

Carers Consultation to support the draft 2018-2021 Torbay Carers Strategy





# **Contents**

Introduction	3
Analysis summary	3
Section 1: Identification of Carers	4
Section 2: Information, advice and support services	5
Section 3: Support for the person cared for	6
Section 4: Carers' information	7
Section 5: Education Courses for Carers	8
Section 6: Looking forward	8
Recommendations	9
Detailed Account of Findings	10
Identification of Carers	
Information, advice and support	
Support for the person you care for	23
Carers' Information	28
Education Courses for Carers	32
Looking Forward	35
Thanks	38
Response from Torbay Carers Services	38
Contact us	40

## Introduction

This report is an analysis of a questionnaire prepared by the Torbay Carers Service and sent to all Adult Carers registered with the service. The information provided in the responses will be used to take forward the Torbay Carers Strategy for 2018-2021. Healthwatch Torbay was asked to undertake the analysis in their role as an independent consumer champion for health and social care services in Torbay. Our joint intention is to ensure that the voice of adult carers is a real and meaningful contribution to the development of the strategy.

The questionnaire was distributed in both paper format (posted) and in electronic format through an online website. There are approximately 4,100 Carers on the register. Of the 800 responses received 147 were entered directly on the website by recipients. The remainder were manually entered by the Healthwatch Team as they arrived in the office. The consultation was closed at midnight on 12th January, having been opened on 28th November 2017 and the first response received on 11th December. Healthwatch Torbay was asked to have the report finalised by 25th January 2018.

To support the development of Carers strategies, NHS England has prepared a tool-kit to help health and social care organisations work together in identifying, assessing and supporting the wellbeing of carers and their families. This states that:

"By finding out when someone is caring or looking after someone else we can make sure they receive the right help at the right time and that they are able to enjoy life outside of their caring role.<sup>1</sup>"

In addition, the Department of Health has asked the National Institute for Health and Care Excellence (NICE) to prepare a guideline about supporting adult carers and this will be published within the life-time of the refreshed Torbay Carers Strategy<sup>2</sup>. This states:

"Caring for someone can take its toll on a person's health and wellbeing. The 2011 Census indicated that there were around 6.5 million unpaid carers in the UK (with 1.3 million being over 65): this figure is rising... In a survey conducted by Dying Matters, 70% of people expressed a wish to stay in their own home, and to die at home. Guidelines on supporting carers are therefore urgently needed.

#### **Analysis summary**

The questionnaire consisted of 33 questions/supplementary questions to be addressed. The majority also included some form of free text opportunity to expand on the answer or to make additional suggestions. As a number of questions were formatted in a complex way, a significant number of responders, often over 100 responded in the free text area. Where possible and relevant, Healthwatch was asked to separate out the responses for Carers of cared-for under the age of 18yrs (74 responses). Not all responders completed the questionnaire with only 498 reaching the Triangle of Care question (number 32). Wherever

<sup>&</sup>lt;sup>1</sup> https://www.england.nhs.uk/commitment-to-carers/carers-toolkit/

<sup>&</sup>lt;sup>2</sup> NICE Guideline. Carers: provision of support for adult carers final scope. Expected pub July 2019.

possible, the full analysis includes, verbatim, the actual free text responses to give a strong Carers' Voice.

The questions were arranged in sections:

- Identification of Carers
- Information Advice and Support services
- Support for the person cared for
- Carers Information
- Education Courses for Carers
- Looking Forward

#### Section 1: Identification of Carers

Age: Responders identified their age in a bell curve form of distribution across all age categories, peaking in the working age range. When this was split, by age range of the people cared for, those caring for those under 18yrs old were predominantly aged 26 to 50 yrs and over 25% of those caring for people over 18yrs old were in the 75yrs and older age group.

**Postcode:** Responses were distributed evenly across all of the Torbay postcodes with slightly more across the Preston area of Paignton and north Paignton, diminishing across south Paignton with Goodrington and slightly less from Brixham.

Difficulties/Disabilities: Carers, for people under 18yrs old, cared predominantly for people with learning disabilities, with an indication that these had been diagnosed in the autism spectrum or as a result of congenital disorders. In the older age group, physical disability predominated and this was described in various ways including COPD, neurological disorder and frailty of old age including incontinence and falls.

Who first identified you as a Carer?: For those caring for under 18yrs old, "self" predominated as the means of identification. GP identification accounted for approximately 14% in this group. The question format does not enquire if the "self" diagnosis was transferred to General Practice. This is relevant to future development, as the NHS toolkit states:

"The registration of Carers in General Practice is key to this as being identified as a Carer will generate a READ code on the Carer's personal medical record and this will accompany that Carer whenever and wherever they use the NHS in England (by being shown on the Summary Care Record). Within integrated services, social care staff will have access to the Summary Care Record."

For those caring for over 18yrs old people, over 30% identified "self" but the recognition by General Practice had increased to approximately 25%. Again there was no indication if this information had been transferred to General Practice.

#### Could you have been identified as a Carer at an earlier opportunity? By whom?

Over half (54%) of all respondents considered that they could have been identified earlier and 68% overall (of these) considered that they could have been identified sooner in General Practice.

From the National Carers Survey we know that Carers' health and wellbeing has dropped significantly since the last survey 2 years ago. What one thing would most improve your health and wellbeing and why?

Verbatim comments are included in the full analysis. Responses showed:

Carers for people under 18yrs: Respite: 30% (17), Caring support: 14% (8), Advice: 12% (7), Counselling/Mental Health: 10.5% (6), Improved sleep: 10.5% (6), Professional support: 10.5% (6), Financial support: 9% (5), Self-help support: 7% (4)

Carers for people over 18yrs: Respite: 24% (99), Professional support: 15% (64), Caring support: 9.5% (40), Self-help support 9% (39), Single point of contact 9% (39), Counselling/Mental Health: 6% (25), Financial support: 6% (26), Advice: 5.5% (23), Reassessment: 3% (13), Improved sleep: 1.5% (6)

#### Section 2: Information, advice and support services

How do you prefer to receive information about Carers' support? Please rank your top 3 by putting a number in the box (1 being the most preferred)?

For the Carers of people aged under 18 years, e-mail and Signposts magazine was the most popular. For Carers of people aged over 18yrs, Signposts magazine and brochures were the most popular. In this latter age group, though, there were some comments about visual and mobility problems and the need for face-to face conversations.

#### Please rate all of the Carers' services that you have used. Any comments?

There were four response options for this question from "extremely helpful" to "unhelpful" listing 27 services. Carer's free parking had the most "ticks", followed by the general practice support worker (CSW). As responders would only tick those that they had used, it quite difficult to give a ranking of popularity and the graphical representation may aid interpretation. The "Weighted" section is an approximation to describe effectiveness.

Using this approach it seems that 'Support Workers' of various kinds were valued the most, with 'Carers Assessment by team' following. Signposts newsletter came third in number of votes but had a low weighted score. Some Carers had not heard of some of the services, this is reflected in the verbatim comments which are recorded in the full analysis.

Do you feel there are gaps in Carers services? Suggestion for how these would be met

A third of responders skipped this question, giving: Yes (203) No (276)

Suggestions are reported verbatim and reflected individual circumstances. In addition 26 asked for services that are already known to them to improve, 26 stated lack of knowledge about services and 105 stated they were "not sure".

Overcoming isolation and loneliness seemed to feature in many of the suggestions. Frustration about the conflict of work and caring and needing services to run in the evening were key concerns. A gap for cared for as they transition from 18yrs to older age group was highlighted.

#### Section 3: Support for the person cared for

This was the most complex presentation of questions generating some confusion amongst responders.

## Does the person you care for receive any support that helps you or gives you a break?

For carers of people under 18yrs only 25% identified the list of services provided in the "last section", with 35% not sure how to get support. Only 3% identified a voluntary service as giving support.

For carers of people over 18yrs this gave a contradictory response with 37% saying 'not required', which does not correlate with later comments about the need for a respite. This may imply a misunderstanding of the question e.g. "support" may be interpreted as funding. 18% (110) stated that the person they care for would not accept the service. Overall, care must be used in interpreting this question response.

If the person you care for receives support that helps you or gives you a break, please indicate whether this support meets your needs as a Carer. (only those answering Yes - they did receive support - to the last question directed to this one)

Again, this required a complex matrix response with 12 options rated as "Meets all my needs/Meets some of my needs/Doesn't meet my needs" and a column for "Receive via direct payment"

On the whole, for the Carers of people under 18yrs, most ticked the "does not meet my needs" column. This response should only be used as an indicator rather than an absolute answer, as this was not the outcome with other (verbatim) question responses. It may be that this response is about the service and earlier responses in other questions were about the person supporting the carer.

For the carers of over 18 people there is a similar situation although "meets some of my needs" does carry more weight. In this category there does seem to be a lack of understanding of the formal terminology used, so the score may reflect this. Home care, equipment and community alarm being the most popular.

#### If any have not met your needs as a Carer, please can you give more information?

84 responders from all Carers answered this question with a greater number not identifying any of the given reasons (again in a matrix from service too expensive/Not enough availability/Unable to book in advance). 'Too expensive' and 'not enough availability' being were the most common reasons.

Other reasons tended to be personal reflection on their own situation and are reported verbatim.

# If using Direct Payments, how satisfied are you with the support to manage these payments?

The majority of responders were satisfied with their support.

#### Section 4: Carers' information

#### How do you receive Signposts newsletter?

Of the responders twice as many read in paper format as electronically and a few wished to revert to paper copy.

#### Which parts of the Signposts Newsletter do you find most useful?

Most sections were considered useful. The Young Carer/Young Adult Carer response is the most ambivalent, which may reflect comments from those not of this age-group.

#### What other information would you like to see included in the Signposts?

43 ideas for this section which ranged from Quiz to more explanation about specific conditions. Nearly every idea is unique but some suggestions might be helpful in general terms i.e. personal stories, a day in the life of one of the services. Reminders seem to be required i.e. when courses happen, also a rating for respite quality (Trip advisor - or perhaps a link to Healthwatch Rate and Review?)

## Use of the Torbay Carers website and if Yes how useful? Suggestions for improvement.

Only used by 1 in 7 of responders. Of those who used the site it was found to be useful on the whole. Suggestions for improvement included 'formatting issues' (size of font for poor sight), 'keeping it up-to-date', and including financial information and other factsheets e.g. manual handling. Further feedback included 'less words and more pictures' and a question around the potential use of easy reading content.

#### If you have not used please tell us why?

This was clearly related to lack of computer literacy skills.

#### Section 5: Education Courses for Carers

#### Usefulness of Core courses (rate from 1 to 3 for the 3 most useful)

There were 160 responses from all Carers, which may reflect the level of use of these courses. (Or the difficulty in deciding which was best!)

First Aid was the clear winner in this section with Pocket Emergency Plan failing to hit the mark.

#### Usefulness of "recreational" courses. (rate 1 to 3 for the 3 most useful)

Only 101 responses for this question with Creative Crafts and Exercises for Better Health most popular. Silk painting did not hit the mark!

#### Suggestions for other courses?

For men, cooking was the most suggested. The other suggestions were related to keeping fit in some way. All would relate to meeting other people in a social setting.

#### Would you access short video courses online if made available?

Approximately 50:50 Yes:No

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

Of the 169 responses all seemed equally useful. The "other" suggestions may be spin-offs from the items offered.

#### Section 6: Looking forward

At this point 498 responses were still active and 90% agreed with the principle of the Triangle of Care as a partnership across professional, person and carer. When asked if willing to be part of developing Carer-led projects and increasing support from volunteers the split became 20:80 (Yes:No)

If you have had a Carers Assessment or Carers Health and Wellbeing Check, please give us any feedback in the box below:

Of 175 responses for all Carers, approximately 50 stated 'not applicable'. Of the verbatim comments below, these fall into 3 categories:

- Assessment circumstances now out of date as no follow up
- Excellent and useful often appreciative
- Have not had any

The verbatim responses are identified in the full report following.

#### Anything else to add including contact information:

As personal data was provided in answer to the question, this information is not included in the report and has been transferred directly to the Torbay Carers Service for further action.

### Recommendations

This report aims to represent the Voice of Carers and much is reported verbatim in the following section of the report. There is always a challenge to be truly representative when 1 in 5 of those on the register responded and not all had participated in the same services.

Although it did seem that just under a half of the responders did not complete the questionnaire, some themes did give a small window onto the way forward and clarity about the issues:

- General Practice early identification of Carers is critical.
- Consideration needs to be given to isolation and need for professional contact and social contact.
- Address the stress of caring, reflected in the need for a break or respite, as the cared for person has a high dependency on the carer.
- As carers grow older and themselves frailer, re-assessment is required to address their changing needs.
- End of life support is not raised (with reason, in this format) but is implied in a few responses about what comes next. This needs to be addressed.

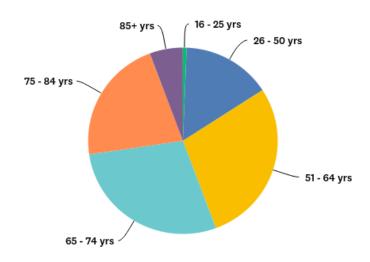
To end on a note of celebration, the Voice of the Carers was on the whole very appreciative of the support they receive with specific names being mentioned (not shown for data protection) and this includes the value placed on the Torbay Carers Service as a whole.

# **Detailed Account of Findings**

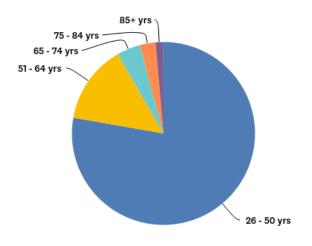
#### **Identification of Carers**

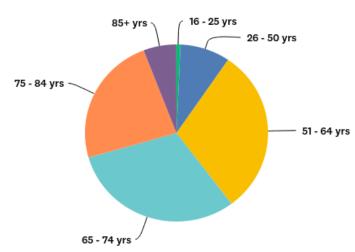
794 people completed this section

1. Age range of responders (see right):
All carers (794)

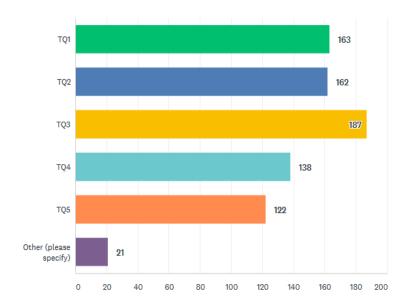


2. Carers for people under 18yrs (72 responses) Carers for people over 18yrs (722 responses)





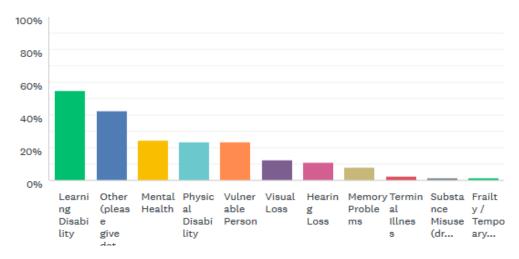
#### 3. Postcode identification: 700 people completed this section



7 responders identified as out of any TQ area, the remaining "other" (14) identified as TQ areas in South Devon

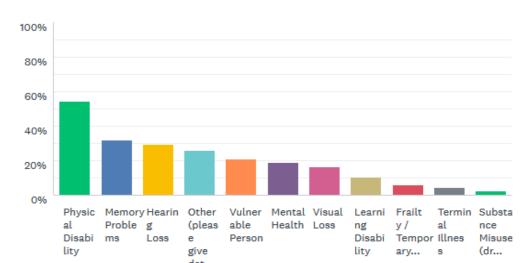
#### 4. What difficulties/disabilities does the person you care for have?

#### a) Caring for people under 18yrs (73 responses)



**Key in order:** Learning Disability, Other, Mental Health, Physical Disability, Vulnerable Person, Visual Loss, Hearing Loss, Memory Problems, Terminal Illness, Substance Misuse, Frailty/Temporary Illness.

This category also provided 31 "other" responses of which 19 identified autistic spectrum disorder or attention deficit hyperactivity disorder. The remaining 12 identified congenital disorders.



#### b) Caring for people over 18yrs (701 responses)

**Key in order:** Physical Disability, Memory Problems, Hearing Loss, Other, Vulnerable Person, Mental Health, Visual Loss, Learning Disability, Frailty/Temporary Illness, Terminal Illness, Substance Misuse.

This category also provided 183 "other" responses half of these were described by diagnosis (see below) and not by symptom. The remainder related to frailty i.e. described as incontinence, falls, mobility, epilepsy.

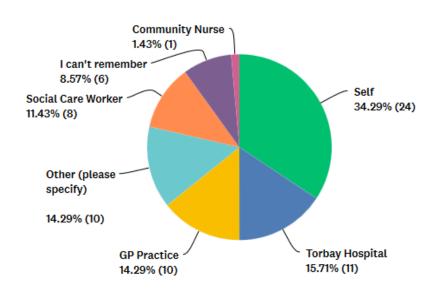
Autistic spectrum	5.40%	10
Cancer	4.92%	9
COPD	7.65%	14
Diabetes	8.20%	15
Multiple Sclerosis	4.92%	9
Parkinson's	11.48%	21
Stroke	8.75%	16

#### 5. Who first identified you as a carer? (70 responses)

#### a) Caring for people under 18yrs

Of the 34% identifying "self "as first identified it was not asked if this had been shared with General Practice.

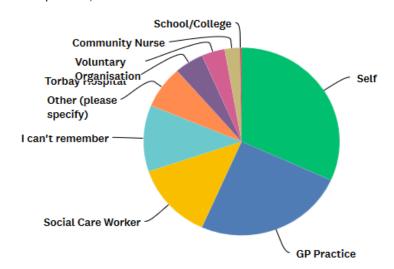
Of the 10 people identifying "other" organisations outside this list 2 identified SENDIASS and early years key worker. The remainder could be classified as "self" as concepts such as "a friend" were included.



#### b) Caring for people over 18yrs (683 responses)

Of the 32% identified as "self" if was not asked if this had been shared with General Practice.

Of the 50 people identifying "other", 6 stated Torbay Carers' service (in some form), the remainder were identified as:



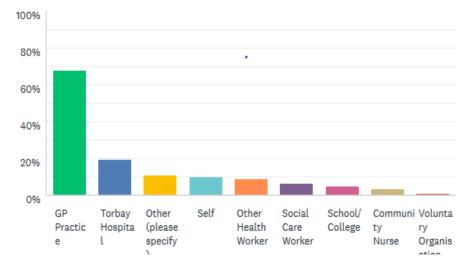
Where the "Professional person" was part of health or social care but not General Practice.

Family or Friend	26.00%	13
Job Centre/DWP	6.00%	3
Pharmacist	4.00%	2
Professional person	28.00%	14
Torbay Carers' Service	12.00%	6
Voluntary/Charity	24.00%	12

## 6. Could you have been identified as a Carer at an earlier opportunity? (761 responses)

In all cases and within the error of the reporting the response showed that over half of all - 54% - considered that they could have been identified earlier.

## 6b) If Yes, who could have identified you as a carer sooner? (All responders 436, skipped 364)



Key in order: GP Practice, Torbay Hospital, Other, Self, Other Health Worker, Social Care Worker, School/College, Community Nurse, Voluntary Organisation 364 skipped the question, which could imply that they did not know who could have identified them earlier. General Practice is 68% of all responses. Of the 11% stating "other", an additional 4 identified General Practice and 11 identified self, even though the chosen suggestions are existing choices. 14 stated a professional person not in General Practice and 17 stated that they did not know.

7. From the National Carers Survey we know that Carers' health and wellbeing has dropped significantly since the last survey 2 years ago. What one thing would most improve your health and wellbeing and why?

The following responses, in both categories, are verbatim and indicative of all comments. The full list is available on request to Healthwatch Torbay.

a) Caring for people under 18yrs (57 responses) in the following categories:

#### Advice: 12% (7)

- "Someone to talk to ask for advice, someone who actually gets back to you when they
  promise I have been let down at every level"
- "Being listened to and people understanding the condition of the person I care for"
- "Advice on money and mood swings in adolescence."

#### Support for caring role: 14% (8)

- "More local help"
- "A bit of help now and again to do the housework"
- "More clubs / activities for young person to attend"

#### Counselling/Mental Health: 10.5% (6)

- "Access to counselling to cope/manage the impact that receiving a diagnosis brings.
   Increased availability of 'early bird' courses or similar. Stronger centralisation of relevant peer-to-peer support groups. e.g. SENDIASS parent/carer coffee mornings"
- "Counselling- never had it and feel it would've have helped to deal with aspects of my daughter deafness"
- "Counselling/someone to talk to about my daily struggles. Nobody I know has experienced this or understands"

#### Financial support: 9% (5)

- "Money. Because I am having to struggle between fuel and food for us both"
- "A higher threshold for carer's allowance"

#### Improved sleep: 10.5% (6)

- "Less stress and Good night sleep as a person a care for 24/7 doesn't sleep well at night"
- "More respite care to enable me to have some 'down time 'and get some undisturbed sleep"

#### Professional support: 10.5% (6)

- "More understanding and recognition from professionals"
- "it would have improved my health if I didn't have to spend 5 years of my life trying to get my children assessed due to their individual needs re learning disabilities. I am still

trying to get them their diagnosis and help. Children's mental health at Torbay is an absolute joke"

"Get to see Doctors"

#### Respite: 30% (17)

- "respite/buddy programme for son (promote independence for him)"
- "Respite I have not had a break from both for 5 years only one or the other. It is very wearing 24/7"
- "Some time away from being a carer to be myself again"

#### Self-help support: 7% (4)

- "Better support network and groups so I don't feel alone"
- "Having time and the money to complete a computer course because IT changed so fast and rapidly I have been left behind whilst caring."
- "A free gym pass so I could lose some weight whilst having a bit of time out to think."

#### b) Caring for people over 18yrs (422 responses, 281 skipped) in the following categories:

#### Advice: 5.5% (23)

- "Having acquired direct payments from D.C.C before transferring to Torbay would have liked more guidance, support etc. Especially in the initial stages. Just talking through the options available, different ways of spending the budget etc."
- "help in supporting carers to remain in work not enough support form agencies to do this"
- "Having more support in understanding what processes are available to help look after elderly parents when we don't live nearby. More information about what to expect with dementia."
- "help filling out forms like these"
- "Being able to enjoy social activities with my husband without having to consider if there is sufficient seating or if booking a holiday that we mattress toppers to make sleep possible and a million other considerations. Maybe I need to think more positively - hard to do some times."
- "an understanding that 2 individuals can care for one another would help health professionals to understand all caring roles don't fall in a standard category. Torbay Young carers age range to be higher, 30yrs as I feel when I turned 25yrs the services available won't suit me or my age range
- If my husband would accept help from others beside me"
- "Support with my wife's illness. I do feel it is misunderstood, also more understanding from my workplace, they just don't want to know or help me"
- "A yearly appointment with a Social care worker, because as a carer everything is in place for the person we care for but nothing is in place for the Carer"

#### Support for caring role: 9.5% (40)

- "Someone who would be willing to visit my husband and keep a keen eye on his wellbeing. Also, my husband had to leave a residential home when it closed and I had to find him a place which turned out to be the only available empty room, which upset him. Their knowledge, watchfulness and reporting on him is not always satisfactory so I need to be vigilant and check on him 5 times a week, which is exhausting."
- "More support for lone Carers"
- "Better support and understanding"

- "More help with caring"
- "Knowing there are people or organisations to help you. When you really need that extra help"
- "Anxiety as need more support sometimes"

#### Counselling/Mental Health: 6% (25)

- "Emotional support. Failing health means less able to deal with ageing emotion problems of caring"
- "meet people with similar problems"
- "I feel very anxious sometimes trying to balance everything"
- "Offloading stress"

#### Financial support: 6% (26)

- "not to have to work whilst being a carer"
- "more support with housing issues. Help getting husband the support he needs not me"
- "earning money is really hard for me to earn as I'm still in college and the careers allowance process is a long process and I find it quite stressful"
- "not having my DLA cancelled by PIP as I now have to rely on my husband for transport. He feels trapped his stressful job as I cannot work and the loss of this benefit means I have to keep asking him"
- "Attendance allowance refused- acceptance would help with payment towards, household chores. But feel wife's ability to see to her personal care has made us ineligible from A.A."
- "Less worrying about my husband and the future without him, emotionally and financially"
- "financial support towards the upkeep of essential equipment it is a constant worry"
- "Being able to reduce hours I work in my paid job. Would have more energy to help my husband who I care for. (can't afford to reduce the hours I work)"

#### Improved sleep: 1.5% (6)

- "Good night's sleep and perhaps someone to take my husband for a walk"
- "Improved sleep pattern. Arthritic pain wakes my partner frequently at night"

#### Professional support: 15% (64)

- "Advice from GP"
- "Access to GP appointments when necessary. We have to telephone after 8.30am and it is extremely difficult to get through."
- "Reception staff at surgery being more understanding when you are desperate to get help for the one you are caring for."
- "Better access to and information support also GP liaising with external agencies etc."
- "Support from Social Services (no support currently). Provision of key safe, grab handles, mobility aids."
- "In the early stages one is without experience of the developing and potential demands which are/will be made. This is v frustrating and sapping of physical and mental strength. Targeted information on care of the elderly in leaflet form (concise) or access to a counsellor attached to GP surgery / referred by GP perhaps would be very helpful. "What to expect"."
- "to have a contact and be able to talk to someone when things go wrong or just for reassurance. This doesn't exist anymore"
- "Community nurse or similar to make further assessments."

"Support when coming out of hospital, they just release the person home, give you the
responsibility without district nurses visits and when you are trying to hold down a full
time job it is very hard to keep your job going and do what the NHS expect you to do,
when the cared for person is sent home."

#### Re-assessment: 3% (13)

- "been caring for my husband for so long I am now frail and of ill health none to support me"
- "I would be okay except my daughter is also unwell (about 10 years now). My elderly neighbour needs a bit of help & three poorly friends. I think I'll leave home and kids!!"
- "Not having to fight the systems, supporting my adult daughter is hard enough without "the systems". Really a support worker for me, to help me actually get things done e.g.:- form filling, contacting the various agencies. My health is very poor now."
- "Help with removing the bath and replacing with a shower to assist me as my husband needs a shower more than once a day and he is unable to have a bath. I have to assist with his showering with a shower head over the bath. As he is a large man it would assist me"

#### Respite: 24% (99)

- "More breaks Respite"
- "unable to leave him for a few hours maybe a day centre? Sounds selfish but after 6 years, need a break. Much as I love him"
- "Respite which doesn't prove too difficult to arrange"
- "A holiday. have not had a respite care place for my mother now ST Kilda's has closed"
- "Having a young adult hospice open so I could have a break. Have used children's hospice, but son is now too old. Haven't had a break for over 5 years"
- "A break from time to time to enable my husband and I to have some time on our own. I is just knowing you haven't got that responsibility for a short time so you can recharge your own batteries especially as my own health is not great."
- "I would love a nice rest, as I get very tired, now I have a few heart and other problems of my own, but we have been married 67 years and I will not leave him. My daughter and granddaughter are very good to us, but we do not wish to become a burden to them. I am managing at the moment but worry over how much longer I will be able to cope."
- "Being offered some type of respite. A male companion to befriend my husband and give him male company that he craves"
- "More affordable respite. I haven't had a break away for 12 + yrs it is starting to affect my own health now"

#### Self-help support 9% (39)

- "carer health and wellbeing check. I would have liked this as I have neglected my own health"
- "Carers Support Groups are the most valuable help I have found plus courses".
- "General health and wellbeing, including physical strength"
- "keeping fit"
- "Access to free education from home, i.e. Online courses leading to recognised qualifications. Education is an area I feel I am missing out on because of being a stayat-home carer."
- "An outlet/support to prevent my social isolation, I value my care support worker and the activities offered to Carers for groups/education."
- "Gymnastic exercise"

#### Single point of contact 9% (39)

- "One point of contact I work full time (have to until at least retirement age of 66) I
  am sometimes confused about who does what. I am unavailable during the day most
  support networks are in the day. I would like to share experience with someone
  similar."
- "More support and better information as to help that's available. People don't realise
  they are a carer at first, it sort of happens then it's ongoing and until you find help it
  doesn't come to you."
- "Consistent support from a third party"

59 responses are uncategorised as responders did not know, or described their illness.

#### Information, advice and support

8. How do you prefer to receive information about Carers' support? Please rank your top 3 by putting a number in the box (1 being the most preferred)?

#### a) Carers for people age under 18yrs (62 responders):

Adjusted score is a weighted response taking into account ranking and numbers voting. This type of assessment is difficult to quantify as there are different numbers voting for

each item.

## Other (13 responses):

- e-mail (8)
- print (3)
- did not know (2)

Service	No of votes	Adjusted score
Web based information - carers e-mail	33	11.03
Written information Signposts magazine	27	10.33
Web-based information - web site	23	10.04
Written information - brochure	22	10.14
Web based - Facebook	20	9.75
Face to face Carers Centre	18	8.67
Face to face worker	17	8.65
Written information leaflets	16	9
Written information posters	14	9
Telephone - Signposts information line	13	8.38
Face to face - hospital advice point	11	6

#### b) Carers for people aged over 18yrs (650 responders)

Service	No of votes	Adjusted score
Written information Signposts magazine	325	11.01
Written information - brochure	263	10.49
Web based information - carers e-mail	219	10.83

Written information leaflets	197	10.58
Face to face worker	175	11.16
Face to face Carers Centre	162	10.93
Web-based information web site	122	10.25
Telephone - Signposts information line	95	10.2
Written information posters	71	10.01
Face to face - hospital advice point	67	10.27
Web based - Facebook	51	9

#### Other (46 responses):

- e-mail (15)
- Print (13)
- Face to face (9)

- "internet" (1)
- did not know (8)

#### 9a) Please rate all of the Carers' services that you have used

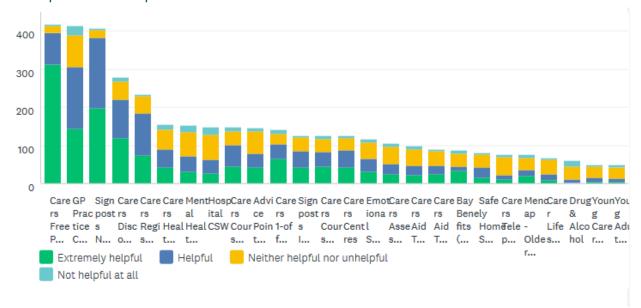
All responses 687, skipped 90

Weighted score = rated highly to rated lower, for those that voted for that service

Service	No of votes	Weighted score
Carers' free parking at local hospitals	418	1.31
GP Practice Carer Support Worker (CSW)	413	1.97
Signposts Newsletter	407	1.58
Carers Discount Card	279	1.82
Carers Register (Emergency Back-up Plan)	233	1.9
Carers Health and Wellbeing Check	156	2.24
Mental Health CSW	152	2.43
Hospital CSW	149	2.52
Carers Courses (Related to Caring e.g. First Aid	148	2.08
Advice Point at Torbay Hospital	147	2.24
Carers 1-off Direct Payment	141	1.87
Signposts Information Line (01803 666 620)	127	2.05
Carers Courses (As a break from Caring e.g. Craft	126	2.06
Carers Centres	126	2.02
Emotional Support Scheme	118	2.26
Carers Assessment by Zone/Team	106	2.38
Carers Aid Torbay (was Crossroads/Carers Trust Phoenix) - Advocacy	98	2.36

Carers Aid Torbay (was Crossroads and Carers Trust Phoenix) - Other Support	91	2.27
Bay Benefits (John Dudley)	87	2.18
Safely Home Scheme	82	2.35
Carers Telephone Line (Tuesday Nights)	77	2.64
Mencap - Older Family Carers	76	2.37
Carer Lifestyles Worker	68	2.59
Drug & Alcohol	61	3.02
Young Carers Worker (age <18)	50	2.72
Young Adult Carers Worker (age 16-25)	49	2.8

**KEY**: Graph below corresponds to table above in the order listed



Other: 7 identified a charity that they used, 15 had not used any service and 19 gave information not relevant to the question.

#### 9b) Any comments about the above?

279 responded of which 75 gave a useful comment most praising the service they voted for and in many cases mentioning a person they valued or just said "Thank you".

A selection of others identified lack of contact and not being aware of services:

- "Most carer's courses seem to be on a Thursday and even when on other days they start at 10am. This is restricting those I can use as my wife doesn't go to day care until 10am."
- "A lot of them I had no knowledge of especially any hospital support. Last time I had
  to go to my husband in A&E and the Doctor who interviewed him didn't let me tell her
  what had happened, she was only interested in his account even though he has little
  or no memory but is very inventive and inaccurate"
- "I have only seen the GP Practice CSW only once have only had contact with the MH team when mother was diagnosed with dementia 2016. Nobody bothered with me since"

• "I have not been offered Carers Health and Wellbeing check by GP. I have not had the time to find out about the carers discount card, and have no information about free parking at the hospital etc."

#### 10. Do you feel there are gaps in services?

All responses: 479 responders, 298 skipped

203 = yes

276 = no

#### If yes please suggest how to meet these gaps

All responses: 209 of which 52 specified a perceived gap, 26 asked for services already known to them to improve, 26 stated lack of knowledge about services and 105 stated they were "not sure".

Of those specifying a gap (responses are verbatim):

- Not really a carer's service problem but I wish there could be a closer relationship between the doctor and the Carer. IE the doctor of the person I care for & me the Carer"
- Would welcome something more autism specific for adults e.g. a Carers group, access to specialists in this field
- Emotional support
- Anything for ages 30 -50
- Having a 24 7 phone number, in case it is needed
- advertise yourself in local shops, post office, GP practice, Libraries etc. Signposts
- I just need some help for me, at home, but this won't happen as need help to apply for help. I get organised or whatever, sorry suffer from pain so find it difficult to thing about these issues.
- There are now lots of gaps because of lack of funding. One is the Cool House, so many people were helped there.
- More organised outings.
- Provision of mobility aids and key safes
- It is not so much gaps as so many different organisations wham isn't easy to negotiate
- I think getting a Social Service Assessment takes too long from referral to someone coming to see you. The carer's courses are not always convenient or are not in your home town meaning petrol and car parking fees so in the end you stop going. Why can't they be held at different places so you could perhaps get to one nearer home?
- I believe more work needs to be done on supporting carers within their role, rather than focusing on giving carers a break from their role.
- Groups for caring parents to socialise and meet up with other parents who are also Carers. Being a parent carer and a single mum can be very isolating.
- Sessions on how to deal with situations that arise caring for someone with dementia regarding conversation actions and disagreement. Dealing with anger spells
- Sometimes you can feel isolated, as a carer of my 44 year old daughter (due to brain haemorrhage stroke) I am a carer that doesn't have a lot in common with many not a young carer or carer of elderly.
- Volunteering needs more information on how to be a Carer. Meetings once a month in Torbay. Carers should help other Carers in their jobs.

- Most meetings etc. are held during the daytime As a working Carer I am unable to access any of these. I feel most are aimed towards Carers of elderly relatives or spouses
- A phone call once a month would be good Wednesday afternoon
- Discrepancies between 'types' of carers. There seems to be huge support for carers of the elderly, but support for carers of children/young people can only be accessed through social services, which is off putting as they approach the 'offer' of support in a rather intense way.
- Predominately lack of assistance in caring for mental health.
- I wish I knew how to combat loneliness with no proper 5 days a week day centre.
- marketing how where when support is available
- massive gap between 25 30 as I feel carer aid torbay is aimed at a higher age bracket
- middle aged carers aged 40 -65
- more emotional support and more activities for my age group not just older or younger people
- By keeping in touch, just a phone call would be lovely.
- Many carers work in the day are there evening parent to parent contacts available
- Evening courses and maybe someone to just call either Doctor or Carers team and ask if everything is ok.
- Carers support meetings always seem to be in daytime when I cannot attend as I work
- Carers I feel are left to their own devices. Maybe a Carer Worker should visit some of the disabled groups across the bay.
- it seems a lot easier to get involved if you are caring for older rather than younger people
- Still a lot of carers who do not know what is available. GP practices could be more proactive
- Towards mental health support for anorexia
- Could the services be 'joined up' more? A one point phone number / website
- for carers in the 30 50 age range for special needs support groups required
- Sometimes you can feel isolated, as a carer to my 44year old daughter (due to brain haemorrhage stroke) I am a carer that doesn't have a lot in common with many not a young carer or carer of the elderly
- Need for more direct contact with Carers i.e. Email information telling Carers of their entitlements
- Most of us don't know about a lot of the things that are going on and when you want help there is only 9-5 help.
- knowledge regarding help for carer is not well known to the general public who care for others. There is a need for a more robust advertising campaign
- I don't know but I do feel very isolated most of the time
- again relating to people aged 25yrs+. After 25yrs seem to be left until they are in 40+ which is a huge gap.
- general help transport to hospital and surgeries
- There needs to be more joined up checking between physical and mental health carer support sources. The deterioration between a carers mental health as they care for their loved one is just as important as their physical decline. This is often treated secondary-more money needs to be put in too!
- practical access to respite. Also more support targeted at carers of disabled children
- Evening/weekend groups.
- Most courses/meetings etc. are during the day which for a carer and daytime worker it is not possible to attend or benefit from.

- Consistency, an annual check that carers are still coping. It would be nice to have someone else whom my son could contact for help & reassurance. My husband & I are getting too old to cope with everything these days.
- One stop shop. I understand the system but navigating through it is a nightmare
- Face to face visits I know are difficult to make due to cost constraints but a 6 monthly visit from a care worker would make a difference

#### Support for the person you care for

11a) Does the person you care for receive any support that helps you or gives you a break?

#### a) Carers for people aged under 18yrs (63 responses, 11 skipped)

No - Not sure how to get support/what is available	34.92%	22
Yes - Services referred to in Question 11b	25.40%	16
No - Not required	19.05%	12
No - Not eligible for support	9.52%	6
No - Because of cost	7.94%	5
No - The person I care for won't accept the service	6.35%	4
No - Availability issues	6.35%	4
Other (please specify) Response	es 6.35%	4
Yes - Voluntary sector/Community support	3.17%	2

#### Other:

- No not aware that we are eligible for anything
- not sure if eligible
- Respite received through a CiN plan- funded by children's services due to the impact of our disabled son's behaviour on his siblings and family
- Told 'not eligible' illegally

#### b) Carers for people aged over 18yrs (607 responses skipped 96)

No - Not required	37.23%	226
No - Not sure how to get support/what is available	23.06%	140
No - The person I care for won't accept the service	18.12%	110
Other (please specify) Response	es 13.18%	80
Yes - Services referred to in Question 11b	11.20%	68
No - Because of cost	7.41%	45
No - Not eligible for support	6.92%	42
No - Availability issues	2.31%	14
Yes - Voluntary sector/Community support	1.81%	11

#### Other responses:

No (key worded from free text open question):

- Not required (7)
- Will not accept the service (5)
- Cost (3)
- Not eligible (6)
- Not sure how to get/what is available (1)
- Availability issues (4)

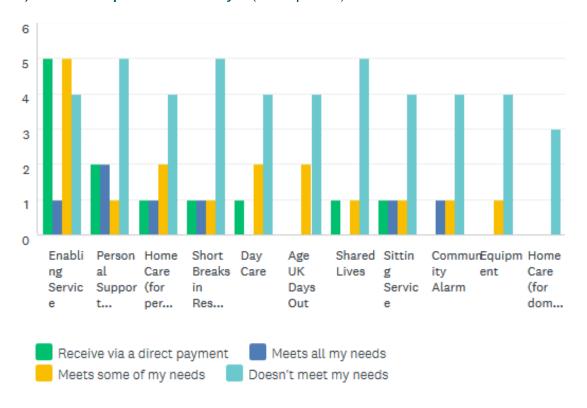
#### Yes:

- Voluntary sector or family (19)
- Carers Services (18)

11b) If the person you care for receives support that helps you or gives you a break, please indicate whether this support meets your needs as a Carer. Please also indicate if you receive this via a direct payment (Responders were asked to select this question based on a "Yes" response)

(Care with interpretation as number stating "Yes" does not correlate with numbers answering the following questions)

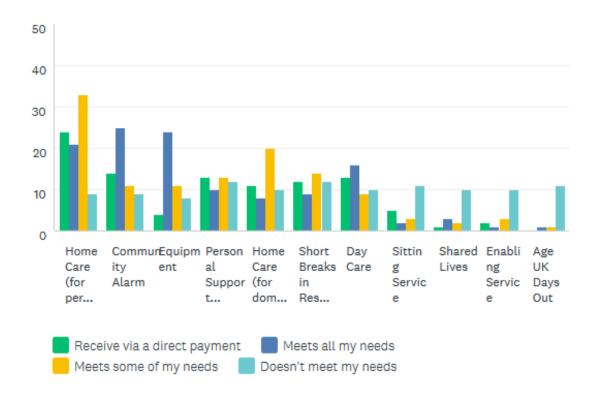
#### a) Carer of a person under 18yrs (19 responses)



	Received via direct payment	Meets all my needs	Meets some of my needs	Doesn't meet my needs
Enabling Service	5	1	5	4
Personal Support Workers	2	2	1	5
Home Care (for personal care	1	1	2	4
Short Breaks in Residential Care	1	1	1	5
Day Care	1	0	2	4
Age UK Days Out	0	0	2	4
Shared Lives	1	0	1	5
Sitting Service	1	1	1	4
Community Alarm	0	1	1	4
Equipment	0	0	1	4
Home Care (for domestic care e.g. cooking/cleaning)	0	0	0	3

<sup>&</sup>quot;Other" 7 responses: VisualEyes, Overnight Respite and playscheme in holidays. Remaining responses stated that this question did not apply to them.

#### b) Carer of a person over 18yrs (155 responses)

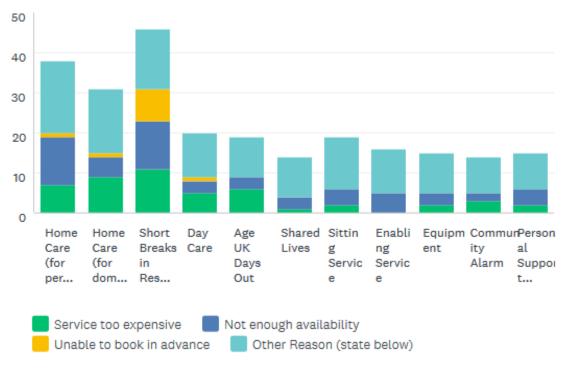


	Received via direct payment	Meets all my needs	Meets some of my needs	Doesn't meet my needs
Home Care (for personal care)	24	21	33	9
Home Care (for domestic care e.g. cooking/cleaning)	11	8	20	10
Short Breaks in Residential Care	12	9	14	12
Day Care	13	16	9	10
Age UK Days Out	0	1	1	11
Shared Lives	1	3	2	10
Sitting Service	5	2	3	11
Enabling Service	2	1	3	10
Equipment	4	24	11	8
Community Alarm	14	25	11	9
Personal Support Workers	13	10	13	12

49 comments for "other". The majority stating that this question did not apply to them. Remaining gave information not relevant to the question but implied lack of understanding or lack of knowledge about the services.

## 11c) If any have not met your needs as a Carer, please can you give more information?

84 responses from all Carers answering the question (112 ticked 'doesn't meet my needs' in last question)



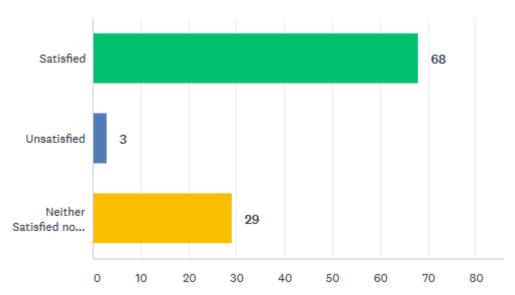
101 comments responding to "Other reason" - which was the next question

The majority respond as not required or not known. Of the remainder the following are the verbatim comments:

- Still awaiting Personal Care Package to be arranged for AM. From November 2017
- Need alternative as he refuses to go to allotted residential short break
- Psychologist care co-ordinator and community OT for Combat Stress
- Visiting carers have not passed information between each other regularly. Often get telephone calls about things carers should already know.
- When you have savings, have to decide what helps most needed so have help overnight so I can sleep. So it's too expensive to get day help so I can go out more than a few hours a week.
- Mother pays for 4 days day care. No finances for anything else.
- While fit enough better to try to do things together gives my wife something else to think about
- As I suffer from OCD and have anxiety mental problems I have been in residential homes in past, and my partner who I look after does not receive enough care from Quality Care TQ who come in twice a day.
- We try to manage as much as we can.
- lack of flexibility, unable to meet sudden change and minor emergencies

## 11d) If using Direct Payments, how satisfied are you with the support to manage these payments?

#### 100 responses from all responders



40 comments for all responses of which the majority either said "thank you" or "do not receive". A few expressed confusion about terminology used. Of remainder the following are verbatim:

- We are being encouraged to move onto Direct Payments despite us saying that we do not feel confident in managing them and don't want them. Children's Services want us to move onto them, but we don't understand why. I assume it's to do with whose pot funding comes from, but from our point of view, we just want respite provided as easily as possible from our point of view as caring is so stressful. We don't want to be involved in funding rows.
- I have only just started using direct payments but I think it will allow me more flexibility and is a very well organised service.
- we had direct payments for day care was told how to use it, did not suit our needs

#### Carers' Information

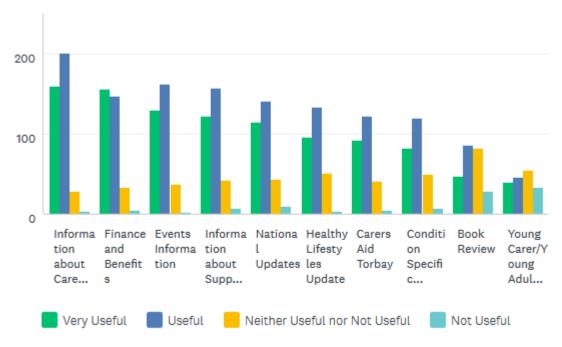
#### 12. How do you receive Signposts newsletter?

#### 630 responses from all Carers

Paper Copy	60.48%	381
Electronically (happy to receive in this format)	31.59%	199
Electronically (would prefer paper copy)	7.94%	50

#### 13. Which parts of the Signposts newsletter do you find most useful?

#### 544 responses from all Carers



(Label key in order of presentation): Information about Carer Support, Finance and Benefits, Events Information, Information about Support for the person you care for, National Updates, Healthy Lifestyles Update, Carers Aid Torbay, Condition Specific Articles & Information, Book Review, Young Carer/Young Adult Carers Pages

Other in this section (29 responses) all related to not receiving the newsletter, repeated options already presented or answered a different question.

#### 14. What other information would you like to see included in the Signposts?

111 responses from all Carers (666 skipped) 43 items relevant, remainder in "do not know" category:

- how to access aids for blind people and also wheel chairs things that you do not have to pay for, maybe a whole article on all FREE and available items for a whole range of disabilities
- More information about special educational needs
- Political influence e.g. local for subsidised water rates or national for women's pension age. We seem to have to work harder for longer as well as caring for parents and spouses.
- Carers breaks or holidays
- Quiz.
- I am only able to access courses during school hours due to my personal circumstances. I would be increasingly grateful if courses/groups/events could fall within school hours! (I know there are some courses for which I'm very grateful).
- More craft groups
- Perhaps more carer studies

- My husband, amongst other ailments has diverticulitis and is a very poor eater information about diets would be helpful.
- How I could do more to help my wife
- any information about support for the person I care for (mental health)
- Heath and Social Care info for cared for person. Detailed info concerning community care Assessment/Financial Assessment for cared for person.
- I like Signposts but would like to see a transport service which is pretty flexible and reasonable advertised on it.
- Poetry about patients.
- Where the meetings are and what time.
- Things on kidney failure.
- Local support.
- where to go for local support, a free phone number if possible. Perhaps I just haven't seen this information. More regular information, monthly.
- include other hospital/towns that we can use the card in
- more course/programs available in the area for groups you could join
- real life stories i.e. people progressing in life
- some remedies re improvement for stiffness
- I do not see it due to being in email format but would like more information for my age group such as local carers groups or emotional support in my area
- a paragraph about different services e.g. what they do opening hours etc. job role
- Maybe having a 1-1 chat could be made available?
- day trips out
- a carers advice line
- help with the benefits for carer and cared for. Instead of having to hear it from others often months later. This creates stress that could be so easily avoided for all
- Up to date info on arthritis
- anything re ADHD/ depression and anxiety
- how to get rapid help for young children with possible Asperger's & ADHD
- More stuff that is for babies/toddlers under 5's and under 18's. Paper very much for adults that have a condition.
- maybe an advice type page or more comprehensive list of services available to carers
- more articles on what you do when caring ends. how do you adjust, what opportunities are there for the carer.
- More support for acquired head injury
- Guide to new policies and changes and Signposts for further info.
- Maybe couple of puzzles/crosswords or more gardening tips.
- Carer charity specific-highlighted. I.E info-on what charities can do for supporting carers.
- How to write a care plan for myself
- Recommended, reliable respite facilities
- More information for carers of disabled children.
- Grants/Support available outside of the statutory services.
- Practical information especially where to locate equipment and assistance

## 15a) Have you ever used www.torbayandsouthdevon.nhs.uk/carers?

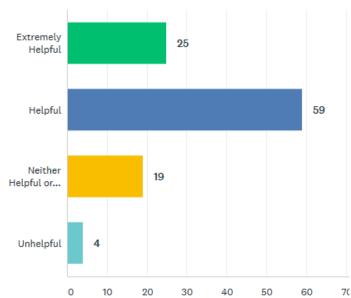
#### 672 responses for all Carers

Yes 92
No 580

## 15b) If Yes how useful did you find the information on

www.torbayandsouthdevon.nhs.uk/carers?

107 responses for all Carers



#### 15c) Do you have any suggestions on how it could be improved?

53 responses from all Carers 12 relevant to the question. Other replying as "No" or "I will have a look"

- Make sure it is kept up to date, i.e. courses that have already passed need to be removed.
- We do not understand and are in need of someone to explain to us with the help of a BSL interpreter
- Bigger font size. Brighter colours. Bolder writing.
- More up to date
- Again more information/links for under 18's and over 5's
- Be more user friendly for the elderly. More picture driven-less work like
- to find the link required guicker
- More content regarding funding for care and how to claim and more information about how to deal with the masses of paperwork involve with such claims for help
- All based on physical disabilities, same as training. All things like manual handling, medication etc.
- Yes. Help for people, and Carers who have to pay for all services themselves.
- More about support for the cared for
- TO TIRED OF IT ALL TO CARE (caps as responder)

15d) If you have not used our website, please tell us why?

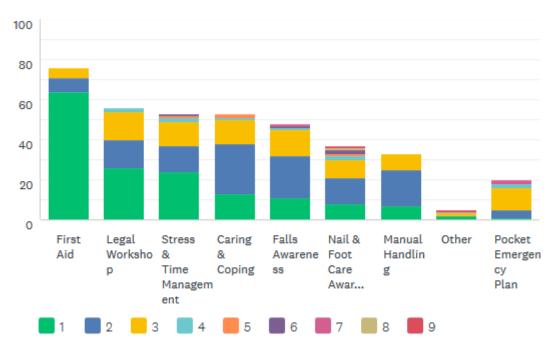
Don't own a computer		29.24%	157
Not aware of website		41.34%	222
Prefer to access information in a different format		23.65%	127
Other (please specify)	Responses	9.50%	51

Of the "Other" responses (51) these repeated that they did not have a computer, or it was not working or they had not needed it as other information sources (often telephone) was found more useful or they could not remember the url, or they did not have the skills to use a web-site. No other type of reason specified.

#### **Education Courses for Carers**

160 responses from All Carers

16a) Which 3 "core" courses did you find most useful? (Rate 1,2,3 if 1 is best)



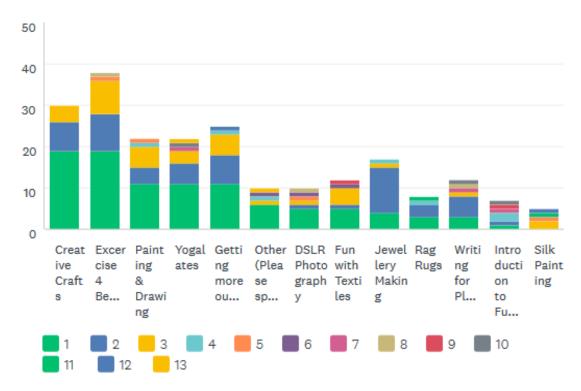
**Other:** 48 responses from all Carers (this option available on web responses only). The majority stated that they had not attended or did not know about them. Following are relevant verbatim responses:

- Maybe more courses specific to certain conditions e.g. Dementia, Mental Health etc.
- Attended something on cooking held at Occombe farm interesting and useful but would have liked another male (all ladies)
- behaviour management

Results extracted for the 75plus age group showed that First Aid followed by Caring and Coping were significantly higher than the average and rated 1 and 2

#### 16b) Which 3 "recreational" courses did you find most useful? Rate 1.2.3

#### 101 responses from all Carers



Key to labels in order: Creative crafts; Exercise for better health; Painting and Drawing; Yogalates; Getting more out of your computer; Other; DSLR photography; Fun with textiles; Jewellery making; Rag rugs; Writing for pleasure; Introduction to fused glass; Silk painting

Results extracted for the 75 plus age group showed that Exercise and getting more out of your computer were 1,2 rated the most.

#### 17. What other courses should we run? Any particularly of interest to male Carers?

147 free text responses from all Carers, verbatim indicative example are:

- cooking for men was particularly inspiring for my husband
- Men's discussion group
- Others: (some may include men it is not possible to extract in this way)
- Basic cooking Free Zumba classes.
- Book group
- Language classes: to keep the little grey cells stimulated. Self-employment for carers. Opportunities for volunteering and other community work.
- walking football
- Exercise 4 Better Health could be run on a different day. Not all courses are timed well for school hours.
- Tai Chi
- Mosaics

- would prefer perhaps a weekly meet and walk e.g.:- around seafront, however I appreciate any help that can be given to carers.
- UTIs; Dementia; How to spot early signs; What to expect as we age; Don't leave it too late POAs; Care Homes; Legal stuff and social/financial implications, requirements.
- Music (singing, piano) etc.
- I suggest a general forum for Carers to help each other cope with their problems, say 1
  per month
- Some courses for blind patients.
- deprivation of liberty
- sports perhaps a social active bowling for example or crazy golf, walking groups etc.
   General interest family history, music, events, shows and concerts
- I would like a place to go locally where I can meet people in my age group not just older or younger
- Local history
- Would prefer more courses to be Torquay based. Not all in Paignton College
- model boat days out
- I would like to see courses run in the evening so I could attend when I am not working
- I'd like to see some recreation courses closer to Torquay, quite a lot are at Paignton.
- parents are desperate for safe handling and non-violent resistance training. schools have it so why don't we when we are on the front line
- definitely more mindfulness please
- Basic computer literacy for beginners
- Young children with autism/ADHD etc. Makaton
- Dealing with incontinence

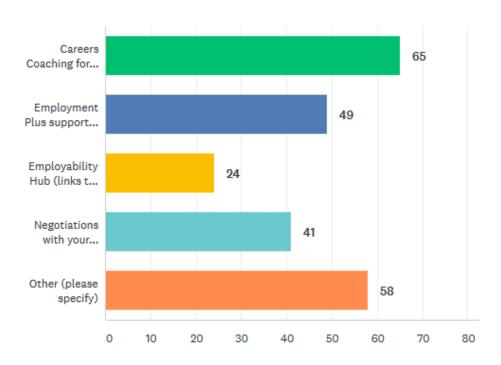
18. Would you access short video courses online if they were made available?

Yes 52% (324)

No 48% (300)

## 19. Which of the following services would you find useful to help you to either stay in or go back to employment/training? Please tick below (if applicable)

#### 169 responses from all Carers



#### Other:

- Training with a college course.
- CV and interviewing techniques
- how to get working for yourself e.g. taxi
- I wish I had the energy to get even a part time job. I sleep on average 2 nights a week in my caring role
- Financial help to reduce the hours I work.
- advice on caring role relating to work and legalities
- More courses to help you back to work after your caring has finished.
- Work experience

All other responses in this group state not applicable or retired or too old

#### **Looking Forward**

20. We feel that the principle of the "Triangle of Care" is important - equal partnership between professional/person/carer. As a Carer do you feel that Torbay and South Devon NHS foundation Trust should adopt this principle?

498 responses from all Carers:

Yes 90% (448)

No 10% (50)

21. In order to meet Carers' needs without spending more money, we would like to develop our Carer-led projects and also increase the support from our volunteers. Would you like to find out more about how you could get involved?

509 responses from all Carers:

Yes 21.5% (109)

No 78.5% (400)

22. If you have had a Carers Assessment or Carers Health and Wellbeing Check, please give us any feedback in the box below:

175 responses for all Carers approximately 50 of these stated not applicable. Of the verbatim comments below, these fall into 3 categories:

- Assessment circumstances now out of date as no follow up
- Excellent and useful often appreciative
- Have not had any

#### Verbatim examples:

- To offer one off assessments is not enough. We need more regular assessments with a broader range of support.
- Assessment was approx. 5 years ago, circumstances have changed since then
- helpful and supportive
- I think this may have been 6 or 7 years ago, I have no details but I think someone followed it up with a tape recorder and I believe it went on the website CARERS NEED TO BE KEPT IN THE LOOP!
- never had one
- Again needs following up on
- Had a carer's assessment 18th months ago because of Baytree closure. When it was
  done it was mainly to make sure we had sufficient respite. No information or
  indication when will have another one which would be good
- It's nice that you take care of the Carers, I feel sometimes we are forgotten
- Helpful to consider my wellbeing. Spurred me to get help with looking after mum.
- Useful to stop and give consideration to myself in carers health & wellbeing check.
   Also really valued counselling sessions received via the emotional support scheme.
- Nothing recent had assessment etc., re late mum but that was 10 years or so ago
- This was very useful and I actually felt listened to. I was Signposted to other things which I wasn't always able to do but were helpful.
- Seen v quickly and assessor was thorough although when asked what would have helped would have been easier if she had a list and explanation of what they were.
   Being a new carer don't know what any of the services you listed are and to get them.
- I have worked in mental health for 33 years I was disappointed by the assessment which did not hit the important areas for me. A factor was having a pension / not being on benefits.
- Had carer's assessment helpful, in fact I have received help with live-in respite as my daughter tried several different ways of having respite in residential situations where she was so unhappy - so I felt I was listened to and assisted in getting alternative breaks.
- It didn't really help in any way, I don't understand its purpose.
- Impressed with phone call service volunteer remembers things I have said.

- I found that the last assessment I had was very helpful and was awarded £200 for myself to go out for a few hours, hairdressers and relaxation class if available. I find this very helpful.
- I have had two Carers Assessments as my circumstances are constantly changing. They are also very helpful as much it is good to discuss your circumstances with a third party.
- Carers assessment with (...) can't speak highly enough about her warmth and empathy. 2. Health & Wellbeing check professional and informative about what is out there
- good to talk through my needs and my own health issues
- The Carer's Assessment was very useful, although this was nearly 12 months ago and needs have changed since. Am due a Health & Wellbeing check in January
- Not had one. Nobody seems to care about me.
- Carers Assessment Wellbeing Check could be more frequent.
- Haven't had one, would really like one as I struggle caring for my wife and stepson.
- I think we had a check about 18 months ago and we had a raised Toilet seat, a walking frame and an alarm for night time in case my wife needed help or me, it was organised from Midvale Road Clinic
- I had an assessment done in April 2017, I felt it was very 'long winded', lots of questions to answer, and at the end I was told I did not meet the criteria. I just felt it was a waste of time going. At the time I was under DAS and they asked me to get an assessment done.
- I had a check approx. 2 or 3 years ago while caring for both my parents. Mum was terminally ill so we had support but have been feeling abandoned by the system since her death as Dad's health problems are not as dramatic.
- After 7 years of caring this year we received a carers assessment finally. The lady was lovely butt after she heard what had happened to us over the last 7 years she did not really know where to start in helping us.
- Brunel surgery check my health every 6 months and very good
- Carer's assessment was simple and straight forward. Not sure of outcome yet
- I had one at my GP surgery. I've only had 2 appointments not enough and just felt I'm a nuisance to be honest
- Unaware of this service
- Carers assessment helpful but at time more the future getting closer
- No follow up Needs to be done regularly e.g. annually to pick up on actions and any changes to situation. GP Carer Workers could keep Carers Health & Wellbeing up to date otherwise it is a useless exercise.
- I had to go to the ombudsman to get a carers assessment and cared for an I am still not getting what the assessment said I should get
- Carer's assessment was helpful in fact I have received help with live-in respite as my daughter tried several different ways to having respite in residential situations when she was so unhappy - so I felt I was listened to and assisted in getting alternative breaks
- It didn't really help in any way and I don't understand its purpose
- Carers health and wellbeing check, was useful to be introduced to the support worker.
- Was very useful in principle but again because of husband was unable to implement most of it.
- I had a health check with my GP support worker and received my £200 voucher and 10 emotional support scheme sessions. This is great but I feel that social care input is very unsatisfactory as it is dependent on my husband agreeing to support as the cared for and as this is always going to be no, we as carers are always stuck between a rock and a hard place, ending up struggling without any support. With a score of 5/20 this can surely not be right and needs addressing before the system collapses.

- I haven't had one since I first become a carer and that seems years ago!!! I think to get an assessment I shall have to ask. I thought they would be automatically check how things are but obviously not.
- Having the wellbeing check was like a release valve going off, somebody finally seeing that I'm still a person and one that can't do it all, all of the time.

23. If there is anything else you wish to add, please comment below. If you wish for us to contact you about anything, and do not want your feedback to be anonymous, please write your details below.

108 responses from all Carers

# Answer Giving Disabled Avenue Questions Life Useful Appreciated Husband Torquay Care Group Carers Wife Support Preston Paignton Never Heard Services Courses Brixham Plan Age Future Not Aware

As personal data was provided in answer to the question, this information is not included in the report and has been transferred directly to the Torbay Carers Service for further action.

## **Thanks**

Healthwatch Torbay would like to thank everyone involved in this consultation, particularly all the carers and their families who took the time to contribute to it.

## Response from Torbay Carers Services

"Firstly, I just have to say a huge 'thank you' to the over 800 Carers who gave their time to fill in our questionnaire. It was quite a detailed one and it came out just before Christmas, so I was overwhelmed with the response, and believe it shows that Carers know that we really do listen to what they say! Healthwatch have also done a great job in pulling all the information together for this report in a very tight timescale.

Torbay Carers Services have used the broad themes from the report to draft the main priorities of the Carers Strategy, including how we plan to re-design support to meet Carers'

changing needs. This is subject to formal public consultation as part of the approval process. Healthwatch's report combined with the public consultation feedback will help shape the detail of the Strategy action plan which should be available from the end of April 2018.

We are always striving to improve our services, but part of the value of this report is that it shows us what works well, and therefore what is important to continue. The Carers Hospital Parking was the most helpful service followed by Signposts newsletter (especially in paper form), Discount Card/ back-up plan, 1-off Direct Payment (where people had received one), and GP-based Carer Support Workers.

It also emphasises areas which need continued work or improvement such as GP practice identification of Carers, and the suggestion to have planned Carer reviews. A number of themes, such as support to working Carers and parent Carers including on-line resources, appeared throughout the feedback so these are included in the new Strategy public consultation.

Carers Support only covers support to the Carer and not to the person for whom they care. However, increasing numbers of Carers have been telling us that it is impossible for them to have a break, as there are not enough replacement care (respite) opportunities, especially not those which can be booked in advance. The feedback in this report backs this up and so the public consultation requests that this is also accepted as a priority.

The other thing that is so positive is the number of Carers who said that they would be interested in finding out more about volunteering or providing peer support to other Carers, so we will definitely follow that up!

The Public Consultation is open until Friday 23rd March 2018 at <a href="http://www.torbay.gov.uk/council/consultations/carers-strategy/">http://www.torbay.gov.uk/council/consultations/carers-strategy/</a>. Once the strategy has been fully signed off it will be published at www.torbayandsouthdevon.nhs.uk/carers on the 'strategy' tab."

Katy Heard, Carers' and Volunteers' Lead
Torbay and South Devon NHS Foundation Trust

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