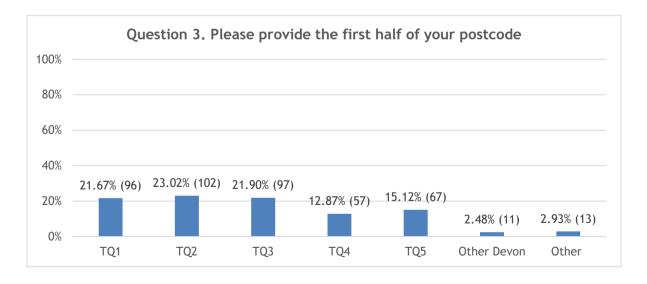


#### Question 3. Please provide the first half of your postcode

443 respondents answered this question and 4 respondents did not answer it.

**45% of respondents (198) were from Torquay (TQ1 and TQ2).** The complete results are highlighted in the table below.

In the 2017 Torbay Carers' Consultation the most popular answer was TQ3 (24%)



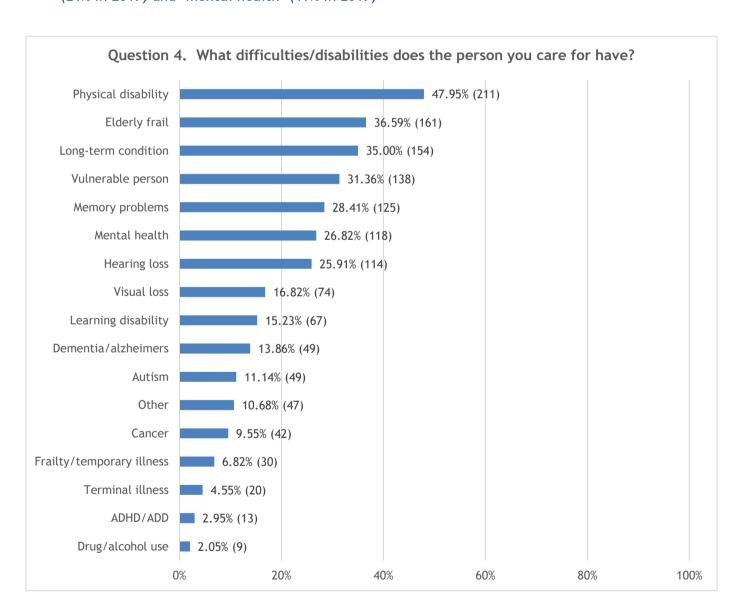
Question 4. What difficulties/disabilities does the person you care for have? Select all that apply.

440 respondents answered this question and seven respondents did not answer it.

As respondents were able to choose more than one response, the total number of responses is greater than the number of respondents and percentages total more than 100.

The most popular answers provided were 'physical disability' (48%), 'elderly frail' (37%), and 'long-term condition' (35%). The complete results are highlighted in the table below.

This is similar when compared to the 2017 Torbay Carers' Consultation, with the notable changes since then appearing to be the increase in those responding 'vulnerable person' (21% in 2017) and 'mental health' (19% in 2017)





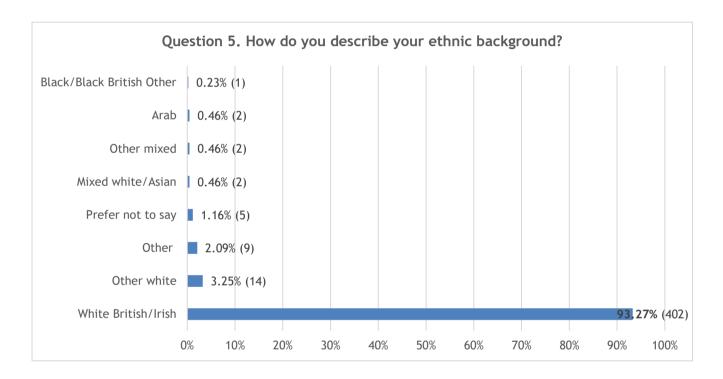
#### Question 5. How do you describe your ethnic background?

431 respondents answered this question and 16 respondents did not answer it.

As respondents were able to select more than one response, the total number of responses may be greater than the number of respondents and percentages may total more than 100.

402 respondents (93.3%) selected "White British/Irish," the complete results are highlighted in the table below with 3.7% non-white ethnic groups.

According to the 2017 Torbay Council Report on Equality Information, Torbay has a resident ethnic minority population (excluding white ethnic groups) of 3,260 (2.5%).





#### Question 6. What is your first language (spoken/signed) if not English?

69 respondents answered this question and 378 respondents did not answer it; however, most of those who answered said "English" or "N/A."

Only eight respondents mentioned a language other than English; these languages were German, Romanian, French, Hungarian, Danish, Kurdish, Croatian, and Portuguese\*.

#### Question 7. What is your first language (written) if not English?

53 respondents answered this question and 394 respondents did not answer it; however, most of those who answered said "English" or "N/A."

Only eight respondents named a language other than English; these languages were German, Romanian, French, Hungarian, Danish, Kurdish, Croatian, and Portuguese\*.

\*NB. According to the 2017 Torbay Council Local Area Profile the spoken 'first' language in Torbay is predominantly English at 97.8%, with Polish being the second highest spoken first language, albeit at only 0.7%.

The following languages are the joint third highest spoken first language, all at 0.1%: Filipino, German, Chinese (all), French, Spanish, Malaysian, Slovak and Italian.

Source: <a href="https://www.torbay.gov.uk/media/12235/local-area-profile.docx">https://www.torbay.gov.uk/media/12235/local-area-profile.docx</a>

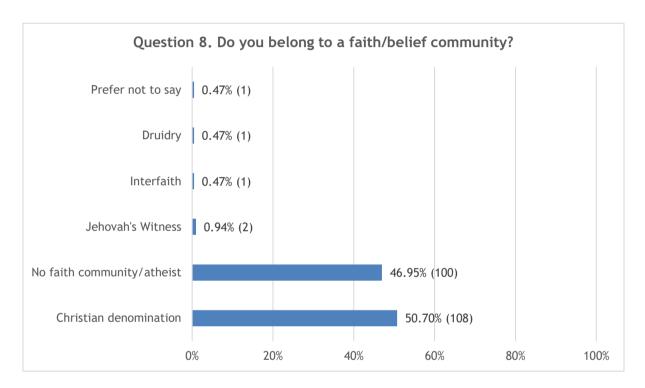


#### Question 8. Do you belong to a faith/belief community? If so, which?

215 respondents answered this question and 232 respondents did not answer it.

The majority of respondents identified as belonging to a Christian denomination (51%, 108), two respondents answered "yes" but did not state which community they belonged to, so their responses were excluded from the analysis. The complete results are highlighted in the table below.

According to the 2017 Torbay Council Report on Equality Information, Torbay has a higher proportion of residents recorded as Christian (63%) and No Religion (28%) than England and the South West.



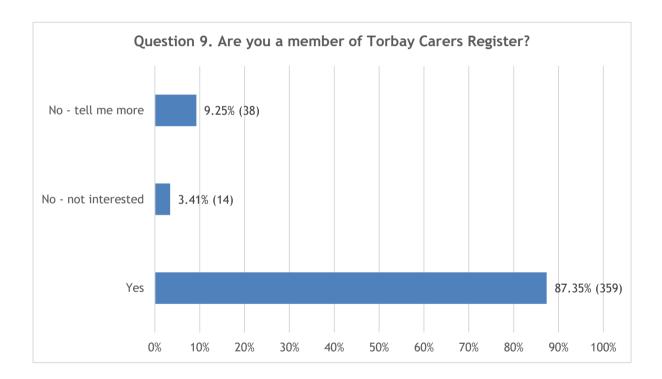


#### Section 2: Identification of carers

#### Question 9. Are you a member of Torbay Carers Register?

411 respondents answered this question and 36 respondents did not answer it.

359 respondents (87%) said they were on the register, 38 respondents (9%) said they were not on the register but were interested, and 14 respondents (3%) said they were not on the register and were not interested.



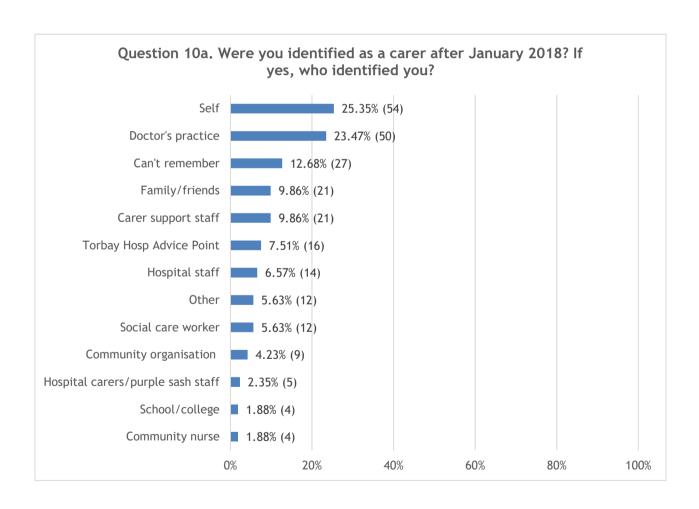


# Question 10a. Were you identified as a Carer after January 2018? If yes, who first identified you?

213 respondents answered this question and 234 respondents did not answer it. As respondents could select more than one answer, the total number of responses may be greater than the number of respondents and percentages may total more than 100.

47% of respondents (104) either identified themselves as a carer or were identified by a doctor's practice. The complete results are highlighted in the table below.

Compared to the 2017 Torbay Carers' Consultation, there is an improvement in Carers being identified by someone else - 25% identified themselves as a carer compared to 32% last time. Those identified by the GP practice has not really changed (23% compared to 24% last time), but there has been a drop in those identified by a Social Care Worker, 6% compared to 13% last time.





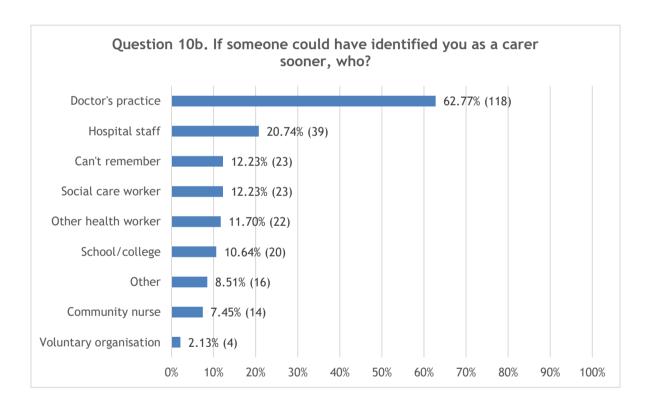
# Question 10b. If identified as a carer since 2018 and someone could have identified you as a Carer sooner, who?

188 respondents answered this question and 259 respondents did not answer it.

As respondents were able to select more than one response, the total number of responses may be greater than the number of respondents.

The majority of respondents (118, 63%) said their doctor's practice could have identified them as a Carer sooner, the complete results are highlighted in the table below.

This figure is lower than the 2017 Torbay Carers' Consultation, when 67% said a GP Practice could have identified them sooner. Again, the only notable difference related to social care workers. In 2018, 7% of respondents said they could have been identified sooner by a health and social care worker. In 2021, this number had risen to 12%.





# Question 11. In brief, what could health, social care, or community services do to make the biggest difference to improve your caring situation?

286 respondents answered this question and 161 respondents did not answer it.

These responses were cross-referenced with the cared-for person's disability/difficulty, but there were no notable differences between the responses.

59 respondents (21%) had specific suggestions for support; these suggestions included someone to check in with them or talk to them, mental health support, transport help, and support liaising with schools and employers. 20 respondents (7%) asked for better help or support but were not specific about what support they needed. 44 respondents (15%) said that replacement (respite) care would improve their caring situation. 39 respondents (14%) also wanted better and more easily accessible information and advice, and 25 respondents (9%) wanted financial advice.

The relationship with health and social care professionals is an issue for many carers; 35 respondents mentioned poor communication, for example, not feeling respected or listened to as a carer. Additionally, eight respondents mentioned continuity of care issues and six had issues with waiting times.

#### The following themes were identified:

#### General support (59 comments)

- "Regular phone calls to check welfare."
- "An unpaid carer's mental health is extremely fragile and susceptible to deteriorating
  a lot more easily than someone who doesn't have those added daily responsibilities
  and stresses to deal with. It would be good to see these specific needs being
  recognised and active support provided the moment that care role starts."
- "Transport for appointments"
- "To support and find carers local in the community that have gone through what I have."
- "Make workplace managers more proactive and supportive. Not make you feel like you're a nuisance when you ask for specific days off or change a shift."

#### Replacement (Respite) care (44 comments)

- "Carers to attend [to my] mother when I go away on holiday and maybe the odd weekend. At the moment she would only need checking on but her condition means she could have a relapse at any time. Currently there is only me to look after her."
- "Have someone to talk to the cared-for people sometimes so the carer can have some time to themselves."
- "Respite care [or] a break for me, as I am 24/7 either on [the] phone or having to cook and see she is alright for the night."



#### Information and advice (39 comments)

- "Providing information and courses that can help carers in the areas that they struggle
  in such as medication."
- "I think having a key worker would be very helpful, if we had one person we could turn to, to guide us to the appropriate services or help we might need. Sometimes we [are] wondering if we're making [the] right decisions, or who we should call."

#### Financial advice and concerns (25 comments)

- "I received no benefits or income for looking after my mum. Eventually I left her and took a step back from being her main carer"
- "Money advice, due to not getting paid enough to fund my bills I am in a lot of money trouble from caring for my family member"

#### Relationship with health/social care professionals

#### Communication (35 comments)

- "Accept that my life is as I describe it, not as they perceive it to be. Involve me when making decisions about me"
- "I have tried repeatedly to get my surgery to note I am a carer and to get the help available but to no avail. My sister at a different surgery is fully supported"
- "Listen to the parents, not make massive judgements based on bias and race. Not keep telling parents their children won't meet criteria for whichever panel before fully understanding the situation which puts families in impossible situations which cause unrecoverable damage."

#### Miscellaneous (16 comments)

• "Previous calls to social care have left me feeling unsupported. Will support be available or not, it always seems to be a lottery."

#### Continuity of care (8 comments)

- "To have one or two doctors that know us well and not ones who don't know us at all"
- "Having a support worker/person that you can talk to that doesn't change all the time."

#### Waiting times (6 comments)

"We have had difficulty getting support from physiotherapy services in Paignton. Been on waiting lists for months on end for equipment and it will arrive incorrect. We have independently helped dad with transfers without any support from health and social care services. We have unfortunately been let down numerous amount of times. If we needed anything or help we would access Torbay Carers services."



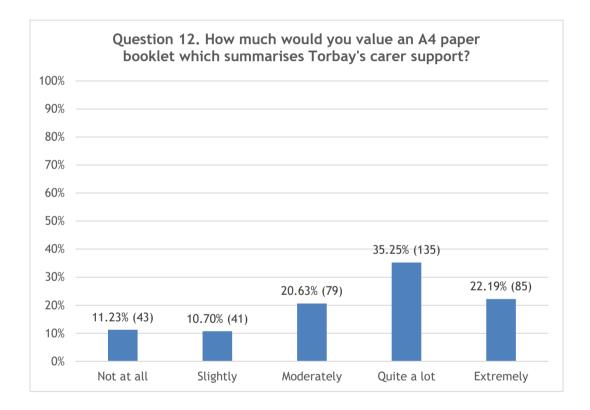
### Section 3: Information, advice, and support

Question 12. How much would you value an A4 paper booklet which summarises Torbay's carer support?

383 respondents answered this question and 64 respondents did not answer it.

The majority of respondents (220, 57%) said they value it "quite a lot" or "extremely."

The complete results are highlighted in the table below.





Question 13. What three main ways do you find out about local (not carers) information? Please rate 1, 2, and 3, and give details.

350 respondents answered this question and 97 respondents did not answer it.

Many respondents provided the name of a group or service but did not rank it, and vice versa. Multiple respondents answered "yes" instead of providing a ranking.

The table below shows the number of respondents who ranked each category as 1st, 2nd, or 3rd, or said "yes" to using the service.

Group or service	1st	2nd	3rd	"Yes"	Total
Friends/family/neighbours	99	42	26	10	177
Online websites	44	36	11	4	95
Local newspapers/newsletters	29	19	36	4	88
Statutory organisations	32	23	18	1	74
Voluntary organisations	21	21	22	1	65
Local radio	10	8	20	1	39
Care agencies/providers	17	16	3	0	36
Other	8	6	13	0	27
Other community	1	2	13	0	16

The groups and services named are listed on the next two pages, with the number of respondents mentioning that service in brackets.



#### Family, friends, and neighbours (177 comments)

No substantive details were provided for this category.

### Online websites (95 respondents)

- Facebook (28)
- Devon Live (19)
- Google (13)
- Torbay/Devon Council (4)
- NHS Trust/CCG (3)
- Healthwatch (2)
- Carers.org (2)
- BBC News (2)
- Tissues & Issues (2)
- YouTube (1)
- In Your Area (1)

- Local MP (1)
- English Riviera (1)
- South Devon Carers (1)
- Parkinsons.co.uk (1)
- UK Carers (1)
- IPSEA (1)
- SENDIAS (1)
- Carers Aid (1)
- Torbay Older Carers Family Initiative (1)
- Gov.uk (1)
- Citizens UK

#### Local newspapers/newsletters (88 respondents)

- Herald Express (24)
- Torbay News (14)
- Torbay Weekly (13)
- Local free papers/newsletters (7)
- MP newsletter (2)
- Western Morning News (2)
- Signal (1)

- Gazette (1)
- Torbay Council newsletter (1)
- Signpost (1)
- National newspapers (1)
- English Riviera magazine (1)
- Torbay Carers magazine (1)

#### Statutory organisations (74 respondents)

- NHS (27)
- Council (9)
- Torbay Carers (6)
- Schools (4)
- Social services (2)
- Public Health England (1)

- Early Help (1)
- Orchard House (1)
- Carers groups (1)
- CQC (1)
- Ambulance personnel (1)

#### Voluntary organisations (65 respondents)

- Age UK (13)
- Brixham Does Care (13)
- Torbay Mencap (4)

- Carers Aid (2)
- Tissues & Issues (1)
- Torbay Community (1)



- Cool House (1)
- Older Carers (1)
- Visual Eyes (1)
- Youth Trust (1)

- Healthwatch (1)
- Memory Cafe (1)
- Young Carers (1)

#### Local radio (39 respondents)

- BBC Radio Devon (18)
- Heart (4)
- BBC Other (3)

- Greatest Hits (3)
- Radio Exe (1

### Care agencies/providers (36 respondents)

- Windmill Centre (2)
- Chadwell Centre (2)
- Signpost (2)
- Palm Tree Home Care (1)
- Bay Benefits (1)
- United Response (1)

- The Key (1)
- Abide Brixham (1)
- Older Family Carers Initiative (1)
- Bay Care (1)
- Alzheimer's Society (1)

#### Other (27 respondents)

- GP/other healthcare service (8)
- News and TV (8)
- Signpost (3)

- Newsletters and adverts (2)
- Charities and volunteering (1)

### Other community (16 respondents)

- SEN mothers (1)
- Down Syndrome group (1)

- Faith group (1)
- Torbay Gateway Club (1)



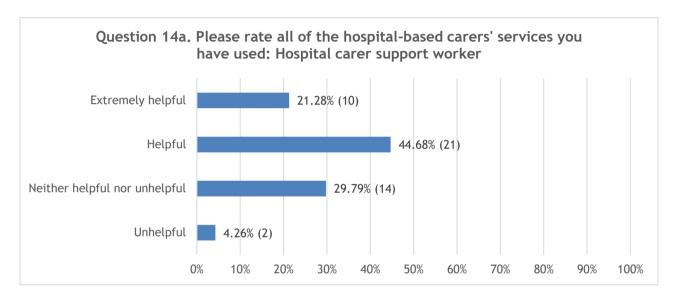
#### Section 4: Hospital-based support

Question 14a. Before Covid, the following services were in certain hospitals. Please rate all of the hospital-based carers' services that you have used.

#### Hospital carer support worker

255 respondents (84%) had not used this service.

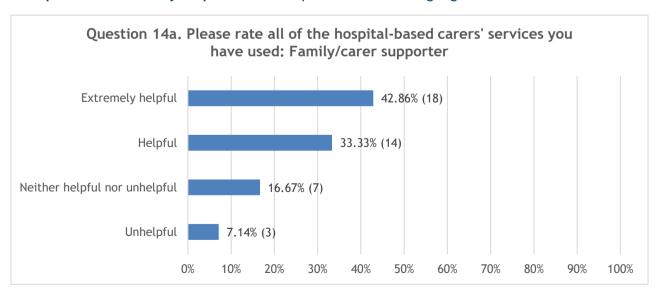
Of the 47 respondents who used the service, the majority (31, 66%) said they found it 'helpful' or 'extremely helpful'. The complete results are highlighted in the table below.



#### Family/carer supporter (purple sash)

249 respondents (86%) had not used this service.

Of the 43 respondents who used the service, the majority (32, 76%) said they found it 'helpful' or 'extremely helpful'. The complete results are highlighted in the table below.

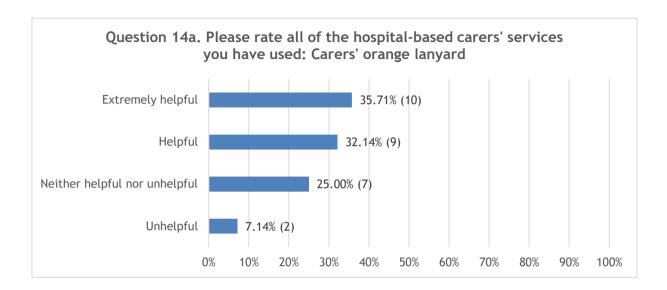




#### Carers' Orange Lanyard

259 respondents (90%) had not used this service.

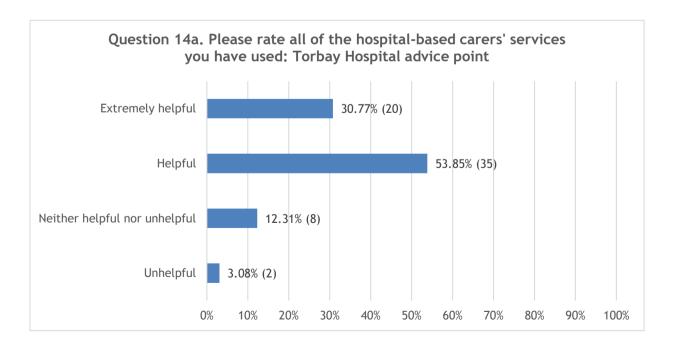
Of the 28 respondents who used the service, the majority (19, 68%) said they found it 'helpful' or 'extremely helpful'. The complete results are highlighted in the table below.



#### Advice point at Torbay Hospital

213 respondents (77%) had not used this service.

Of the 65 respondents who used the service, the majority (55, 85%) said they found it 'helpful' or 'extremely helpful'. The complete results are highlighted in the table below.

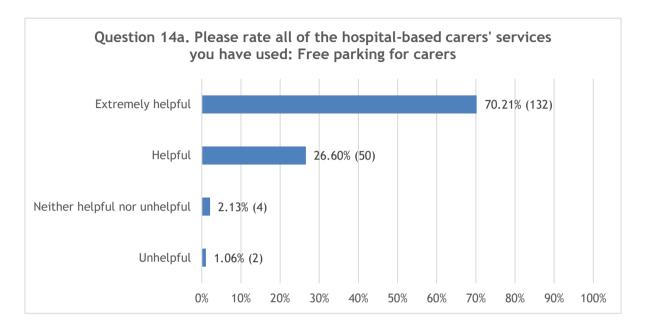




### Hospital main entrance free parking for carers

150 respondents (44%) had not used this service.

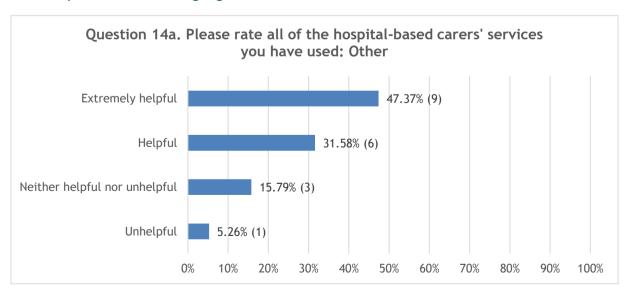
Of the 188 respondents who used the service, the majority (182, 97%) said they found it 'helpful' or 'extremely helpful'. The complete results are highlighted in the table below.



#### Other

89 respondents (82%) had not used "other" services.

Of the 19 respondents who used other services, the majority (15, 79%) said they found it 'helpful' or 'extremely helpful'. Only two respondents, who both rated other services extremely helpful, specified what services they had used (Mencap and carer's services). The complete results are highlighted in the table below.





#### Question 14b. Have you any comments about any of the above?

111 respondents answered this question and 336 respondents did not answer it.

The most common theme among the responses was a lack of information; 26 respondents (23%) said they did not know about the services or would like more information. 16 respondents (14%) had positive experiences with services, describing them as "helpful" and "excellent." 10 respondents (9%) mentioned hospitals, and these comments were mostly negative; some respondents did not feel supported, and some had issues with parking.

Eight respondents (7%) said they were lacking in help or support, but were not specific about what support they were missing.

#### The following themes were identified:

#### Need more information (26 comments)

 "They all need to reach out more and promote themselves better, especially to new carers."

#### Positive comments (16 comments)

• "[I] can't tell you how helpful the hospital guides are. [They] took mum to her hospital appointment while I looked for a parking place."

#### Hospitals (10 comments)

- "In my experience although carers' rights are promoted in the hospital, carers are still
  ignored by medical staff in the hospital environment when supporting the person they
  are caring for when coming into hospital."
- "Hospital staff have little compassion for carers."

#### Parking (8 comments)

• "Parking has been a problem in the past when some staff haven't been helpful in validating the ticket, or giving us a permit from the ward."

#### Need more help and support (8 comments)

- "I think so much more could be done to help carers."
- "I just would like to get registered at my surgery."

Question 15a & 15b. If the person you care for has had mental health support in a mental health unit or hospital emergency department within the last 3 years, please put the name of the service and date below. Please rate how supported you felt as their carer for service 1, 2, and 3, as named above.

49 respondents answered Question 15a and 398 respondents did not answer it.

73 respondents answered Question 15b and 374 respondents did not answer it. Some respondents answered Q15b without providing a name, or vice versa; only respondents who provided a name *and* rated the service have been included in this analysis.

The vast majority of respondents did not provide the date that they used the service, so dates have not been included in this analysis. The ratings received by each service are listed below. The number of respondents that rated a particular service appear in brackets (for example, 8 respondents said they felt "not at all supported" at Torbay Hospital/A&E).

Of the respondents who answered this question, 34% cared for someone under 18 (compared to 13% of all survey respondents). There were no statistically significant differences between the ratings of those who cared for under-18s and those who did not. In other words, those who care for a person under 18 did not feel disproportionately less well supported.

39% of the respondents to this question cared for someone with a learning disability or autism (compared to 20% of all survey respondents). There were no statistically significant differences between the ratings of those who cared for someone with learning disabilities or autism and those who did not. In other words, those who care for a person with learning disabilities or autism did not feel disproportionately less well supported.

#### Not at all supported

- Torbay Hospital/A&E (8)
- CAMHS (2)
- Chadwell (2)
- Crisis team (1)

#### Not very supported

Torbay Hospital/A&E (4)

#### Slightly supported

Torbay Hospital/A&E (2)



- Chadwell (1)
- DANA (1)
- Depression & anxiety service (1)
- Talk works (1)

#### Well supported

- Torbay Hospital/A&E (3)
- Chadwell (2)
- CAMHS (1)
- Cedars (1)
- IATT Newton Abbot (1)

#### Very well supported

- Torbay Hospital/A&E (5)
- Chadwell (1)
- Crisis team (1)

#### Question 15c. Please comment on your experiences

60 respondents answered this question and 387 respondents did not answer it.

24 respondents (40%) described a negative experience; the most common themes were poor communication, lack of help and support, and waiting times. Respondents felt that staff were unsympathetic and did not listen to them, and that information was not communicated correctly or correspondence was inadequate.

Seven respondents described positive experiences; these respondents said they felt listened to and cared for. One respondent had a mixed experience.

#### The following themes were identified:

#### Poor communication (11 comments)

• "[The] young person I care for is over 18 [and] gave permission for us to be kept informed but nothing in A&E visits, no follow ups for [the] person or carers."

#### Lack of help and support (8 comments)

"I got no help at all, just felt like a number in a long queue."

"CAMHS didn't answer their emergency line so [cared-for person] had to be admitted to [the] children's ward for [their] own safety. CAMHS didn't arrive until 11am the following day... he didn't keep to any of the conditions and no-one has actually physically seen him since."

#### Positive experiences (7 comments)

- "Torbay Hospital, where my husband was diagnosed with Alzheimer's. I was listened to and felt that my concerns were of interest."
- "Paramedics went above and beyond to take care not to talk over dad."

#### Waiting times (5 comments)

- "[The cared-for person] was promised support but is still waiting and I have had to manage [their] condition which is severe. Worker only checks in every few months and [promises] to get things moving but nothing happens"
- "We are still [waiting] for her help to be allocated to someone. [Most] departments after meeting with her have referred her to someone else"

#### Treatment of patients with autism (3 comments)

- "Because my son is an adult on the autistic spectrum he finds it hard to explain how he feels. So [he relies] on me. But I get dismissed and told they want words from him."
  - "It has taken years to find support for our autistic son."

#### Mixed experience (1 comment)

"Nurses are excellent, but no other help was given."

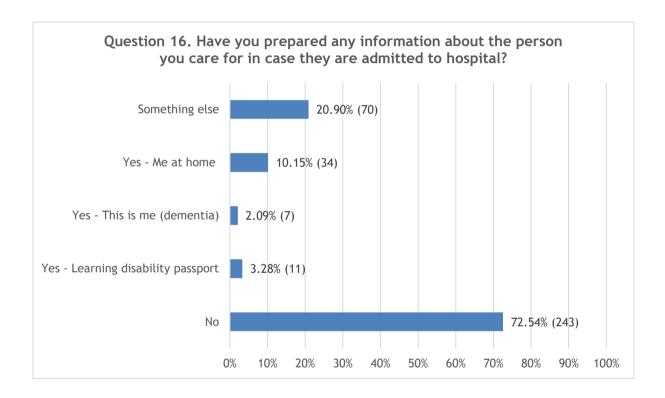
Question 16. As hospital visiting is often restricted at the moment, have you prepared any information about the person you care for in case they are admitted?

335 respondents answered this question and 112 respondents did not answer.

As respondents could select more than one answer, the total number of responses may be greater than the number of respondents and percentages may total more than 100.

The majority of respondents (243, 73%) said 'no', with the complete results highlighted in the table below.

29 of the 70 respondents who said "something else" had prepared a list of the cared-for person's medical details. Four used an ID card, lanyard, or wristband (e.g. Carer, Epilepsy, Autism), three respondents used a hospital passport, and two used 'Message in a Bottle'.





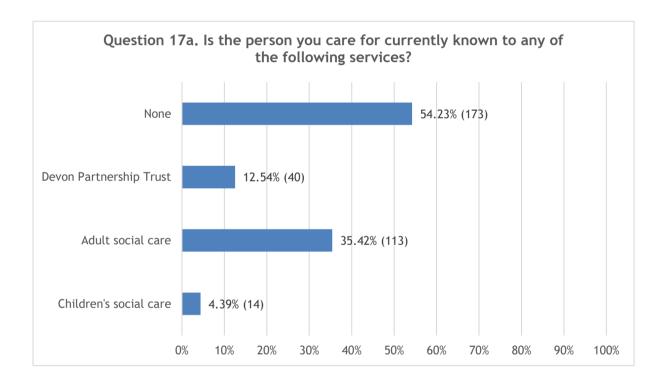
### Section 5: Support at home

Question 17a. Is the person you care for currently known to any of the following services?

319 respondents answered this question and 128 respondents did not answer.

As respondents could select more than one answer, the total number of responses may be greater than the number of respondents and percentages may total more than 100.

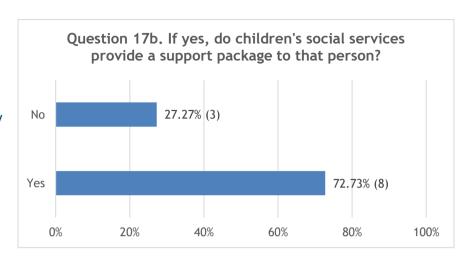
The majority of respondents (173, 54%) said the cared-for person was not known to any of the services. The complete results are highlighted in the table below.



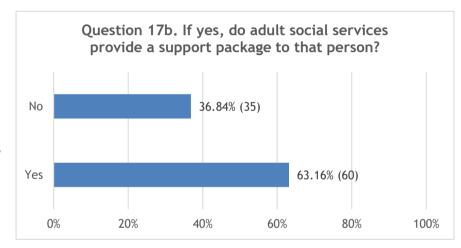


#### Question 17b. If yes, do these services provide a support package to that person?

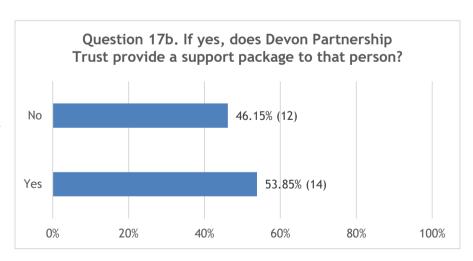
Of those who were known to children's social services, eight respondents (73%) were provided a support package by the service and three respondents (27%) were not.



Of those who were known to adult social services, 60 respondents (63%) were provided a support package by the service and 35 respondents (37%) were not.



Of those who were known to Devon Partnership Trust, 14 respondents (54%) were provided a support package by the service and 12 respondents (46%) were not.



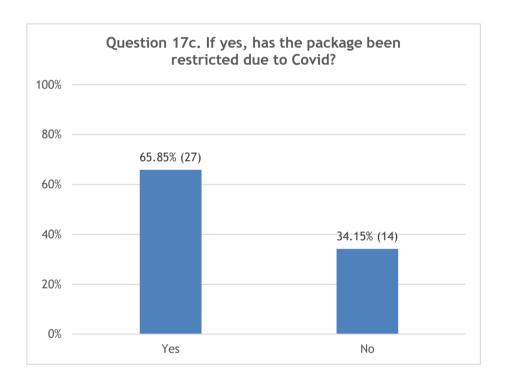


# Question 17c. If yes, has the package been restricted due to Covid (e.g. day care closed)?

Of those who were known to services, 41 respondents answered this question and 11 did not answer it.

27 respondents (66%) said their support package had been restricted due to Covid and 14 respondents (34%) said it had not been restricted, highlighted in the table below.

Those whose support had been restricted said that this was due to the closure of services (schools, respite services, memory cafe) and a reduction in funding and support workers' hours.



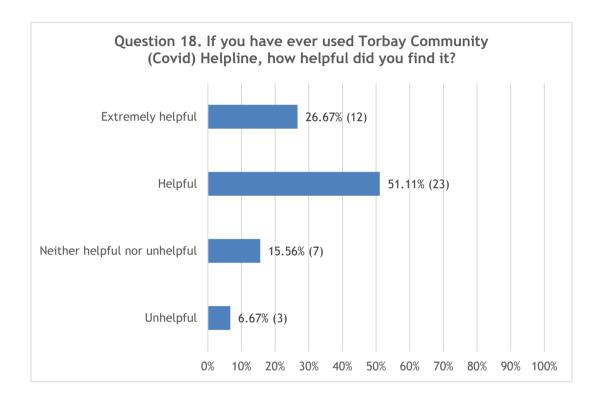


337 respondents answered this question and 110 respondents did not answer.

292 respondents (87%) had not used the helpline.

Of the 45 respondents who used the helpline, the majority (35, 78%) said they found it 'helpful' or 'extremely helpful'.

The complete results are highlighted in the table below.





# Question 19a. Is there anything that would prevent you from using Torbay Community Helpline?

146 respondents answered this question and 301 respondents did not answer it.

Most respondents (102, 70%) simply answered "no".

16 respondents (11%) said that lack of knowledge or information about the helpline prevented them from using the service.

10 respondents (7%) had specific issues with using the helpline; some respondents (5) said they would not use the service because they did not expect it to be useful or were disappointed with the quality of similar services.

One respondent had hearing issues, and another said they had concerns about confidentiality as employees may be working from home.

#### The following themes were identified:

#### Lack of knowledge/information (16 comments)

- "None at all, [I] didn't know about it."
- "I didn't know it existed"

#### Other concerns (10 comments)

- "[It] doesn't cover my husband's or son's illness."
- "My disappointment and frustration with reaching out for any help previously would make me reluctant to request help - the disappointment is worse than not having help."
- "When we did ask for help before from some helpline, they helped us one time and never came back."
- "Confidentiality. Most people answering will be working from home in an insecure environment."
- "Visual and hearing problems."



# Question 19b. Before Covid, which community organisations did you use if you needed support?

196 respondents answered this question and 251 respondents did not answer it.

The organisations named are listed below, with the number of respondents mentioning that organisation in brackets.

- Torbay Carers Service (14), including Signposts (3)
- Carers Aid Torbay (12)
- Brixham Does Care (7)
- Age UK (7)
- Mencap (6)
- Chadwell (5)
- Local churches (5)
- Older Family Carers Initiative (4)
- Alzheimer's Association (4)
- Carer Support Workers (4)
- GP (3)
- Windmill Centre (2)
- Teignbridge (1)
- Bravo Group (1)
- Memory Cafe (1)
- NHS Care Trust (1)

- United Response (1)
- The Key (1)
- Learning Disability Team (1)
- Children's services (1)
- Takota (1)
- Torbay Support Project (1)
- Community Children's Team (1)
- Play Torbay (1)
- Disability Collective (1)
- Baycare (1)
- Rowcroft (1)
- Headway (1)
- Sensory Team (1)
- Parkinsons UK (1)
- DANA Exeter (1)
- Jasmine House (1)
- Torbay Community Helpline (1)

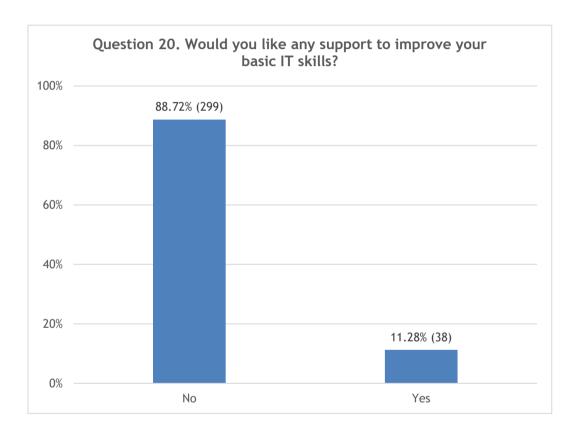


Question 20. Would you like any support to improve your basic IT skills (email, online shopping, Zoom etc)?

337 respondents answered this question and 110 respondents did not answer it.

38 respondents (11%) said they would like IT support and **299 respondents (89%) said** they would not like support, as highlighted in the table below.

Of those who said yes, 30 respondents left their contact details at the end of the survey.



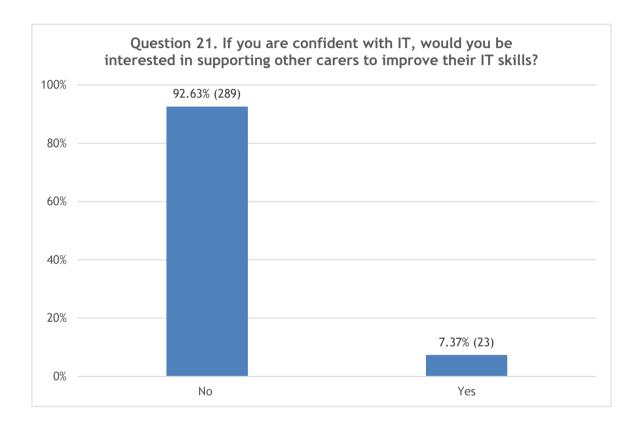


Question 21. If you are confident with IT, would you be interested in supporting other carers to improve their IT skills?

312 respondents answered this question and 135 respondents did not answer it.

23 respondents (7%) were interested in helping others with IT and **289 respondents (93%)** were not interested, as highlighted in the table below.

Of those who said yes, 19 respondents left their contact details at the end of the survey.

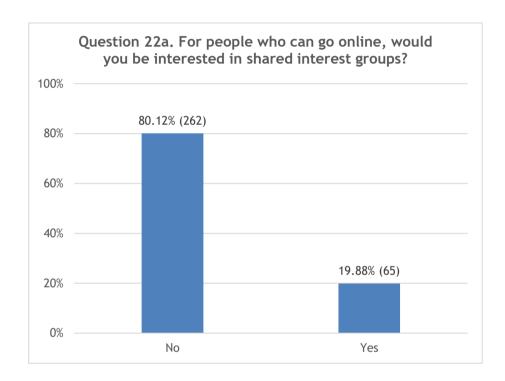




Question 22a. For people who can go online, would you be interested in shared interest groups (e.g. book clubs)?

327 respondents answered this question and 120 respondents did not answer it.

65 respondents (20%) said they were interested in shared interest groups and 262 respondents (80%) said they were not interested.





#### Question 22b. If you answered yes to Q22a, what interests you?

57 respondents answered this question and 390 respondents did not answer it.

The interests mentioned are listed below, with the number of respondents mentioning that interest listed in brackets.

#### Arts & Crafts (34 respondents)

- Sewing, embroidery, crochet & knitting (11)
- Crafting (9)
- Art & music (9)

- Flower arranging (2)
- Photography (2)
- Woodwork (1)

## Books & learning (29 respondents)

- Book club (18)
- Psychology (2)
- Local knowledge & history (2)
- History (1)
- Philosophy (1)

- Biographies (1)
- Poetry (1)
- Language (1)
- Politics (1)
- Law (1)

# General social (22 respondents)

- Social & chat clubs (10)
- Mental wellbeing (3)
- Dealing with being a carer (3)
- Day trips (3)
- Games (2)
- Faith (1)

#### Outdoor & physical activity (16 respondents)

- Wildlife, animals & birds (6)
- Gardening (4)
- Sport (3)

- Walking (1)
- Yoga (1)
- Cycling (1)

#### Skills (11 respondents)

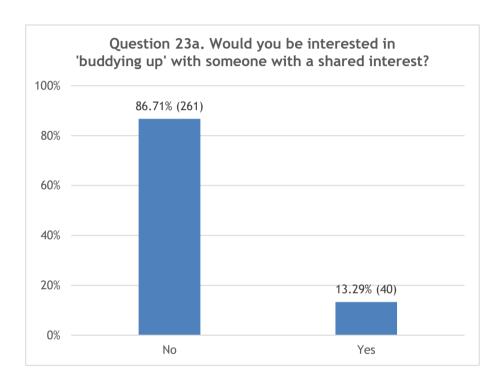
- Cooking and baking (6)
- IT skills (4)
- DIY (1)



# Question 23a. Would you be interested in "buddying up" with someone with a shared interest?

301 respondents answered this question and 146 respondents did not answer it.

40 respondents (13%) were interested in buddying up and 261 respondents (87%) were not interested.





#### Question 23b. If you answered yes to Q23a, what interests you?

33 respondents answered this question and 414 respondents did not answer it.

The interests mentioned are listed below, with the number of respondents mentioning that interest listed in brackets.

#### Arts & crafts (25 respondents)

- Sewing, embroidery, crochet & knitting (10)
- Crafts (7)
- Art, music & film (5)

- Drawing & painting (1)
- Upcycling (1)
- Photography (1)

# Physical & outdoor activity (20 respondents)

- Wildlife, animals & nature (6)
- Walking & jogging (6)
- Gardening (5)

- Dog walking (1)
- Fishing (1)
- Sport (1)

#### General social (13 respondents)

- Social/coffee/chat clubs (8)
- Shopping (2)
- Helping others (1)

- Sharing life experiences (1)
- Spiritual wellbeing (1)

#### Books & learning (11 respondents)

- Book club (5)
- Puzzles (2)
- Astronomy (1)

- Quizzes (1)
- Law (1)
- Languages (1)

#### Practical skills (4 respondents)

• Cooking (3)

• Carpentry (1)



# Question 24. Is there any online support that you are finding useful as a carer, that we could share with other carers?

80 respondents answered this question and 367 respondents did not answer it.

59 respondents (74%) simply said "no," "N/A," or a similar answer.

These responses were cross-referenced with the cared-for person's disability/difficulty, but there were no notable differences between the responses.

#### Information & support (12 respondents)

- Tissues & Issues (3)
- Torbay Mencap (2)
- Carers UK (2)
- Signpost (1)

- Healthwatch (1)
- Benefits advice (1)
- Unique Chromosome (1)
- Food delivery (1)

## Social and chat groups (7 respondents)

- Facebook (4)
- Discord (2)

• Chat groups (non-specific) (1)

## Activities (2 respondents)

YouTube yoga (1)

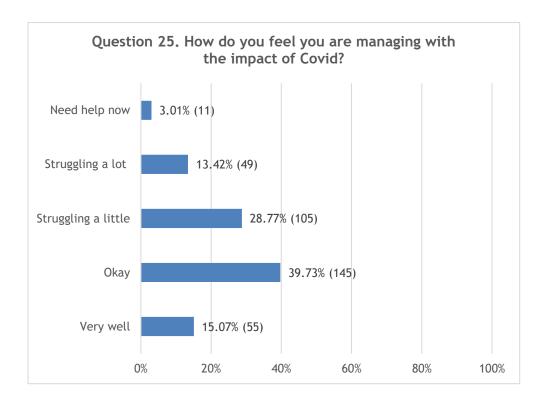
• Zoom craft groups (1)



#### Question 25. How do you feel you are managing with the impact of Covid?

365 respondents answered this question and 82 respondents did not answer it.

11 respondents (3%) said they needed help now, 49 respondents (13%) said they were struggling a lot, 105 respondents (29%) said they were struggling a little, 145 respondents (40%) said they were okay, and 55 respondents (15%) said they were doing very well.

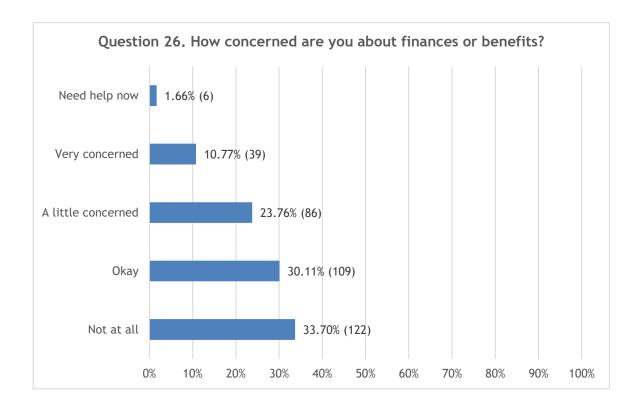




### Question 26. How concerned are you about finances or benefits?

362 respondents answered this question and 85 respondents did not answer it.

Six respondents (2%) said they needed help now, 39 respondents (11%) said they were very concerned, 86 respondents (24%) said they were a little concerned, 109 respondents (30%) said they were okay, and 122 respondents (34%) said they were not concerned at all.





# Section 6: Support with employment

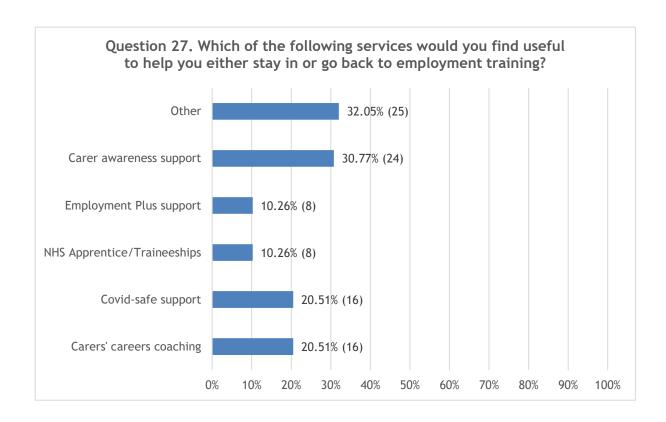
Question 27. Which of the following services would you find useful to help you either stay in or go back to employment/training?

78 respondents answered this question and 369 respondents did not answer it.

As respondents could select more than one answer, the total number of responses may be greater than the number of respondents and percentages may total more than 100.

25 respondents (32%) said other services would be useful; respondents said that flexible and home working, childcare, and more support and understanding from employers would help them stay in or return to employment. 24 respondents (31%) said they would find carer awareness support useful.

The complete results are highlighted in the table below.





Question 28. Given Covid, and that many groups/services are restricted or providing support differently, what alternative support would make a difference to you?

130 respondents answered this question and 317 respondents did not answer it.

These responses were cross-referenced with the cared-for person's disability/difficulty, but there were no notable differences between the responses.

32 respondents (25%) said they would like better communication, contact, and support from services (e.g. someone to phone or check in on them, or a named person they could contact for help or advice).

25 respondents (19%) said practical support (e.g. respite care, employment support, financial help) would help them. 24 respondents (18%) said that social support (e.g. forming support groups with other carers) would make a difference.

#### The following themes were identified:

#### Communication, contact, and support from services (32)

- "Having one main point of contact, like a key worker."
- "A known person with expertise who I could ring for advice if needed. Whether this be on how to manage [a] loved one with dementia, what options are opened to me, etc."

#### Practical support (25)

- "Any support I need would be practical only. We do not qualify for any financial credits or free help with cleaning, gardening, etc."
- "Information on employment rights. Someone to liaise with [my] employer."

#### Social support (24)

- "I loved the free craft groups last year at the college. It was the first time I had spoken to other carers."
- "I find that online communication exaggerates feelings of being isolated. I cope better just getting on with it and meeting friends for a walk. This way, I can feel that all is normal for a while."



# Question 29. Given Covid, how do you think that services/support could develop to meet the needs of carers and the person/people you care for?

126 respondents answered this question and 321 respondents did not answer it.

These responses were cross-referenced with the cared-for person's disability/difficulty, but there were no notable differences between the responses.

48 respondents said their needs could be met through better communication, contact, and support from services; for example, if health and social care professionals were easier to contact, or if somebody would contact them to check in.

23 respondents said practical support (e.g. help with shopping, repeat prescriptions, or respite care) would help them. 15 respondents said that social support would make a difference; for example, being able to socialise with fellow carers.

#### The following themes were identified:

#### Communication, contact, and support from services (48)

- "Communicate with each registered carer to establish a support link and ascertain what needs they have"
- "Regular phone calls from the relevant teams. I find myself chasing around trying to find the right person or team."
- "Being a carer is very isolating, so contact with another person by phone just to let them know that someone cares once a week may be helpful."

# Practical support (21)

- "Online shopping. [It's] very difficult to get a slot."
- "More people available to help carers."

#### Social support (15)

- "We lack a social bubble... A small social group for myself and my son to belong to, going for walks, picnics, etc. would be lovely."
- "Just have someone to talk to even if it's not about the caring side of things. Family is
  one thing but sometimes you need a break and someone else to talk to."



#### Question 30. Is there anything else you would like to add?

109 respondents answered this question and 338 respondents did not answer it.

27 respondents took this opportunity to talk about specific issues and suggestions for how they could be better supported.

10 respondents said they would like to see improvements in the support provided by health and social care services; these respondents wanted services to be more accessible, and for professionals to be better informed and more sympathetic towards carers and cared-for people.

9 respondents said they would benefit from practical help and support, such as IT help, financial support, and help obtaining equipment and medication. 5 respondents said they would benefit from social support or someone to talk to. 3 respondents said they would benefit from replacement (respite) care or support in dealing with the cared-for person's condition.

2 respondents had issues relating to the Covid-19 pandemic; one said they were confused about when unpaid carers would qualify for the vaccine, and one said that testing for carers would enable them to better care for the cared-for person.

14 respondents mentioned difficulties with their care but were not specific about the issue or what could be done to improve it.

10 respondents said they would like better information, advice, or guidance. 9 respondents had positive feedback about the support they were receiving or had received.

2 respondents made comments about the survey; one said the survey was too long and another said the questions were 'poorly worded'.

#### Specific suggestions and issues (27 comments)

#### Health and social care services (10 comments)

- "The last time I contacted adult services about making our house safer, I was told that
  as I owned a house I could just fund it all myself. Then the phone was hung up on me.
  That experience has not yet gone away."
- "Social care signpost to outside agencies that promise things [that don't] happen."

## Practical and financial help (9 comments)

- "[I] could use help to get equipment, to help me cope with deafness."
- "So many people have no computer, no knowledge of how to use or money to buy, set up, pay for internet, etc. We get no help at all it seems."

#### Contact and social support (5 comments)

- "I feel that although I'm a registered carer unless I contact my doctor no-one bothers to ask if I'm okay. Even an email now and again just checking in would be good."
- "I miss the social side of meetings, coffee mornings, learning classes."

#### Help with caring (3 comments)

- "We manage but only by missing out on life. I can't go out or have a social life without feeling my husband has to stay alone, not eating or drinking, waiting for me to come home."
- "I feel more help should be given to carers who have to care for young people with challenging behaviour."

# Covid support (2 comments)

- "Unpaid carers that live with the person they care for do not seem to fall into any groups currently. I don't know if I would get the vaccine at the same time as [my] mother as I do not come under any of the groups mentioned, but I am going out and mixing with lots of people when I have to go shopping."
- "Weekly Covid swabs for carers, so they can attend appointments with the person they care for and it would reassure them they aren't infecting the person they care for."

### Non-specific difficulties (14 comments)

- "My wellbeing is compromised because of all the tasks I now undertake due to lockdown."
- "I have very black times when I wonder how long we shall be able to cope. I have disabilities including deafness and vertigo... there are times when I feel very cut off."

#### Information and guidance (10 comments)

- "You are not given information on what you can claim or are entitled to, you are just expected to know."
- "Guidance as to what resources are available would be helpful to us all."

#### Positive comments (9 comments)

- "I appreciate the immediate help I was given when I arrived at home with my mother, then the prompt offer of help if needed from [the] Torbay Carers team."
- "You do a good job, [I] wished there was more out there for children who are disabled but don't need social care services."

#### Comments about the survey (2 comments)

- "This survey was too long and confusing."
- "[This] form asks if [I] care for more than one person, then most questions ask [about] 'the person you care for' which makes this very hard to answer in full!"



# Response from Torbay Carers Services

"Healthwatch has done an excellent job collating all the information supplied by Torbay's Carers. Almost 450 Carers responded, which was impressive given that it was during lockdown and the fact that Covid has caused so many difficulties for unpaid Carers. However, as this is only 1:10 of registered Carers, the survey has been left open for Carers to complete until end March 2021, although their views are not included in this report. As there was a better rate of return of paper compared to electronic surveys, Carers Services will fund future engagement surveys being posted to all known Carers.

Given the impact of Covid on the NHS, it was encouraging that Hospital identification of Carers had not dropped since the last report and that Doctor's Surgeries had improved, but there is clearly still further work to be done. We hope that the full range of hospital-based support for Carers can soon be reinstated, but the impact of Covid on Carers health, wellbeing, finances and employability will take longer.

All of the feedback in the Healthwatch report has been used to shape Torbay Carers Strategy for 2021-24, so we are very grateful to all the Carers who completed the survey. Some of the actions, such as creating a booklet about Carers Services, are straightforward, but some, such as reversing the drop in identification of Carers by Social Care staff, are likely to take more time. Once the strategy has been fully signed off it will be published at <a href="https://www.tsdft.uk/carers">www.tsdft.uk/carers</a> on the 'strategy' tab."

**Katy Heard** 

Carers and Volunteers Lead
Torbay And South Devon NHS Foundation Trust

# Recognition

Healthwatch Torbay 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.

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