

Review of Local Carers Services in Torbay *Final Report*

September 2014



**Tell us your story ...
Your voice counts**



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Introduction

Background

In May 2014, Torbay Carers Services asked Healthwatch Torbay to undertake an independent review of local Carers Services as part of developing the new Torbay Carers Strategy for 2015-17.

Healthwatch Torbay is the independent consumer watchdog for health and social care services in Torbay, ensuring the voice of the community is used to influence and improve services for local people.

An extensive anonymous questionnaire was created both online via SurveyMonkey.com and in paper version for distribution at external events and various focus groups and Carer's meetings across Torbay. The survey received significant press and media coverage through local press, including radio. The purpose was to ascertain whether Carers were aware of the services available to them and whether they felt the need to improve them in any way.

The responses to the questions were recorded and analysed with the results and recommendations outlined in this report actively fed into the Carers Action Plan, helping to shape future Carers Services.

Response

In the three months that the questionnaire was 'live', we received a total of **721** completed responses covering a wide range of Carers from across Torbay. The results to the questions answered can be found in the following pages.

Summary

Despite the majority of respondents claiming there is sufficient information on Carers Services available, the main issue seems to be getting access to that information. Thankfully, those Carers that were aware of the services on offer had very little trouble accessing them, and were generally satisfied with them, however, there remains a significant amount of Carers unaware of the services on offer to them.

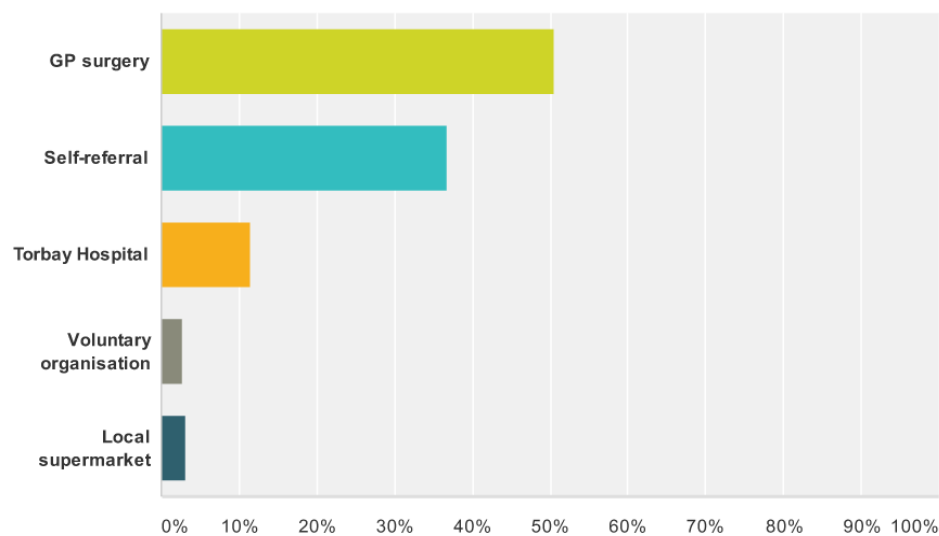
This survey highlights the need to provide information on exactly what Carers Services are available to all Carers. It also demonstrates the lack of Carer engagement and involvement in terms of planning and evaluating services.

Recommendations made include establishing a specific link for all Carers (registered, self-referred or otherwise) who can support them, meeting face-to-face to discuss all options and support services available to them, whilst also maintaining regular contact with the Carer to check on them. A complementary promotional leaflet containing all available services should also be created and Torbay Carers Services should continue to work with Healthwatch Torbay to gather the views of Carers regarding the support services they are offering.

A further recommendation was made to set up additional support groups or services for those Carers in the middle-age, working category, plus the creation of a dedicated Facebook page to be used as an online Forum.

Results Analysis

Question 1 – How were you identified as a Carer?



The most frequent way in which respondents were identified (over half) was through their GP Surgery. Over a third of respondents were self-referred and over 10% were identified via Torbay Hospital.

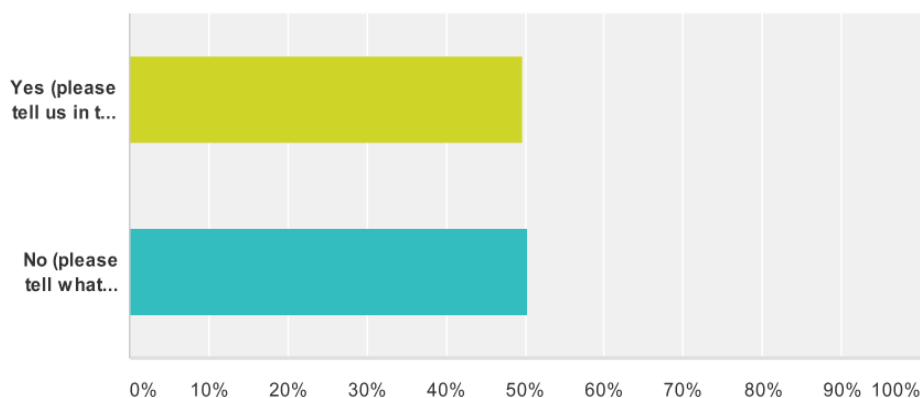
Responses placed under the 'OTHER' section of the question included:

- Other professionals e.g. Occupational Therapist, Nurse, key worker, physio (31)
- **Paignton's Chadwell Centre** (19)
- Family/friend (11)
- Culverhay (10)
- Children nursery/school (5)
- Waverly (4)
- Awareness Courses e.g. RNIB and Early Bird Courses (2)
- Library (1)
- Awareness Day (2)
- Other Carers - when applying for a benefit e.g. attendance allowance (1)

| Answer Choices | Responses |
|------------------------|-----------|
| GP surgery | 50.56% |
| Self-referral | 36.70% |
| Torbay Hospital | 11.42% |
| Voluntary organisation | 2.81% |
| Local supermarket | 3.18% |

Many others could not remember as they had been a registered Carer for some time.

Question 2 – Did you receive any support services as a result of being identified as a Carer?



A near 50-50 split between YES and NO from respondents to this question, with NO slightly edging it at 50.4%.

Of those who answered YES, the most frequent additional support received by respondents were Counselling (23), a Carer Support Worker (75), Financial Assistance (24) and Equipment (23). There are specific quotes from respondents to demonstrate this on the next page.



There are no support groups for my particular age groups – thirty-somethings!



"I was told about agencies available to help us and given phone numbers and contact details and although my experience of carers Torbay has been short term, I am very pleased and feel supported."

"When I was unwell, I was visited by ladies from 'Crossroads' who gave me advice about looking after myself too."

"Steven Black (Carer Support Worker) helped us enormously with applying for Attendance Allowance etc. As well as general support. Also Val Shute at Mayfield Surgery"

"Assessment and equipment for my mother was provided. So far we are managing without anyone visiting. I am not sure she would manage without a commode, raised seat, bed rail, etc."

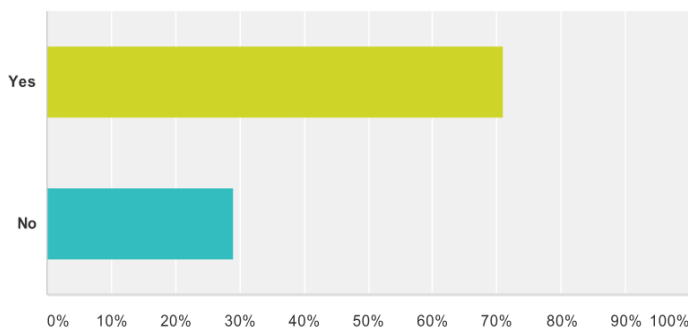
Of the respondents who answered 'NO', the most frequent requested support services were Information (16) and Support (25), with the majority (36) stating that they needed nothing. Some quotes concerning this from the respondents are as follows:

"From my husband's diagnosis in December 2011 no support put in place until April 2012 and only then after Self-Referral. No support and felt completely isolated"

"A recognition of my need for Respite/Holiday once a year. Financial and Cared for refusal to allow this has meant that I have not been able to have any since I started being a full time Carer back in 1997. Any Holiday has always meant my need to continue my caring role. I have now been forced to have a mental and physical breakdown due to this and the need for regular breaks by me, leaving my husband alone for a few hours is the only way that I can cope. Social Services can only offer care for him and not me."

"Not at first, told I was earning too much! We then coped until I had a 'breakdown' and snapped. I phoned a really helpful lady at Crossroads who got a carers support worker to phone me and then help has slowly been coming in."

Question 3 – As a Carer do you feel adequately supported by your GP?



A significant majority (71%) of respondents stated that they do feel adequately supported by their GP.

That does, however, leave 29% of respondents who feel they are not adequately supported by their GP.

For those respondents who answered NO, their most frequent suggestions for what would improve the situation were 'for their GP to acknowledge that they are a Carer' (24), 'help with transport/better-timed appointments/home visits by GP (16) and - by far the most frequent – 'Improved communication/specialist knowledge (48).

The latter responses regarding improved communication centre on people saying that GPs do not listen to Carers; GPs refusing (due to patient confidentiality) to discuss the health of the cared for person with the Carers; and GPs not being able to support with specialised areas such as mental health, learning difficulties, epilepsy, alcohol problems or dementia. Many mentioned that there appears to be a focus purely on crisis management rather than preventative action.

A high number of respondents (105) said they either did not need support; do not visit the GP; or do not know how the GP would support them. Some overall quotes from respondents answering NO to this question and their suggestions for improving the situation are in the boxes below.

"Acknowledgement of my existence as a carer"

"An annual 'phone call would be enough"

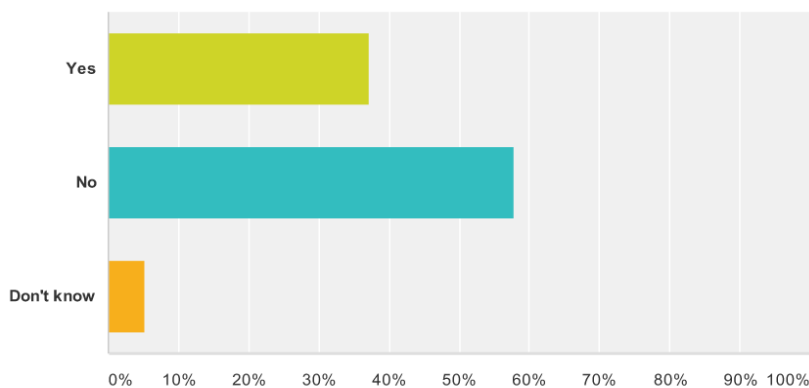
"Carers health checks"

"Have a proper consulting room downstairs for people with mobility difficulties"

"I am unable to get my husband to the GP as he and I no longer drive and I cannot push his wheelchair"

"GP will not speak to me without my husband's consent. When he has an appointment I feel I'm in the way"

Question 4 – Have you had contact with a GP Carer Support Worker in the last 18 months?



37.1% of respondents stated they had contact with their GP Carer Support Worker in the last 18 months, whereas the significant majority (57.7%) said they hadn't had any contact. 5% of respondents were unsure whether they had or not.

Of the respondents who answered YES, the most frequent method of help/support received from the GP Carer Support worker were 'Talking, in person or on the telephone' (54) and 'Information provided/help with form filling/signposting' (52). Other frequent answers included home visits (27); providing advice on money matters/benefits (14); Practical help/advice e.g. getting equipment for the home (13) and giving advice on accommodation/care homes (8).

"My Support Worker has been wonderful in so many ways. I am sorry she is leaving"

"She has been very helpful with small things"

"She has been very informative"

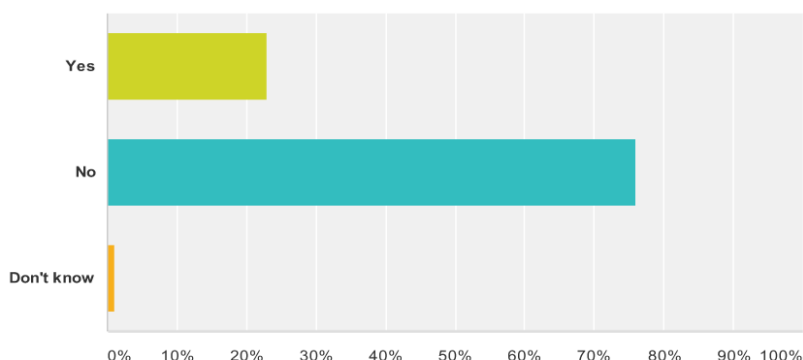
"I call her the tea and cake lady...nice to talk to but ineffective"

"I always feel that my GP asks additional questions enquiring how I am and how things are going. I always feel listened to."

Many respondents (19) stated that they were also receiving support from someone other than a GP Carer Support Worker (e.g. District Nurse, Mental Health Support Worker, Occupational Therapist, Crossroads Care, Practice Nurse or private care provider).

Specific quotes from respondents answering YES to this question are included in the box on the left.

Question 5 – Have you used the Signposts Information Carers Service within the last 18 months?



23% of respondents stated they had used the Signposts Information Carers Service within the last 18 months whereas the significant majority (76%) stated they hadn't. 1% of respondents were unsure whether they had or hadn't used the service.

Those who responded that they had used the service said that it helped them in the following ways:

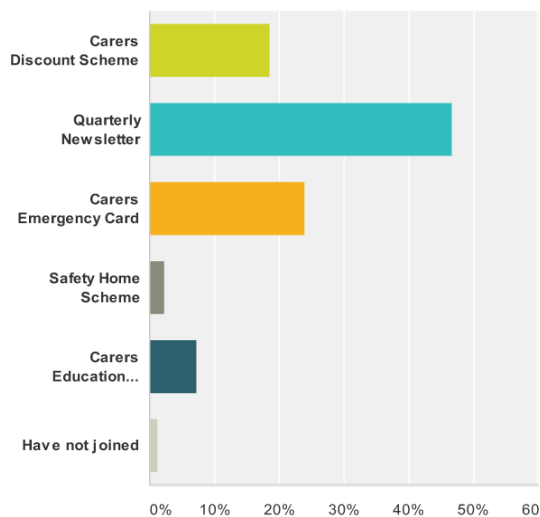
"I appreciate receiving the signpost journal but am not usually able to attend many of the events advertised."

"Attended several free courses for carers and found them useful. I would like more courses available."

"By talking to them I am able to cope better."

- Contact with Alarm Service (2)
- Signposts every 3 months (9)
- Extremely helpful (6)
- Registered as a Carer/Card (3)
- **Courses** (16)
- Met Other Carers (5)
- **Information** (21)
- Breaks (2)
- Events (3)
- Equipment (2)
- Activities (4)
- Crossroad Carers (1)

Question 6 – If you joined Torbay Carers Register, which services have you found most useful?



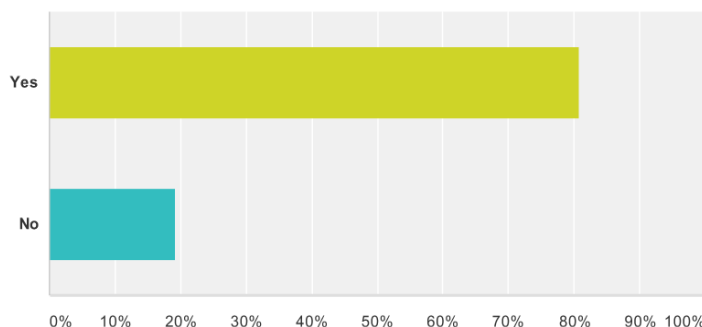
The Quarterly newsletter was the service the respondents found the most useful (46.7%), with the Carers Emergency Card next (24%), followed by the Carers Discount Scheme (18.6%) and then Carers Education Programmes (7.3%). Over 1% of respondents hadn't joined the Carers Register.

The most frequently mentioned 'other' comments were 'Carer Support Workers'. There were also many positive comments regarding the helpfulness of all concerned, but many more highlighting they were unaware of the existence of these services.

| Answer Choices | Responses |
|-----------------------------|-----------|
| Carers Discount Scheme | 18.68% |
| Quarterly Newsletter | 46.69% |
| Carers Emergency Card | 23.94% |
| Safety Home Scheme | 2.21% |
| Carers Education Programmes | 7.30% |
| Have not joined | 1.19% |

Question 7 - Do you feel sufficient information is available about Carers services through leaflets, booklets, website and newsletters?

The overwhelming majority (80.9%) of respondents felt there was sufficient information about Carers services available, whilst 19.1% disagreed.



Those who answered NO to this question were also asked to provide details about what information they would like, in what form and where it should be found. Selected quotes are in the boxes on the right (below) and the most frequent responses for this were as follows:

Type of information

- Just to be advised about help available (12)
- Information about financial support (3)
- Information about specific conditions, e.g. Asperger's/stroke/dyslexia/terminally ill (7)
- Information about practical support e.g. transport/day centres (5)
- Information for middle aged Carers as most focuses on young or older Carers (3)
- Information about drop in centres e.g. time, location etc. (2)
- Carers schemes e.g. Safely Home and Carers Discount scheme (3)

Format for information

- Easy read (1)
- Verbal communication (9)
- Postal (1)
- Email/Facebook (5)
- Website (3)
- Signpost/newsletter (9)

Where to find the information

- Easily accessible (2)
- Charity shops and voluntary groups (2)
- GP surgery (5)
- Hospitals (3)
- School /SENCO (3)
- One central leaflet and point of contact (18)

Other general comments:

"Need to know what help is out there quickly, better response required at the beginning of a crisis"

"Being a Carer, sometimes you haven't got the time to read leaflets or go to meetings"

"I have difficulty reading and writing and need verbal communication"

"Occasional phone call with updates"

"More information available through the website e.g. newsletter."

"Better links and advertising of the website"

"Would like to receive the newsletter more regularly"

"Information provided to patients before leaving the hospital would be great"

"Would like a leaflet with all carers services available"

"If I do not attend a carer support meeting, no information is passed on to you"

"Information seems to overlap in some places and big gaps in other places"

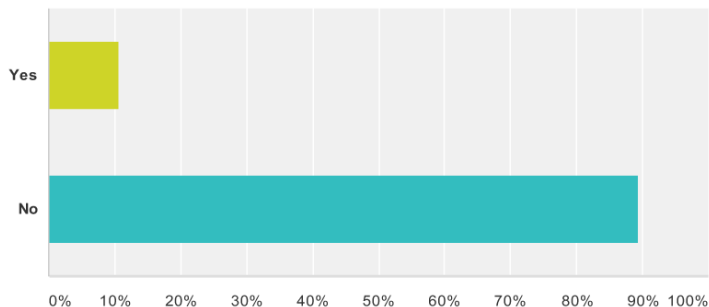
"All services provided do not seem to communicate and because there are so many titles it is difficult to see who is responsible for what"

"Need more support at the Brixham Office for Carers, so more accessible to people"

"The information is there but unless you know where to look you miss out. A link to the new local officer should be provided along with access to someone who can help you through the first couple of months in a coherent way"

**Question 8 – As a Carer have you been involved with planning or evaluating services?
(E.g. Carers evaluators, planning meetings, etc.)**

As you can see in the diagram, an overwhelming 89.4% of respondents claimed they had not been involved with planning or evaluating, with 10.6% of respondents saying they had been involved.



Those who responded YES said they were involved in the following ways:

- Surveys (10)
- Via Parents Participation Forum (6)
- Carers Forum (2)
- Planning meetings (4)
- Survival of Cool House (2)
- Events (2)

Individuals also noted being involved in the following:

- Mental Health Forum
- Learning disability board
- Evaluating Safety Home bracelet
- Carer strategy meeting
- Experts by experience
- Chadwell Review
- ST Kildas MDT meetings
- Specialist Commissioning CCG for ophthalmology
- Older Carer feedback

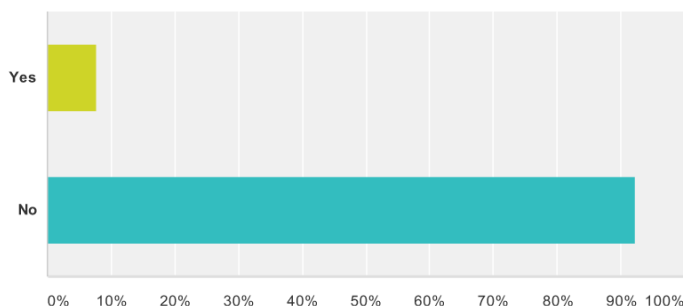
“Since moving to Torquay 3 years ago, I do not feel that there is a lot of carer input into planning or evaluating of services been done up till now but in the last few months I have seen an increase with the formation of Healthwatch and the implementation of government initiatives around Social care Reforms”

“Several years ago, I was a member of various service groups as a parent representative and also a member of Torbay Carers Panel (which folded a couple of years ago)”

Carers also stated clearly that they were involved with the “cared for” ongoing care e.g. medication, appointment and solicitors etc. but find it difficult to get to meetings on a regular basis to provide feedback.

**Question 9 – Have you been asked to share your experiences of services in the last 18 months?
E.g. questionnaires, discussion groups, feedback, etc.**

As in the previous question, the vast majority (92.3%) claim to have not been asked to share their experiences of services, with 7.7% of respondents stating that they have. Carers have shared their experiences in a variety of ways as listed below:



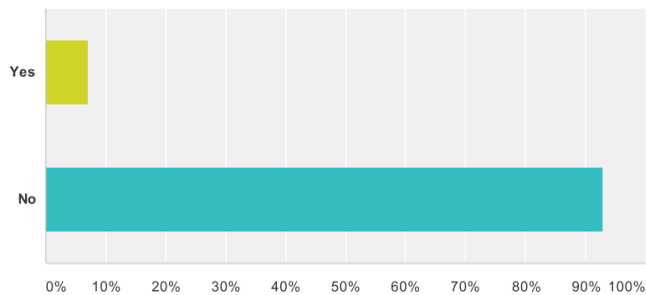
- Surveys (5)
- Parent Participation Forum (4)
- Care Quality Commission (3)
- Support/discussion Groups (3)
- DVD and a video for parents and relatives who have experienced drug/alcohol abuse (1)
- Through Older Family Carers (2)
- Evaluation of the Emotional Support Scheme (2)

General quotes from respondents included:

"I am very pleased with the kind and considerate service that we have received"

"Nothing has changed at all which is a bit sad really"
CCG meeting at the Riveria Centre

Question 10 – If you have provided feedback about services, did you receive information about how the feedback you provided influenced service changes?



Following the theme of the last two questions, a significant majority of respondents (92.9%) stated that they hadn't received information about how they influenced service changes, with 7.1% saying that they had through services such as Cool House, Devon Partnership Trust, Torbay Care Trust, Carers Support Worker, Parents Participation Forum and Older Family Carers.

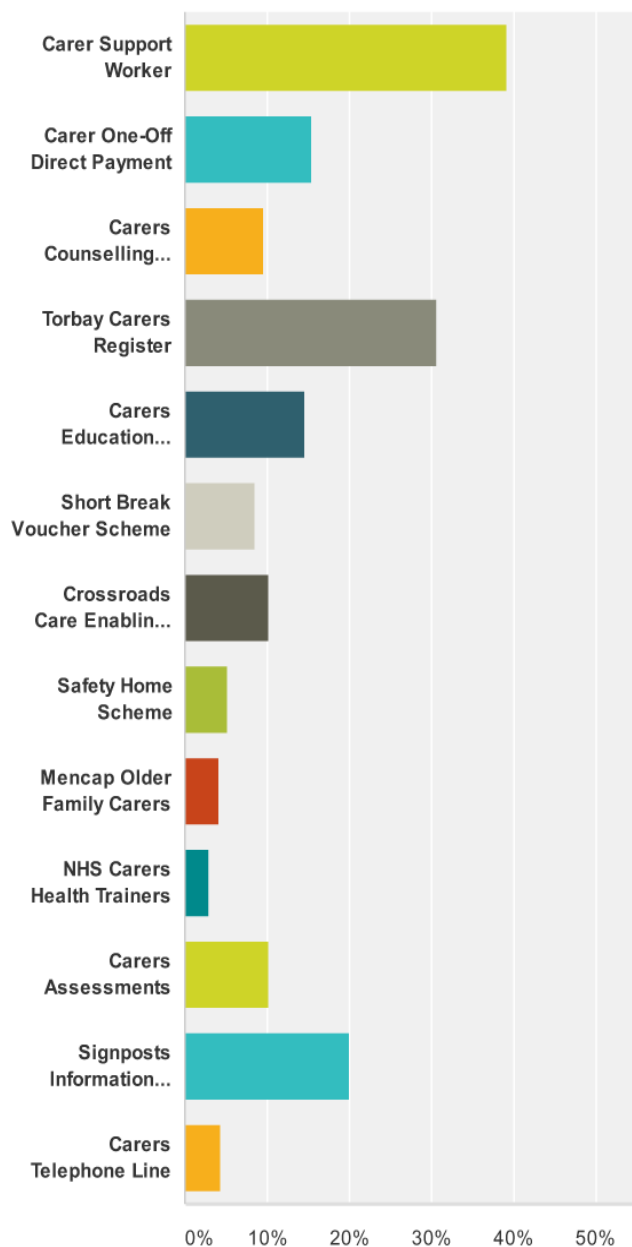
Those who responded that they hadn't received information answered with the following quotes:

"As a carer we receive very little information about changes yet we are the ones supporting those who are most affected"

"Services already decided on, do not take any notice of what we have to say"

"Feedback is usually one sided - Carers are usually left to find out for themselves. As Chair of the Teignbridge Carers Forum from 2001-2004, it was often said by Carers to me 'but we have done all this before - and what changes?'. Unfortunately, my answer is always the same. It is only with little steps that we can make strides and if we all throw pebbles in the pond eventually we will make an island. It would be good to at least be deemed worthy enough sometimes to be given feedback. Everyone has good intentions to do so when they consult with us but in the end time and money and other bigger things get in the way."

Question 11 – Which Carers services listed have you used in the last 18 months?



| Answer Choices | Responses |
|----------------------------------|-----------|
| Carer Support Worker | 39.29% |
| Carer One-Off Direct Payment | 15.38% |
| Carers Counselling Scheme | 9.62% |
| Torbay Carers Register | 30.77% |
| Carers Education Programme | 14.56% |
| Short Break Voucher Scheme | 8.52% |
| Crossroads Care Enabling Service | 10.16% |
| Safety Home Scheme | 5.22% |
| Mencap Older Family Carers | 4.12% |
| NHS Carers Health Trainers | 3.02% |
| Carers Assessments | 10.16% |
| Signposts Information Service | 20.05% |
| Carers Telephone Line | 4.40% |

The most frequent services mentioned were Carer Support Worker (39.3%), Torbay Carers Register (30.8%) and Signposts Information Service (20%), but there was quite a good spread overall for all services.

Responses placed under the 'OTHER' section of the question included:

- Didn't know about any of the services listed (16)
- Carer Support Worker (7)
- Short break vouchers (5)
- Young Adult Carers (4)
- Rowcroft, Telephone line, Carers Emergency Card, Carers Register (2)

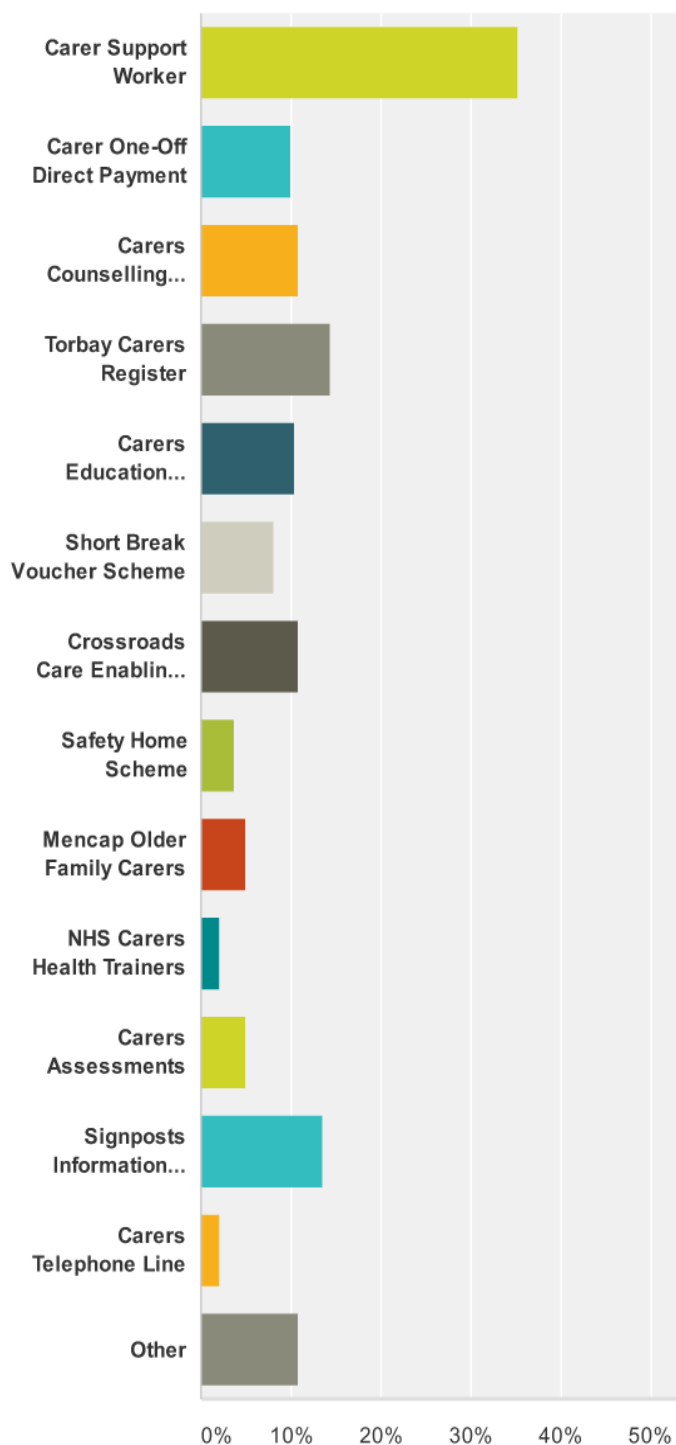
Other services mentioned include: Cool House, Counselling, Sandwell, St Kilda's, Days Out Service, Domestic advise service, Chadwell, Community Matron, Bathing equipment, alarms in the home, and Youth group for ASC families. Quotes included:

"Had vouchers for short breaks but did not use as came too late for us to use"

"Would like information on carer one-off direct payments and short term break vouchers"

"Cannot sign up for any services as it is difficult to persuade my mother - who suffers from dementia - to ask for or accept help from anybody but myself"

Question 12 – Which Carers services have you found most helpful/useful?



| Answer Choices | Responses |
|----------------------------------|-----------|
| Carer Support Worker | 35.35% |
| Carer One-Off Direct Payment | 10.10% |
| Carers Counselling Scheme | 10.77% |
| Torbay Carers Register | 14.48% |
| Carers Education Programme | 10.44% |
| Short Break Voucher Scheme | 8.08% |
| Crossroads Care Enabling Service | 10.77% |
| Safety Home Scheme | 3.70% |
| Mencap Older Family Carers | 5.05% |
| NHS Carers Health Trainers | 2.02% |
| Carers Assessments | 5.05% |
| Signposts Information Service | 13.47% |
| Carers Telephone Line | 2.02% |
| Other | 10.77% |

In an almost identical set of results to the previous question, the most frequent response here was once again the Carer Support Worker (35.4%), followed by Torbay Carers Register (14.5%) and then Signposts Information Service (13.5%).

Responses placed under the 'OTHER' section of the question included:

- Found services helpful/useful (15)
- Informative (7)
- Great educational courses (4)
- Emotional support (3)
- Help completing complicated forms, kind, excellent, brilliant support, and practical support (1)

Quotes from respondents included:



"Signpost is practical and provides realistic information"



"Short breaks to help my little granddaughter"



"Older Family Carers are extremely understanding and helpful"



Question 13 – Have you found it difficult to access any of the Carers services below?

| Answer Choices | Responses |
|----------------------------------|-----------|
| Carer Support Worker | 1.77% |
| Carer One-Off Direct Payment | 1.42% |
| Carers Counselling Scheme | 0.71% |
| Torbay Carers Register | 0.00% |
| Carers Education Programme | 1.42% |
| Short Break Voucher Scheme | 2.13% |
| Crossroads Care Enabling Service | 0.35% |
| Safety Home Scheme | 0.71% |
| Mencap Older Family Carers | 0.35% |
| NHS Carers Health Trainers | 0.35% |
| Carers Assessments | 2.48% |
| Signposts Information Service | 0.35% |
| Carers Telephone Line | 0.71% |
| Other | 93.26% |

The overwhelming majority of respondents didn't find it difficult to access any of the listed Carers services, with the most difficult-to-access listed services - Carers Assessments and the Short Break Voucher Scheme – highlighted by just 2.5% and 2.1% of respondents respectively.

However, 93.3% of respondents did fill out the 'OTHER' section of the question and left their own open-ended comments to explain the difficulty in accessing particular services. Comments included the following:

- Didn't know about services and therefore haven't known to access them (43)
- Lack of service contact details (15)
- Not sure what is relevant and appropriate to me (6)
- No help or support available (2)
- Limited choice of nursing care (1)
- Time, venue and date of services (2)
- Difficult to get transport (2)
- Lack of information on help towards respite, Carers telephone lines and one off direct payments (3)
- Who is my Carer Support Worker/ Care manager (2)
- Courses are often full (2)
- Someone to look after cared for while I access services/support (6)

Other general quotes included:

"Difficult to access as unable to get someone to look after the "cared for" who they accept and like."

"Counselling was not available to carers like me"

"Crossroads is the best place for information"

"Do not seem to qualify for short breaks as my child does not have complex needs"

"As a busy parent I would find it beneficial if someone took a proactive approach and occasionally asked about my needs. When I have spare time I don't always think about looking for extra paperwork/filling in forms"

"No information is given. The signpost magazine seems to be a glossy edition of social events and anything of importance is buried amongst all the chit chat"

"Felt isolated due to trying to work as mostly all services are open during the day and often closed when I have time off. They are good services and helpful, please fund them more"

"If you do not contact them yourself, you are left on your own. Not everyone is prepared to ask for help"

"I would like a website which is a one stop shop for carers who look after adults with mental health problems"

"Initial call to social services is full of barriers, questions and impediments to services not helpful at all. I was too upset and I put the phone down"

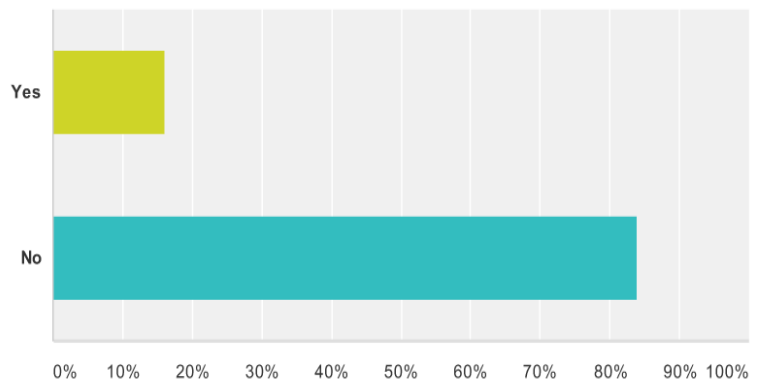
"Not knowing who exactly to contact to approach as the council are unhelpful and don't get back to you when you leave messages"

"Even as a long term carer and someone who now tries to support and signpost others, I didn't realise all these things were available"

"I work Mon to Fri most days until 3pm, then visit my cared for person, there is no time left. [To access services]"

Question 14 – Have you been offered or requested a review of your own needs as a Carer in the last 12 months?

The significant majority of respondents (84%) stated that they hadn't been offered or requested a review, whereas 16% said they had.



Those who said yes said it had been completed by the following:

- Support/key worker (12)
- FAB team (2)
- Disability focus (2)
- GP (2)
- Social Services (5)
- Chadwell (3)
- Culverhay (2)
- Community nurse and OT (3)
- Can't remember (11)

Individuals mentioned by name:

Sera Blewitt, Steve Black, Sally Corbishley, Pennie Evans, Claire O'Brien, Trish Darke, Nina Blandamina, Lynn Healey, John Dudley, Debbie Sandwell, Cheryl Mackinnon, J Milan, Caroline Saunders, Tim Walsh, Debbie Wakeham, Val Shute, David Pike, Karen Hendry.

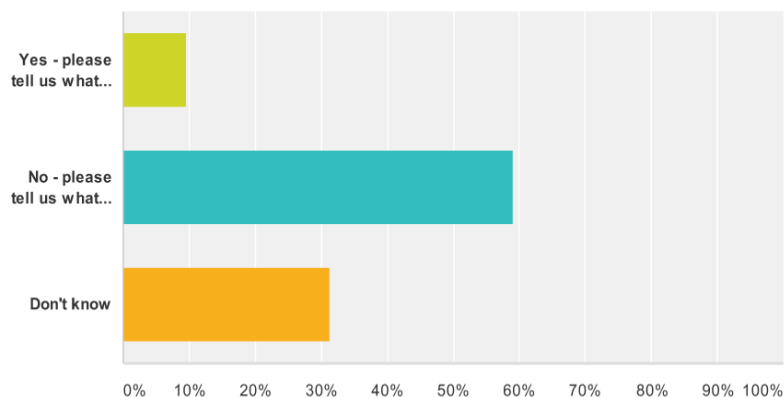
14 people said they had requested a review but hadn't had one, quotes from these respondents included:

"Didn't get one even after a very serious health issue"

"Requested review/assessment in March 2013 but still nothing not even a letter"

"Carer review requested 11 months ago – nothing heard since"

Question 15 – If you have received a Carers assessment within the last 12 months, did your support services change?



The majority of respondents (59.1%) said they had not received a Carers assessment within the last 12 months, 31.3% said they didn't know if they had, and 9.6% of respondents stated that they had and their support services changed.

Of those who responded YES, they commented that they now receive the following services since their Carers assessment: (specific quotes are on the left)

"I felt I was offered everything available"

"I am a new service user (since April 14) only. I have found carers help invaluable, helpful knowledgeable workers, access to useful numbers for help and carers groups with like-minded and age match carers"

"Tripled but the services have not yet been put in place after 6 months"

- An extra day at St Kilda's (1)
- Offered by declined extra support (3)
- Carers counselling scheme (8)
- Increased Carer support (5)
- Sitting service (2)
- Direct payments (2)
- Financial support (3)
- Short breaks (6)
- Emotional support (1)
- General advice (1)
- Food packs (1)

Those respondents who stated that they had not received a Carers assessment within the last 12 months, felt that they were not offered the following required services: (General quotes are below)

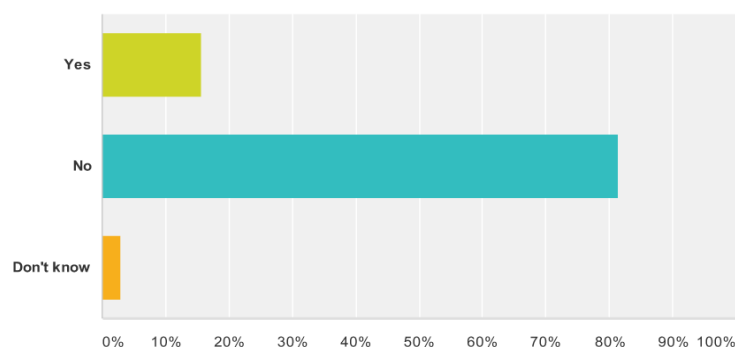
- Babysitting service (2)
- More financial support (1)
- Help filling in forms (3)

"I need advice and support with my son who has Asperger's and OCD. I also carer for my mum and have no support even though I do most things for her"

"Mental health beds crisis. My son has been in Torbay, taken to Cornwall, Black Heath London. How are we expected to visit? It's a disgrace"

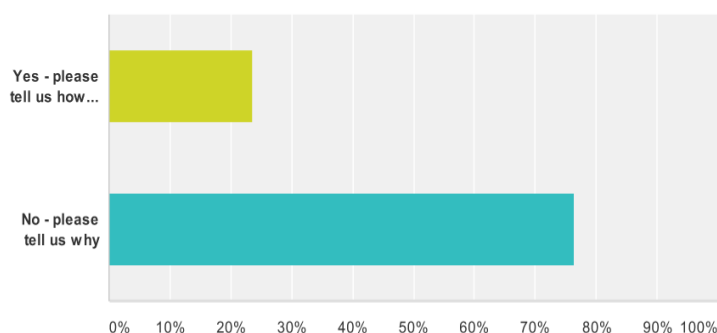
"I needed Respite/Holiday/Time away from my caring role on a regular basis. I completed a Carers Assessment but they were not able to give me anything. There were only able to give my husband 14 hours Care via Direct Debits which he REFUSED as he is not ready to let anyone else do anything for him (he is very private and very stubborn). Although he knew that I needed help, he did not see why he had to have help for me! This has caused even more tension between us and caused me to have even more problems physically and mentally. All I really needed was a break from my daily grind, time to recuperate and to have a change of scenery, long enough to recharge my batteries. Not just a few hours (a couple of weeks). As my respite is dependent on my husband being compliant then he holds the key to the Carer's health and wellbeing. I think that If this is not recognised by Social Care and NHS you will be having more and more Carer breakdowns, as more and more carers, are being pushed to the limit and ending up at crisis point. At the end of the day intervention should have been made sooner, earlier and when things were starting to get on top of me, not when things had got to crisis. I think that the Carer Assessment should be made fit for purpose, and not just a tick-box exercise and signposting people to services that are actually only able to offer information that is not really practical or hands on."

Question 16 – Have you received information about direct payments for Carers?



As the diagram shows, the vast majority of respondents (81.4%) claimed not to have received information regarding direct payments for Carers. 15.7% of respondents stated they had received information, and 2.9% were unsure whether they had or not. There was no 'other' section to this question.

Question 17 – Do you use direct payments to arrange services?



Most respondents (76.3%) stated they do not use direct payments to arrange services. 23.7% of respondents however said they had used them.

Many people also commented not knowing about direct payments (16) and some knew about direct payments but had not been approached by anyone yet (3).

Those who said they did use direct payments to arrange services were then asked how satisfied they were with the support they received to help set it up and who provided the support. Many people didn't answer this follow up question, however, a small number did say they were satisfied with the support they received (9). The majority however, appeared less than satisfied. General quotes from those who commented YES included:

"I would like support to manage direct payments. I would like to know more about direct payments because I am not happy about the Care agency"

"Tried to use it. Absolutely useless!! A waste of time and money. Came from Social Worker"

"I received paperwork and had to work it out for myself as I have it managed with disability - no one has phoned to see how it is going"

"Did not set it up, felt intimidated by extremely pushy lady sent to explain details and offered £25 M&S voucher if we signed up!"

"I am very dissatisfied with this services the accounts department can never get anything correct and I have been using this services for six years"

"I had to research this myself. There is very little information available on Direct Payments that is easy to understand for the general carer out there."

"Very satisfied except we feel we are sometimes harassed several times per year when finances are checked. Once a year should be adequate"

"I am using direct payments for complementary therapies. I am extremely happy with the carer services in Torbay - they are second to none"

"Everything is taken care of, all you have to provide is the time sheets."

Question 18 – In order to influence Carer services in the future, what changes or improvements would be most beneficial to you as a Carer or for the person you care for?

As you may expect, we received a range of numerous answers to this question. Suggestions have been put together in the table below, with the most frequent suggestions in bold and general quotes and comments included afterwards.

| |
|--|
| Better outcome for key groups (2) |
| Info on other services e.g. Physio, audiology (4) |
| Services younger/middle adults (4) |
| More services and support for people with mental health (4) |
| Info on financial options (including) direct payments. (4) |
| Time off (3) |
| Seeing the same person (3) |
| Being listened to (5) |
| Promising help but not following up (2) |
| Unregistered Carer entitled to the same as registered Carers (1) |
| List of places to take cared for out for the day (3) |
| Funding for Older Family Carers (2) |
| Help if Carer is ill (4) |
| Better Communication (6) |
| Info and explanation on Carers services available. (19) |
| Home visits/assessments (7) |
| Better ongoing regular support e.g. CSW (8) |
| Talk time (a friendly voice) (5) |
| 'Me time' (14) |
| Less written info more face-to-face, personal info to be given (3) |
| One to one support & advice (12) |
| More facilities for patients caring for children (2) |
| Better transport (3) |
| One point of contact (14) |
| Support for Siblings (2) |
| Annual/regular assessment by GP/Nurse/Social worker (4) |

The most frequent suggestions from respondents were centred on providing information on exactly what Carers service are available, using a single one-to-one, face-to-face contact to relay all the information.

Another area identified throughout the survey was that if an individual was identified through their GP/Carer Support Worker, they seemed to have more details about what is available compared with individuals who self-referred. Self-referrers seemed to really struggle obtaining information about what support is available.

"The most important change would be to let parents have the say for what is in their children's best interest. Better communication between parents and services to use the full amount of money given by the government to help families."

"I would like support to manage direct payments. I would like to know more about direct payments because I am not happy about the Care agency"

"Tried to use it. Absolutely useless!! A waste of time and money. Came from Social Worker"

"I received paperwork and had to work it out for myself as I have it managed with disability - no one has phoned to see how it is going"

"More 'open meetings' where experiences, concerns and compliments can be expressed and noted. Travel expenses to attend monthly Involvement meetings. Training for professionals on Carers issues."

"GP to be aware of my daughter's needs and my needs as a carer. More facilities for parents caring for children. Current provision is aimed at older age groups. Some pro-active practical support in accessing services."

"A one stop list of any services which may be available to carers in appropriate circumstances and the named person responsible."

"After completing the carers registration form a carer should be made aware of all services available to them and given a phone call to show support"

"Have a central bank of information available in one place make this well-known i.e. GP's surgeries, out patients, dentists etc."

"Carers own health checks, especially when you're on your own. Respite would be good. Plus home visits, people to talk to, and free public transport to help with isolation and getting to appointments."

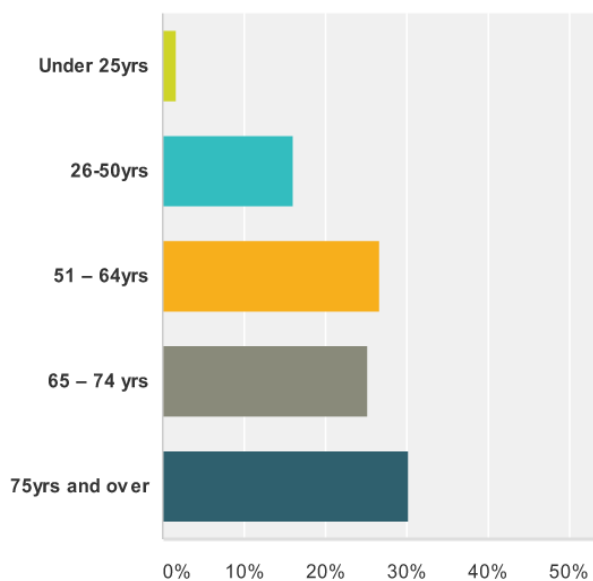
"Days out for the younger people Clubs for younger people and their Carers."

"Support needs to be more easily accessible and Carers should be advised on exactly what help is available. My son was 9 when he was diagnosed, he is now 19 and I have received no help except from school."

"Have evening events, as some days I have booked to attend events but don't have time to attend during the day. Also a dedicated Facebook Page and online Forum."

"Most of the Carers Education seems to be directed more to those caring for older people. Younger carers seem well catered for but we in the middle - looking after school age children - seem overlooked."

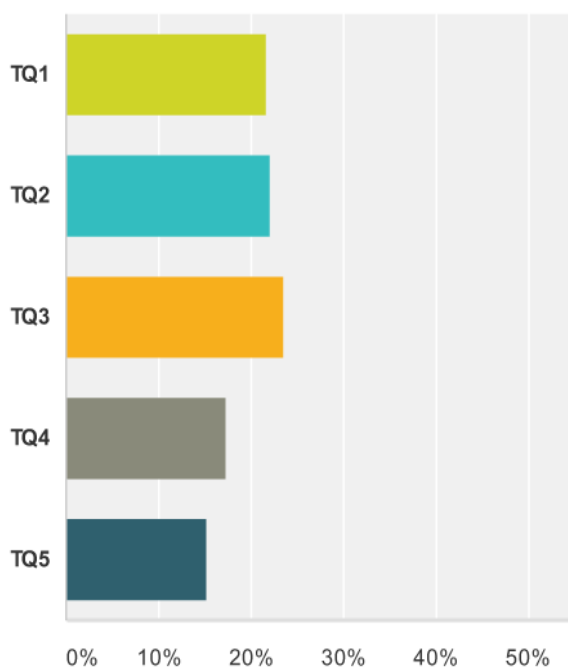
Question 19 – Demographics: Please indicate your age:



| Answer Choices | Responses |
|----------------|-----------|
| Under 25yrs | 1.70% |
| 26-50yrs | 16.01% |
| 51-64yrs | 26.63% |
| 65-74 yrs | 25.35% |
| 75yrs and over | 30.31% |

There was a very wide range of ages amongst the respondents, however, the vast majority (82.3%) were over the age of 50.

Question 20 – Demographics: Please indicate the first part of your postcode:



| Answer Choices | Responses |
|----------------|-----------|
| TQ1 | 21.74% |
| TQ2 | 22.19% |
| TQ3 | 23.54% |
| TQ4 | 17.24% |
| TQ5 | 15.29% |

There was a very good spread of postcodes amongst the respondents too, with 43.9% from Torquay, 40.8% from Paignton, and 15.3% from Brixham.

Conclusion

Validity

This survey and its subsequent report demonstrates a good representation of the Torbay population, with 721 different Carers from all ages represented from each of the three towns in the Bay. As such, it is not a mistaken assumption to suggest that it is a relatively accurate representation of the Torbay population. However, great care will still need to be taken to ensure that any claims are not perceived as 100% factual for the whole of the Torbay, and also that any Healthwatch Torbay recommendations made would be appropriate to 100% of Torbay Carers.

Conclusions

Despite the majority of respondents claiming there is sufficient information on Carers services available the main issue seems to be getting access to the information. Suggestions from respondents were centred on the need to provide information on exactly what Carers service are available, using a single one-to-one, face-to-face contact to relay all the information needed to a Carer in the first few months and whenever updates are needed. This is reflected in the results that find the Carer Support Worker the most useful service for all Torbay Carers (not just those on the Carers Register).

A further gap that the survey has identified is a potential gap in Services offered to those Carers in the middle-age, working category, with many stating they are unable to access services in their time off as most are only available during the day when they are working and/or caring. Many highlighted the need for a dedicated Facebook page to be used as an online Forum.

Thankfully, those Carers that were aware of the services on offer had very little trouble accessing them, and were generally satisfied with them when they did access them; however, there remains a significant amount of Carers unaware of the services on offer. There also seems to be a lack of Carer engagement and involvement in terms of planning and evaluating services, coupled with a lack of feeding back any information on Carer involvement, or influence by those Carers actually involved in the process.

Another issue for Torbay Carers appears to be with assessments. Only 16% of respondents were offered/requested an assessment in the last 12 months, with a number still waiting to be assessed. Over 90% of those that were assessed stated that there had been no (or they didn't know of any) changes to the services they received following the assessment.

Also, nearly 85% of respondents claimed not to have received information regarding direct payments for Carers. Of those that have used them, the majority were not entirely satisfied with the service, citing lack of information and support as the main reasons.

It would appear that there is a correlation between those Carers that were identified by their GP surgery and subsequently assigned a Carer Support Worker, these being generally much happier with the Carers Services they receive - including support from their GP. They feel they have sufficient information regarding the services on offer to them, often from the quarterly newsletter, which the majority of Carers on the Carers Register found most useful.

At the other end of the scale there are those Carers that are self-referred who feel the opposite. Many are unaware of services on offer, feeling isolated and unsupported, particularly by their GP. Less than a quarter of respondents had used the Signposts Information Service, with many Carers unaware of its existence.

The majority of respondents highlighted a desire for a dedicated person who regularly contacts Carers to check how they are doing and discuss support options with them, such as respite care.

Suggested Recommendations from Healthwatch Torbay

It is apparent that all the services information needed for Carers is out there but very hard to find for those Carers without regular support workers.

A specific link should be provided for ALL Carers, registered, self-referred or otherwise, along with access to someone who can support them through the first couple of months, meeting with them face-to-face to discuss all options and support services available, including requesting Carers assessments and support with setting up direct payments.

As an added method of support, the same link should then make regular monthly contact with the Carer (either over the phone or in person) to check on their progress and discuss any updates or changes to Carers services.

To complement this, a new promotional leaflet showing all the Carers services on offer, with a small brief of what each is, how they can help and how to find out more about each should be created and distributed via all available external outlets (including hospitals, Doctors Surgeries, dentists, opticians, chemists, libraries, Connexions, etc.) as well as an electronic version distributed via email to all professional staff (including GPs, Counsellors, Social Workers, etc.) and a targeted Facebook advertising campaign via a dedicated Carers Services homepage. The leaflet should also give details on how to give feedback on services and how Carers can get involved to share their experiences and make a difference.

As an independent consumer champion for health and social care services, Healthwatch Torbay can help with gathering the views of Carers regarding the support services they use. Setting up specific online pages for specific Carers services in our online rate & review system could provide a dedicated means for Carers to share their views and experiences independently and see their input actively influencing services.

Another recommendation would be setting up additional support groups or services for those Carers in the middle-age, working category, with many stating they are unable to access services in their time off as most are only available during the day when they are working and/or caring. Many also highlighted the need for a dedicated Facebook page to be used as an online Forum.

NB. The full transcript of all individual comments and/or results can be requested by contacting Healthwatch Torbay.

Thank you for reading. If you have any further questions, please:

visit www.healthwatchtorbay.org.uk
email info@healthwatchtorbay.org.uk
or call free on **08000 520 029**