healthwatch
Devon
Better services through public involvement

Replacement Care Survey Report

September 2016

THIS WORK WAS COMMISSIONED
BY DEVON COUNTY COUNCIL

Contents

About this report

This report has been produced by Healthwatch Devon – the independent consumer champion for health and social care in Devon. Healthwatch Devon would like to thank everyone who took the time to respond to this survey, as well as the organisations and individuals who helped to promote the survey through their own networks.

Registered Charity Number: 1155202 Healthwatch Devon CIO

Introduction

Devon County Council (DCC) wanted to understand the views of people who need replacement care when their family or unpaid carer is unable to look after them or needs a break so that they can do other activities.

To do this, Healthwatch Devon supported DCC to undertake a survey seeking to understand what type of support the cared for person would like to receive when their carer is away, whether for a few hours or longer.

Another specific engagement took place with people living with dementia. This will be reported on separately and be available on the Healthwatch Devon website when completed.

39 cared-for individuals and 90 carers responded to the survey:

- 66% of those responding do not currently receive any replacement care
- Two thirds of carers, 67%, provide over 50hours of care a week
- Of those providing over 50 hours of care a week, 58% do not receive replacement care.

It is also clear through a number of written comments in response to the survey that, despite explaining what replacement care is, some respondents are confused as to what replacement care is, who might pay for it and what it might cover.

Most carers reported that they themselves arranged replacement care or it was arranged by another family member or friend, which might expected given that the majority of respondents advise that the cared-for person receives a direct payment for replacement care. They are therefore more likely to organise something appropriate for their cared-for person.

Over 70% of carers in receipt of replacement care consider it to be the sort they would want for the cared-for person. 80% of carers would recommend the replacement care received, whereas 65% of cared-for would recommend the replacement care they received.

The responses from service users and their informal carers have provided valuable insights into the difficulties which people are experiencing and the degree to which people understand what is meant by “replacement care” and how to access it. The suggestions received about what type of support would be acceptable to the cared-for person have provided a better understanding of what will (help to) maintain a carer’s ability to continue caring and reduce avoidable crises.

Key Findings

From the responses given the following key findings can be drawn out:

1. Those already in receipt of replacement care would like a mixture of options available to them (see fig.8, p.8), whereas those not currently in receipt expressed a preference for day time replacement care, either in the home or the community (see fig.13, p.13).

2. 57% of people responding to the survey who expressed an opinion regarding assistive technology would be comfortable using telecare to allow them to leave the cared-for person for short periods. (see fig. 8, p.8 and fig. 13, p.13).

3. Those not in receipt of replacement care would prefer to receive a Direct Payment from DCC. (see fig.15, p.15). Of those who receive replacement care, the majority received a personal health budget rather than a direct payment. (see fig. 10, p.10).

4. The majority of cared-for respondents said they would agree to pay for replacement care, whereas the majority of carers thought the cared-for person would not agree to pay (see fig. 16, p.15).

5. If the cared-for person is a self-funder, over 80% of cared-for respondents would like DCC to arrange care for them, whereas only 44% of carers would like DCC to do this. (see fig.17, p.16). The comments from carers who had experience of DCC arranging care had found it unsuitable, unreliable and wouldn't trust them in future. (see comments p.16).

6. A majority of carers, 60%, report that they care for somebody with behavioural difficulties. (see fig. 20, p.19).

7. Almost half, 47%, of carers experience financial hardship as result of their caring role. (see fig. 26, p.21).

8. 57% of carers experience sleep disturbance. This is commonly every night, on two or three separate occasions. (see fig. 28, p.23 and following comments).

9. 28% of carers who said they were currently employed, either full- or part-time, also received replacement care.

10. 57% of carers reported that they had longstanding health conditions. (see fig. 25 p 22)

Next Steps

This engagement activity has helped to focus on people's experiences of the pathway to replacement care, their ideas on what could work better and the types of services which they would they would like to have access to within Devon.

The findings within this report will be used to:

- Support the delivery of the Devon's Carers Strategy
- Inform a plan to address the accessibility of replacement care support and the range of services available in Devon

Data Analysis

What follows is a summary of the responses to each question.

All comments have been read by Healthwatch Devon, and the complete set of responses to this survey has been provided to commissioners along with this report.

There were in essence four surveys as part of this work:

1. For carers when the cared-for individual receives replacement care
2. For carers when the cared for individual does not receive replacement care
3. For the cared-for individual who receives replacement care
4. For the cared-for individual who does not receive replacement care

Questions within the surveys overlapped and where possible responses have been grouped together in the following report to make analysis and comparison easier.

The numerical figures that appear in the following charts are the number of respondents selecting that option.

Do you (or your cared-for individual) receive replacement care when their carer is away?

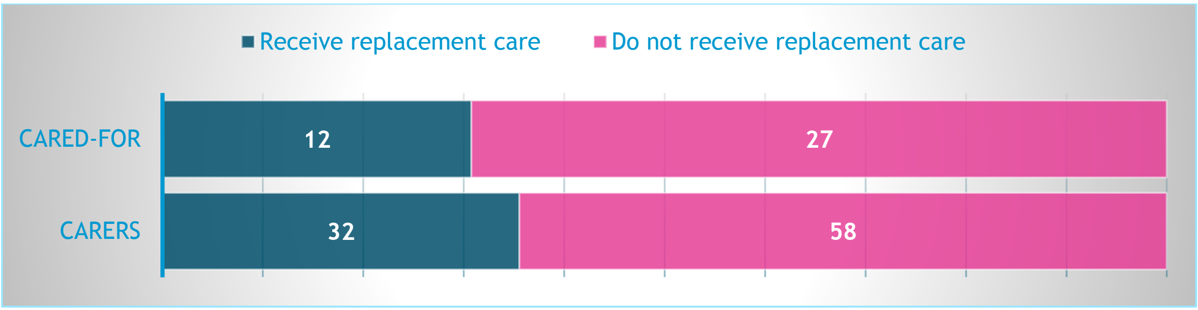

Figure 1

Following the first question, the survey was then split in to two parts dependent on whether the cared-for individual was in receipt of replacement care.

In Receipt of Replacement Care

The next question asked how many hours of care the carer provided each week:

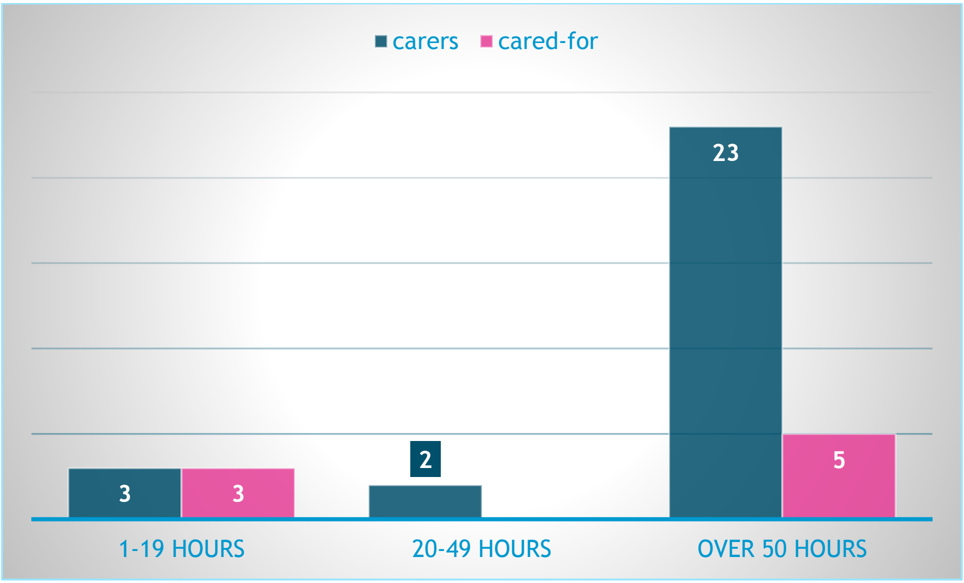

Figure 2

The cared-for individual was asked what sort of support they usually receive:

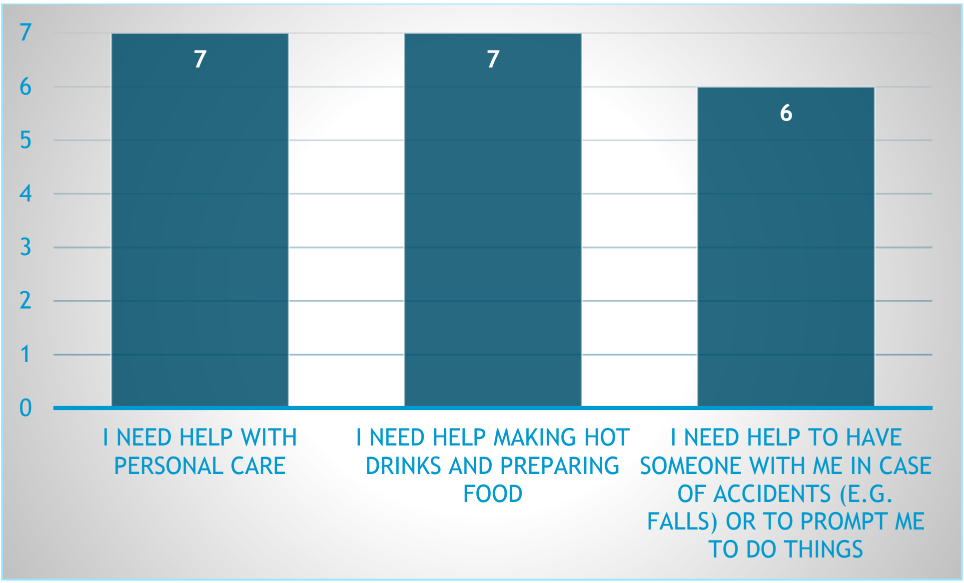

Figure 3

The next question asked how the respondent found out about replacement care:

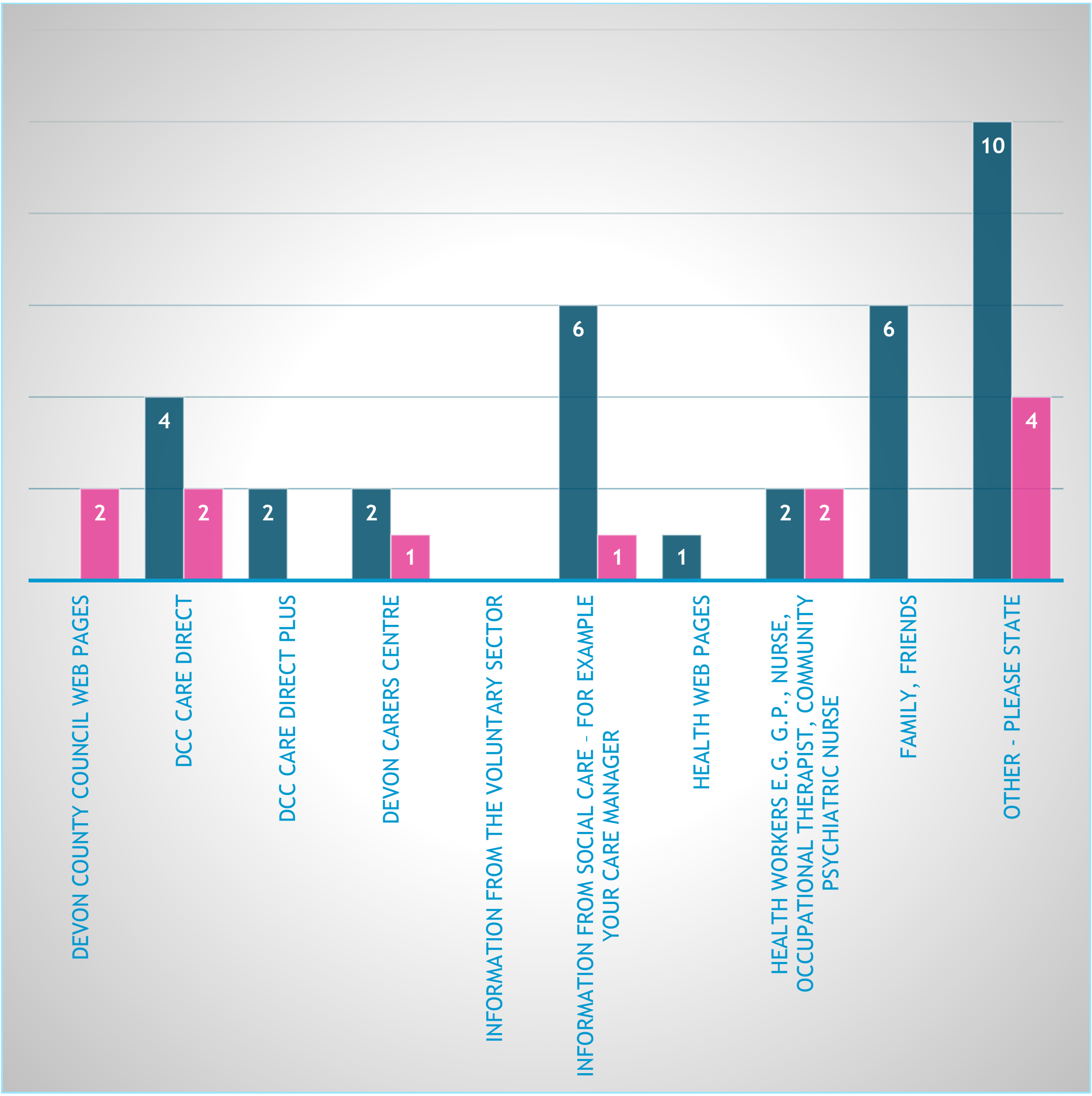

Figure 4

'Other' was the most common response and covered a wide range of sources:

The carers said:

> *"We work it out with family."*
>
> *"Situation is changing, as yet no experience of it."*
>
> *"CHC replacement care part of package."*
>
> *"Northam Lodge."*
>
> *"Local contacts."*
>
> *"Can't remember, I think it was from a respite carer themselves."*

> *"Already know someone from Estuary League of Friends."*
>
> *"Personal research."*
>
> *"Carers forum that used to exist."*

The cared-for said:

> *"Some care/staff cover holidays."*
>
> *"The agency I employ."*
>
> *"Lyndridge Care."*
>
> *"Email from Living Options Devon."*

Respondents were asked who helped arrange the replacement care:

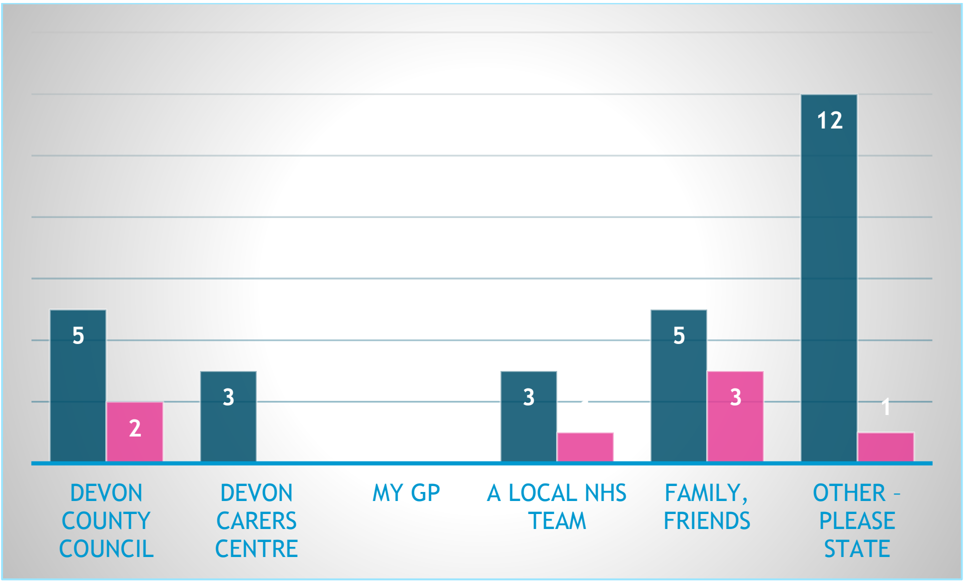

Figure 5

The 'other' comments from carers were:

> *"Private care company."*
>
> *"In the process of arranging with DCC."*
>
> *"Nobody."*
>
> *"Northam Lodge staff."*
>
> *"Local contacts."*
>
> *"Social worker provided funding, I have had to organise it myself."*
>
> *"Myself"*
>
> *"No one, doctors and care direct refused to help."*

> *"No one. I had to do it myself."*

> *"Community volunteer service; Helping Hands care agency."*

> *"Nobody. It is tough to be given a personal budget without further support when the only reason you/I get/got a personal budget is because you/I have eligible needs. Replacement care is a bit of a fallacy in my case. It creates a layer of work which is often an utterly inefficient use of my time."*

> *"Myself."*

7 of these respondents report that the carer themselves organised the replacement care, making this the most common response.

Respondents were asked if the replacement care was the sort they wanted:

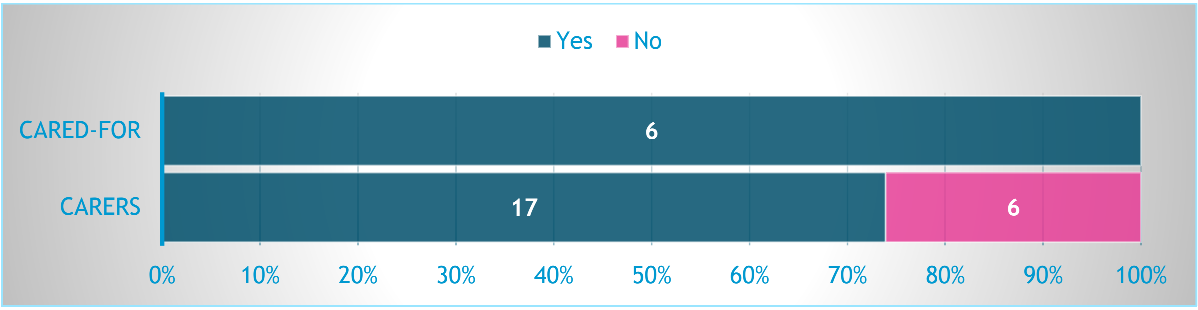

Figure 6

Respondents who answered 'yes' were asked to describe what was received.

The carers said:

> *"Not clear cut. I receive 1 hour per week."*

> *"Family members take over."*

> *"Local care company."*

> *"Overnight care to segue with day care at Rose Hill. Currently 25 weekdays only P.A. but cannot have whole week as Tuesdays not spent at Rose Hill,& therefore can only take Weds or Thurs. Not very flexible, but better than nothing!"*

> *"Computer lessons locally for two hours a week for a number of weeks."*

> *"Privately arranged respite care."*

> *"I actually wasn't given a choice - it's just respite hours from social care, not funding for activities. Devon Carers didn't provide any replacement care, only funding for activities and on assessment my needs on one of the three family members I care for - so only a third of my caring role.*

> *It needs to be a balanced between replacement care and funding for activities and for all caring."*

> *“A payment to enable me to have a break away and paid for a membership so I could have 2 hours’ time out once a month.”*
>
> *“Direct payment.”*
>
> *“3 x a day visits by paid carers from Estuary League of Friends.”*
>
> *“Occasional visitors to chat to Mum and Dad to offer a window on the world and outside interest. My husband usually stays in whilst I attend carer meetings. My sister stays here if we go away overnight.”*
>
> *“A personal budget based upon the banded rate of replacement care from an agency.”*
>
> *“My daughter goes to a local respite unit once a month for a weekend.”*
>
> *“Yes, by doing it myself, not all capable of doing this though.”*

The cared-for said:

> *“A live in carer.”*
>
> *“30 mins personal care from agency staff. 24 hour living support from a personal assistant.”*
>
> *“I went to a Residential Care Home, but did not like it.”*

Those that answered ‘no’ to the above question were asked why they did not receive the type of replacement care they wanted.

Whilst a selection of options was provided in response, only one respondent chose an option: The type of care requested was not available. The rest provided written reasons:

> *“Voluntarily arranged with family. Does the replacement care meet the needs of the cared for person?”*
>
> *“Family have offered.”*
>
> *“None offered.”*
>
> *“I only get the equivalent of a couple of hours a week.”*
>
> *“It doesn't exist. The budget is too small to offer meaningful employment for the level of skills and expertise required. I am the carer (fulltime). The replacement budget covers menial tasks, such as cleaning and house maintenance that are less skilled and do not require specialist knowledge of medical conditions.”*

Respondents were asked to rate the replacement care they had received:

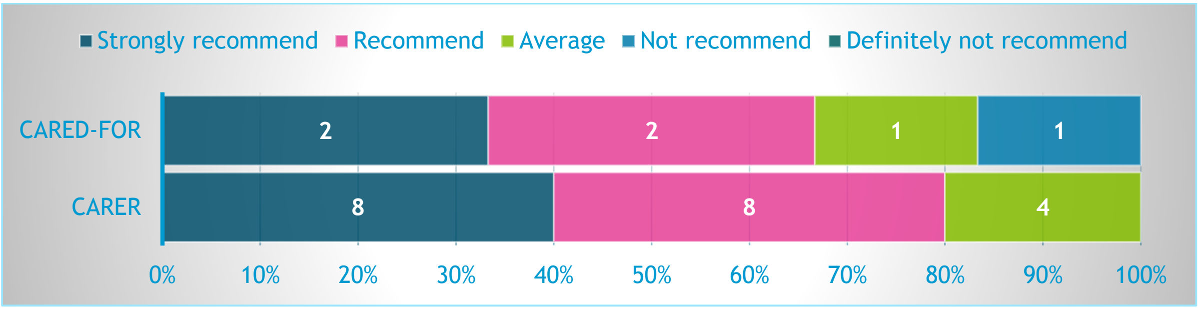

Figure 7

The next question provided a range of replacement care opportunities and asked which respondents would prefer:

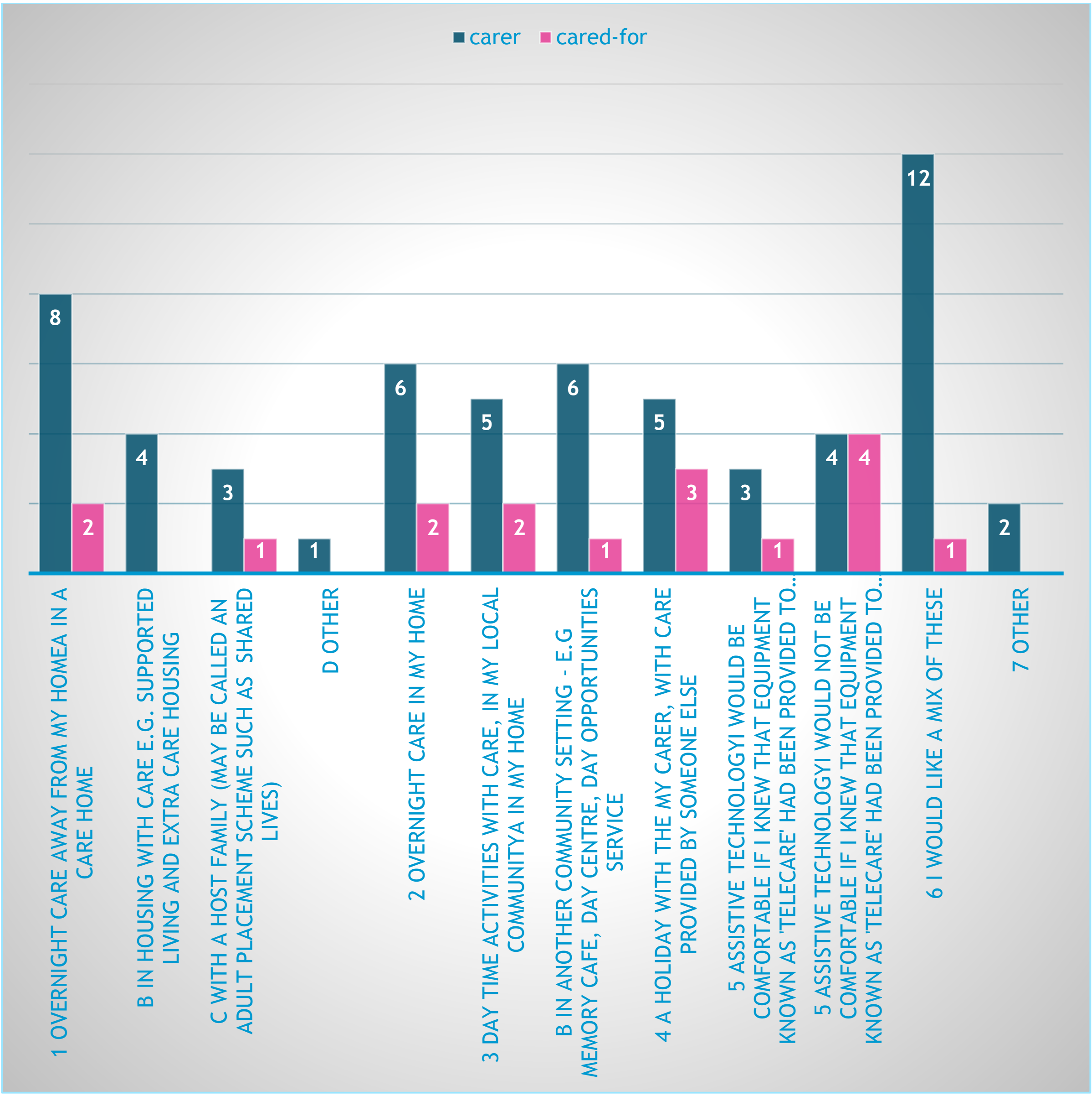

Figure 8

Although only two people chose ‘other’, six comments were provided by carers:

> *“A mix.”*
>
> *“21a only drawback, not ensuite, which it should be.”*
>
> *“It is important the care provided is flexible.”*
>
> *“Note re no 5 - not sure about this. Who is watching and how could they respond?”*
>
> *“More distinct terminology. 'Care' is so general it disregards all the bureaucracy associated with disability or old age that is immensely time consuming and requires detailed and specialist knowledge of both the disability, the person with the disability and the nature of the organisation offering support.”*

Respondents were next asked how they paid for their replacement care:

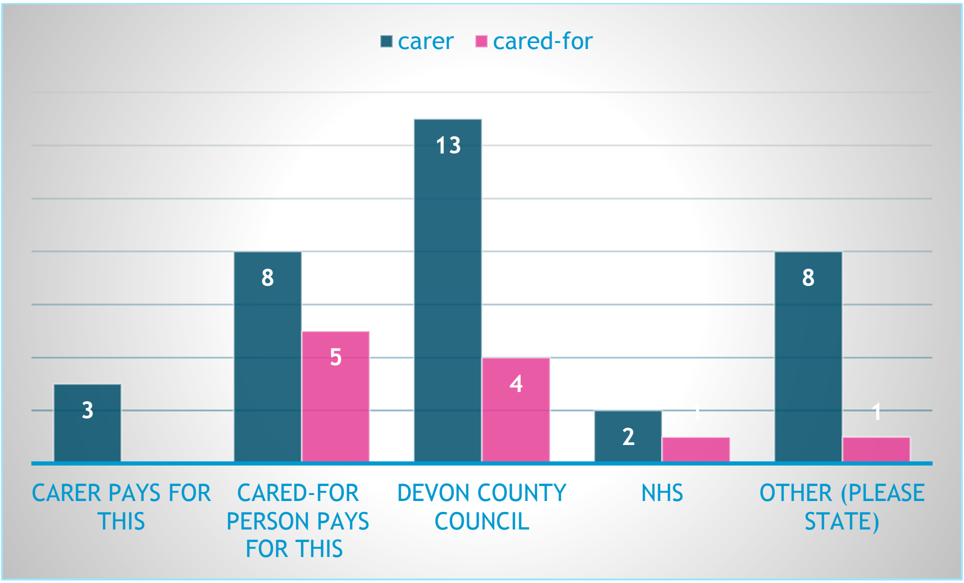

Figure 9

The ‘other’ comments from carers were:

> *“Don't know how costs can be met.”*
>
> *“Family is free.”*
>
> *“D.C.C. with small contribution from me.”*
>
> *“I pay for day care. DCC paid for computer lessons.”*
>
> *“Receive full attendance allowance.”*
>
> *“Within your benefit entitlement DWP / PIP.”*
>
> *“Our volunteer from CVS cares totally voluntarily, often bringing flowers or cake.”*
>
> *“DWP disability and income related benefits.”*

Finally, for those who had received replacement care they were asked if the cared-for person received a Direct Payment or Personal Health Budget:

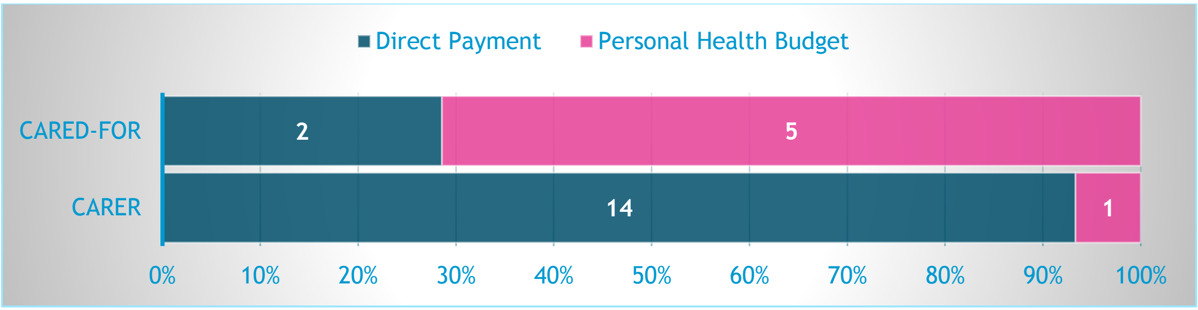

Figure 10

Not in Receipt of Replacement Care

Those not in receipt of caring were asked how many hours of caring the usually receive or provide:

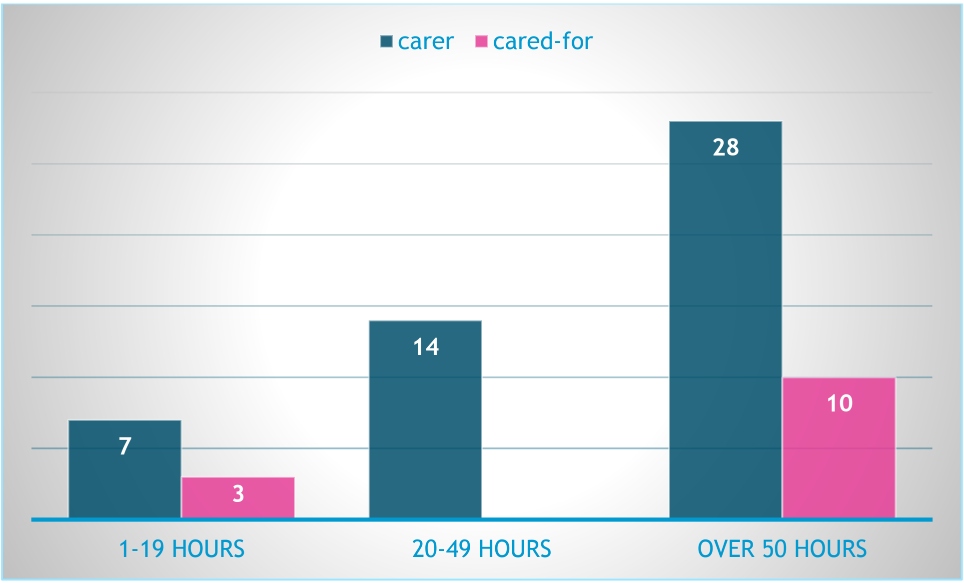

Figure 11

Respondents were asked where they would go to find out about replacement care. The most common response was ‘Don’t know’, the second most common was ‘Devon Carers’. Another popular responses was it wasn’t wanted or the cared for individual would not accept it.

Aside from these themes, a range of other phone help-lines, online source, care workers, doctor/GP and friends or relatives were suggested.

Respondents were then asked if they needed help arranging replacement care who would they seek support from:

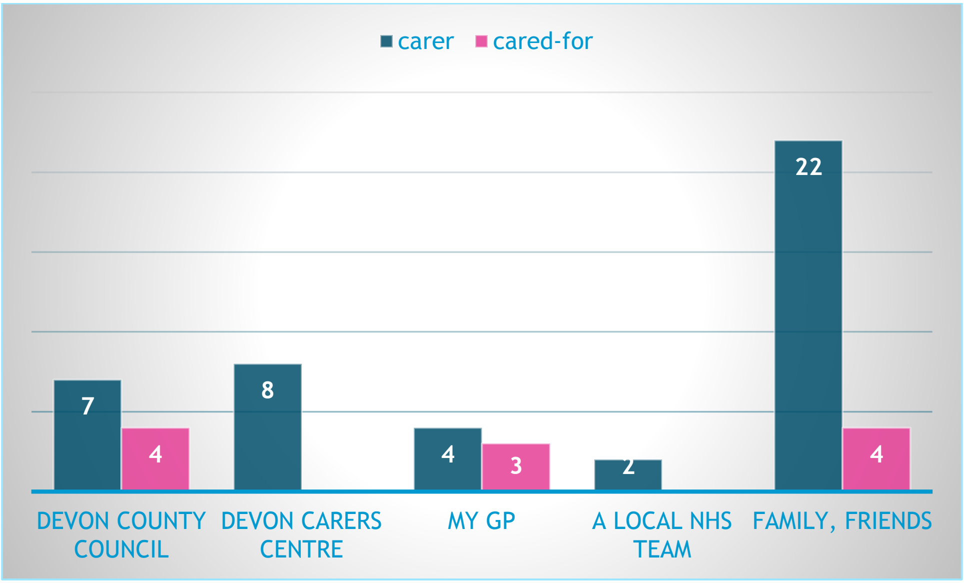

Figure 12

A range of comments was also provided, from the carers:

> *“Carers direct.”*
>
> *“Devon Carers, Care Direct.”*
>
> *“No idea.”*
>
> *“Google.”*
>
> *“I don't know who to get help from.”*
>
> *“Google”*
>
> *“Care Direct LD team.”*
>
> *“Private care provider.”*
>
> *“Any.”*
>
> *“I have only ever needed to seek a sitting service from local care agencies. Now that take-a-break tokens are no longer there to help with the costs I need to pay £17 per hour instead of £3.”*
>
> *“Social services.”*

The cared for said:

> *“Rely on help as always from DPT suppose. Reason why I support St John's Court.”*
>
> *“Living Options Devon.”*

Respondents were then asked what kind of replacement care they would prefer:

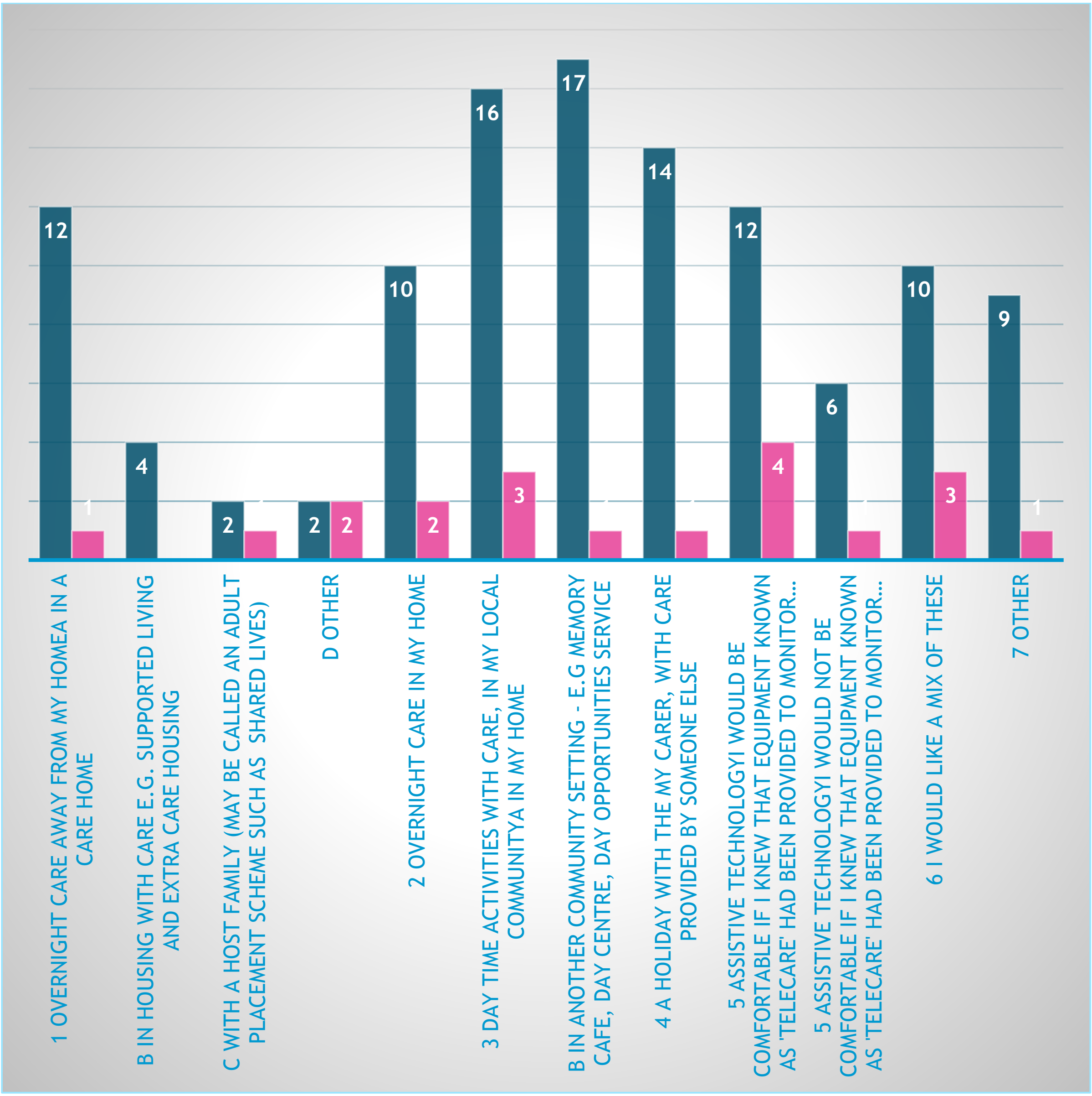

Figure 13

Carers provided the following additional comments:

> *“None.”*
>
> *“Mental illness problems”*
>
> *“A dedicated person that young person could call/ text instead of me.”*
>
> *“Respite care for carer holiday.”*
>
> *“Cared-for person would be unlikely to be able to use Telecare.”*
>
> *“I sort this myself with family.”*
>
> *“A wider range of carer options, tailored to the cared for.”*

> *"Replacement care to allow me a short break either alone or with friends."*
>
> *"4 - Transport would be an issue."*
>
> *"None, give carers more money."*
>
> *"Care I could actually rely on; not currently available."*

The cared-for said:

> *"If occasionally I had a visitor-have great support seemingly from DPT."*
>
> *"Visits by a care worker."*
>
> *"I would like someone to be with me while my carer has his own time."*

The next question asked how respondents would expect any future replacement care to be funded:

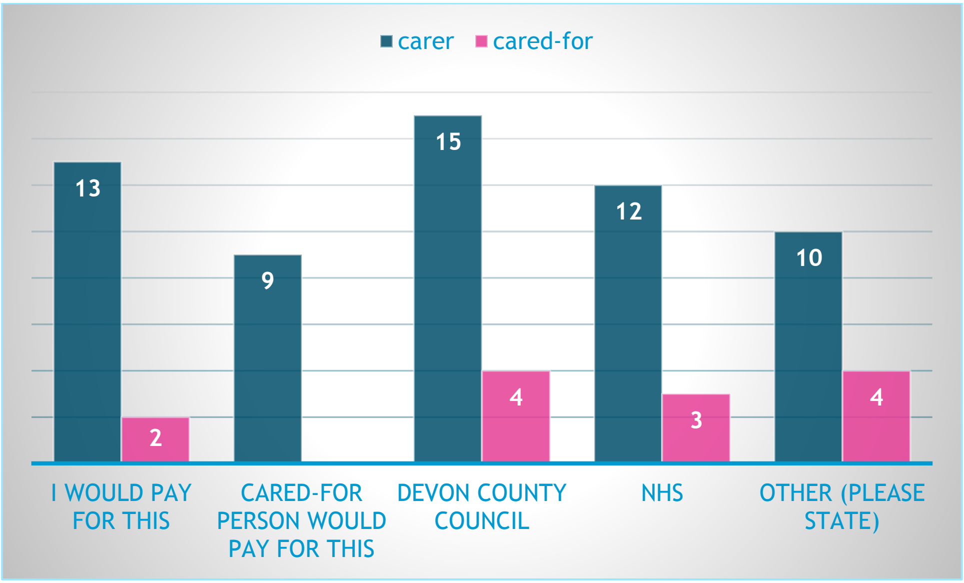

Figure 14

The 'other' comments from the carers were:

> *"Some DCC funding with a possible top up from the cared for person if absolutely necessary."*
>
> *"Not expecting any."*
>
> *"A mixture of state funding and a reasonable (affordable) contribution from the cared-for person."*
>
> *"No idea, I couldn't pay, mum has limited means, guess it's means tested."*
>
> *"Don't know what is available"*
>
> *"NOT ME OR CARED FOR PERSON"*

> *“Unsure”*
>
> *“As classed as self-funding, I assume I would have to pay although my actual income is low.”*
>
> *“? DCC.”*
>
> *“Rather have the money.”*

All the cared-for responses were comments:

> *“Presumably as now my own 'wit'.”*
>
> *“Mixture.”*
>
> *“Not bother.”*
>
> *“Don't know.”*

Next respondents were asked if the DCC or the NHS were to pay for replacement care, whether they would prefer to receive it as a Direct Payment or Personal Health Budget:

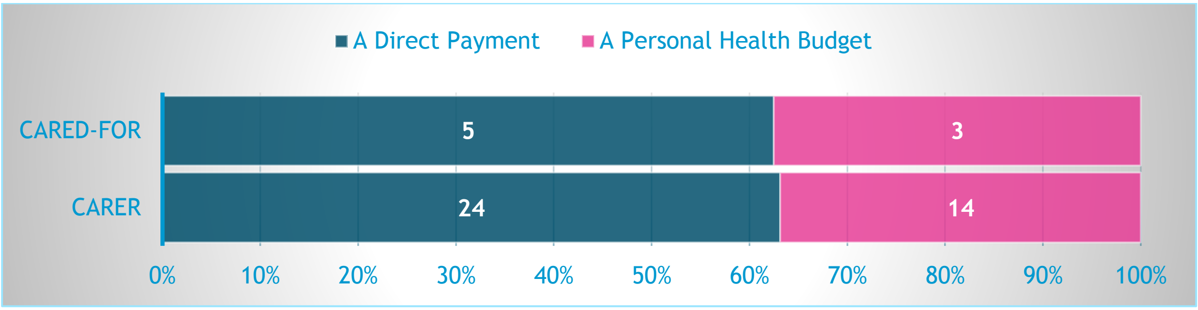

Figure 15

Respondents were then asked if the cared-for person would agree to pay for replacement care:

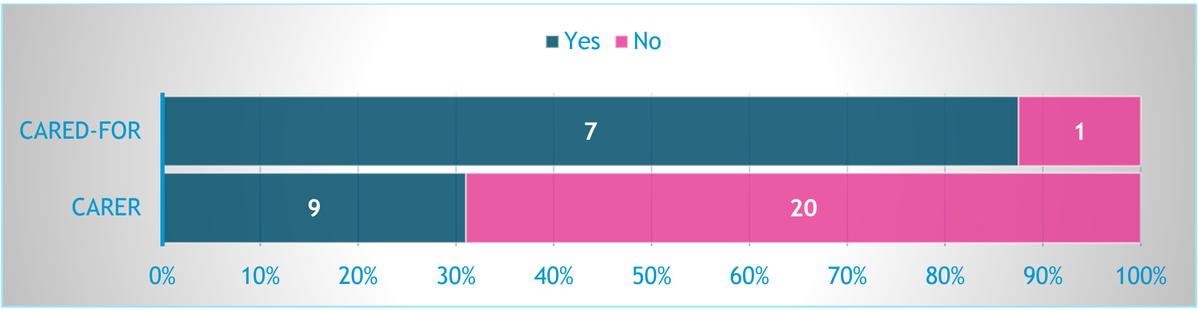

Figure 16

Finally, in this section, if the cared-for person is a Self-Funder, would the carer or cared-for person want DCC to arrange the care for them:

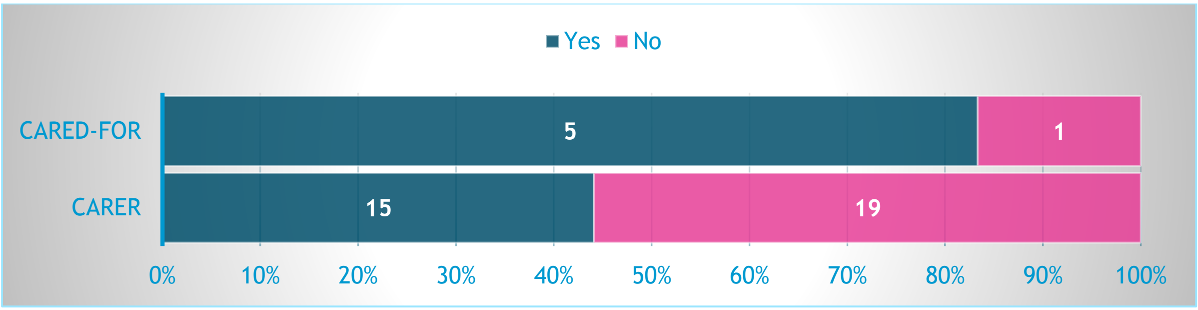

Figure 17

Carers provided the following additional comments:

> *"I'd rather arrange my own care."*
>
> *"I'd rather arrange it myself."*
>
> *"That really is pie in the sky, I would need to be dead before they would do anything."*
>
> *"Answered no as I would need to look at all options available until a vision was made regarding the extra care."*
>
> *"Not a self-funder."*
>
> *"Wouldn't trust Devon Council to do this."*
>
> *"Unknown - possible yes."*
>
> *"Don't know - more info would be needed."*
>
> *"Possibly."*
>
> *"I tried this and thought the offer of care was unsuitable. I provide respite through Shared Lives to whom I am very grateful. I used to use Lyndridge before the care home in Chagford closed but now they are full. Their care was very good."*
>
> *"CAN'T BE TRUSTED."*
>
> *"Depends on how high the charge is, how good the care, how much choice."*
>
> *"In an ideal world it would be lovely to have someone arrange something for me instead of me arranging everything for everyone else."*
>
> *"What sort of care would be decided?"*
>
> *"Yes, because you are the experts in this field."*
>
> *"No, I would want something reliable."*

The cared-for said:

> *“Whatever if anything I would expect to be listened to after possible care etc. have been fully explained to me. Else I shall be happy to carry on as now.”*
>
> *“Don't know.”*

Part Three

A number of additional questions were asked to understand more about the people responding to this survey. Some were the same for the cared-for and carer and some differed. This section includes all the responses to these additional questions.

Respondents were asked which of the following describe the cared-for person:

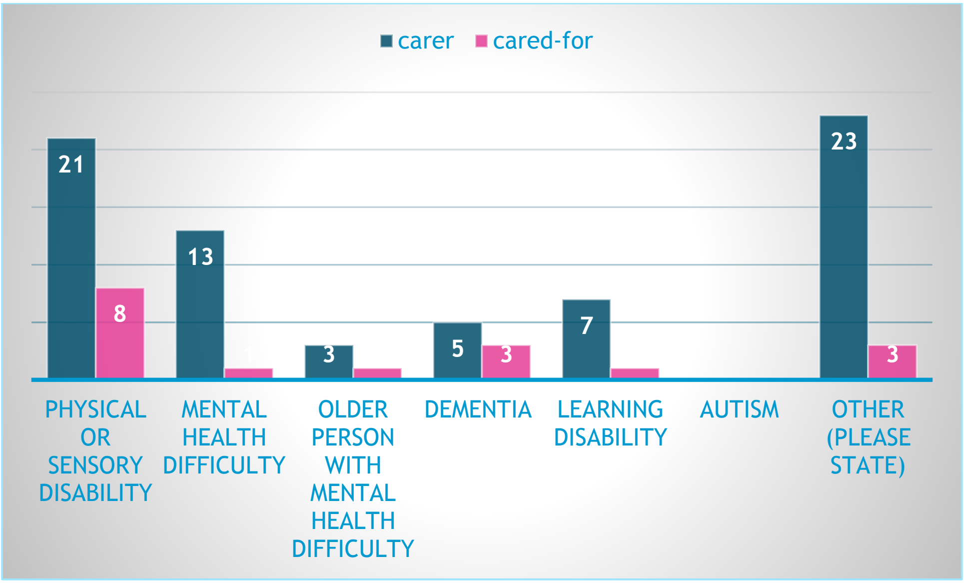

Figure 18

Respondents were also asked if the cared-for person received any additional support with personal care:

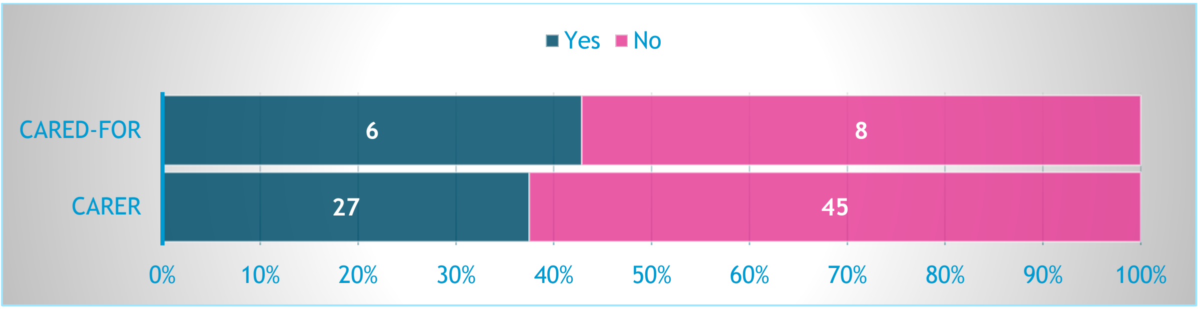

Figure 19

Those who answered 'yes' were asked who provides the support. Carers said:

> *"As an NHS patient, anything required."*
>
> *"A carer who gets him up, showers him and puts him to bed. We are self funding."*
>
> *"Local care company."*
>
> *"Wife and daughter help wash, dress and walking."*
>
> *"Her day care staff."*
>
> *"Care company."*
>
> *"I have to help wash, dress my 10 yr old."*
>
> *"Only really someone to motivate them."*
>
> *"Shared Care funded by local authority."*
>
> *"Easy Living."*
>
> *"Local care agencies."*
>
> *"They have enablers to support them with social activities and my Mother with reading."*
>
> *"Wife, me."*
>
> *"PERSONAL ASSISTANTS AS NO CARING COMPANY HAS CAPACITY"*
>
> *"Care company."*
>
> *"Local company employing trained care staff."*
>
> *"I do."*
>
> *"Estuary League of Friends."*
>
> *"Respite carers."*
>
> *"A carer comes to the house twice a week to shower and put her to bed."*
>
> *"30 mins x 5 days weekly from DCC."*
>
> *"Carer/friend."*

The cared for said:

> *"Day care (Barkwells)."*
>
> *"Family support."*
>
> *"I have either one or two live in carers. I have a carer who can come in by the hour. My wife helps."*

> *"As previously stated, 30 minutes Mon-Fri from Horizon agency."*
>
> *"Easy living TiVvy."*

Respondents were then asked if the cared-for person had any behavioural difficulties as part of their condition:

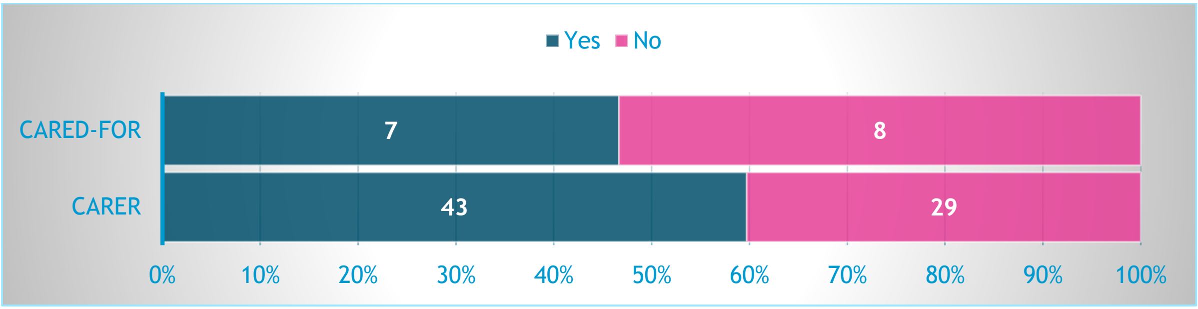

Figure 20

The cared-for person was asked if they experience any of the following:

Figure 21

Carers were asked if the person they care for requires supervision for most or all of the day:

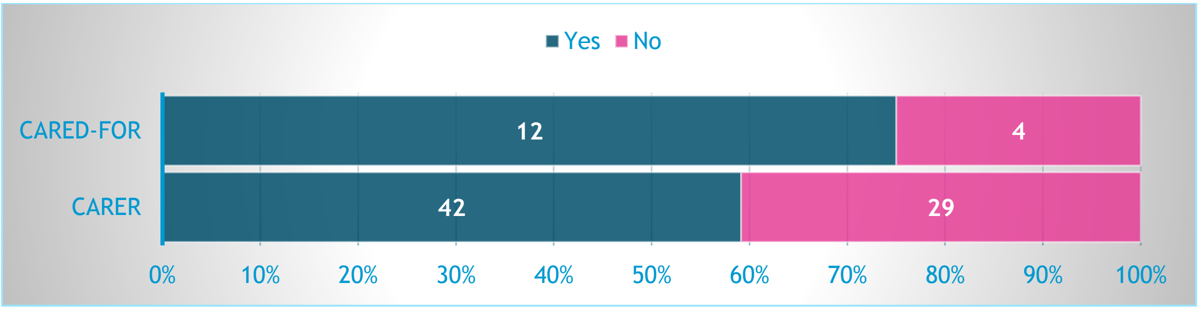

Figure 22

The survey asked about the relationship between the carer and the cared-for person:

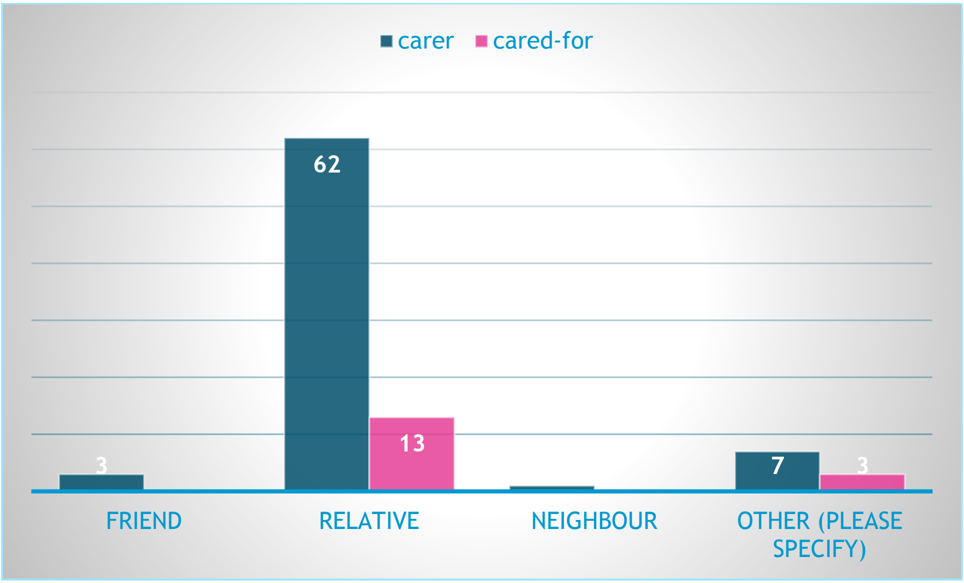

Figure 23

Most of the ‘other’ comments were relatives, one was ‘partner’.

Respondents were asked if the carer helps with dressing, washing and feeding:

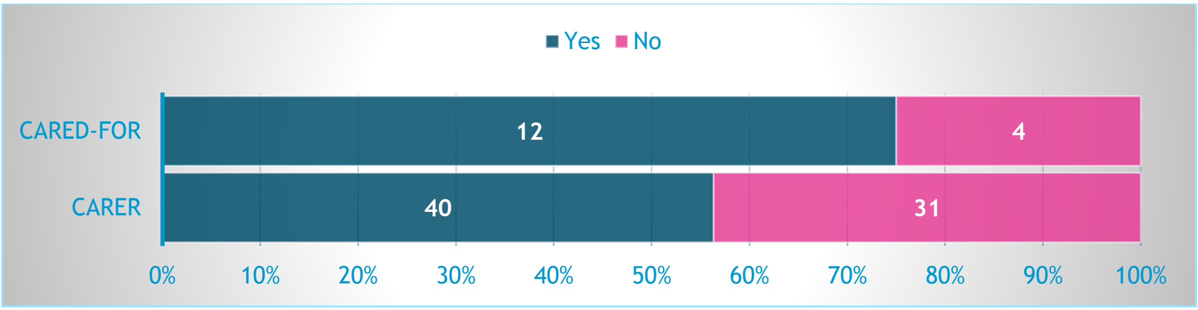

Figure 24

Respondents were asked if the carer themselves has any longstanding health issues or disabilities:

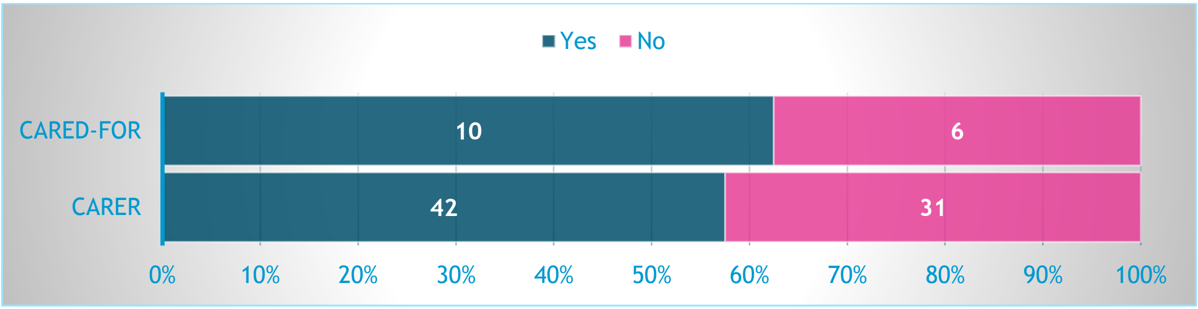

Figure 25

Carers were also asked if they experienced financial hardship as the result of their caring role:

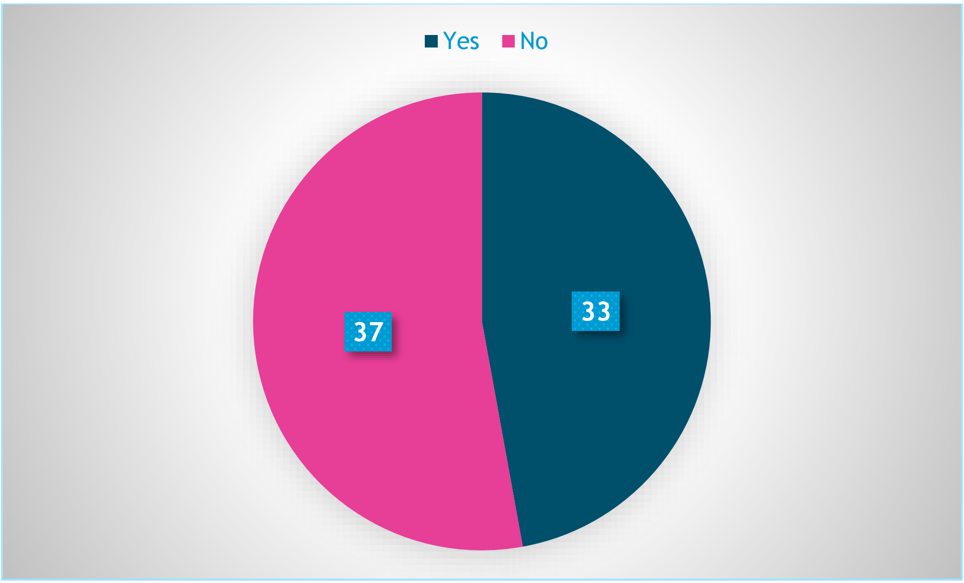

Figure 26

Carers were also asked to comment regarding financial hardship:

> *"Receive a direct payment to help with housework."*
>
> *"Being disabled is an expensive lifestyle."*
>
> *"I drive a 70 mile round trip every week to care for my mother in various ways this is going into the 21st year now."*
>
> *"Carer is almost 80."*
>
> *"I have angina, diabetes, memory issues. Stress, all domestic duties, shopping, supervision clothing, control of medicines, well-being and physical condition of wife."*
>
> *"No health issues thankfully but may not last for ever. I'm not 21 either."*
>
> *"It is not possible to work full-time."*
>
> *"Living on benefits, Income Support and Carers Allowance is not enough to survive on!"*
>
> *"I have had to reduce my working time from 25 to 15 hours a week the rest of my week is taken up with caring. I have lost a lot of income from this and no longer have a job with a pension provision."*
>
> *"My caring role x 3 and all the admin organising carer, dealing with social carer and with meetings and appointment leaves me no time to work. I want to start my own business which would be more flexible than employment but I am struggle to even do this."*

> *“Due to us both having illnesses / disabilities we have to claim benefits and it’s hard to meet costs of daily living. We are on a very tight budget.”*
>
> *“Retired so not now but did for many years.”*
>
> *“Yes and no. Caring always means some kind of financial consequences, define hardship. Are you talking about unmet needs, met needs, sort of met needs but there is still a large cost that takes up a big chunk of the budget. What is the point of this question? What are you trying to find out? Another poorly designed question. We know you know what you are asking and that you think this question asks it, but the reader is not telepathic, so you have to say what you are looking for and how the answer relates to the information you are seeking.”*
>
> *“Often had to go without when the children were younger and I was not able to work due to care responsibilities and no family to help out.”*
>
> *“The amount of Carers Allowance is quite simply insulting. I get a "to up" of Income Support luckily, which helps us. Without this, I'd have no money for myself. No ability to travel independently, no ability to contribute to the household financially, I'd have to pay for my own medication, and so it goes on. A decent level of Carers Allowance would enable carers to have a life, and dispense with claiming anything extra. Also, ALL carers should receive FREE prescriptions, as well as bus passes.”*
>
> *“I have arthritis. I also share the costs of taxi fares which he needs.”*
>
> *“Yes stop wasting money on bullshit "support" and reduce bills for carers.”*

The cared-for person was also asked if they experienced financial hardship due to their disability:

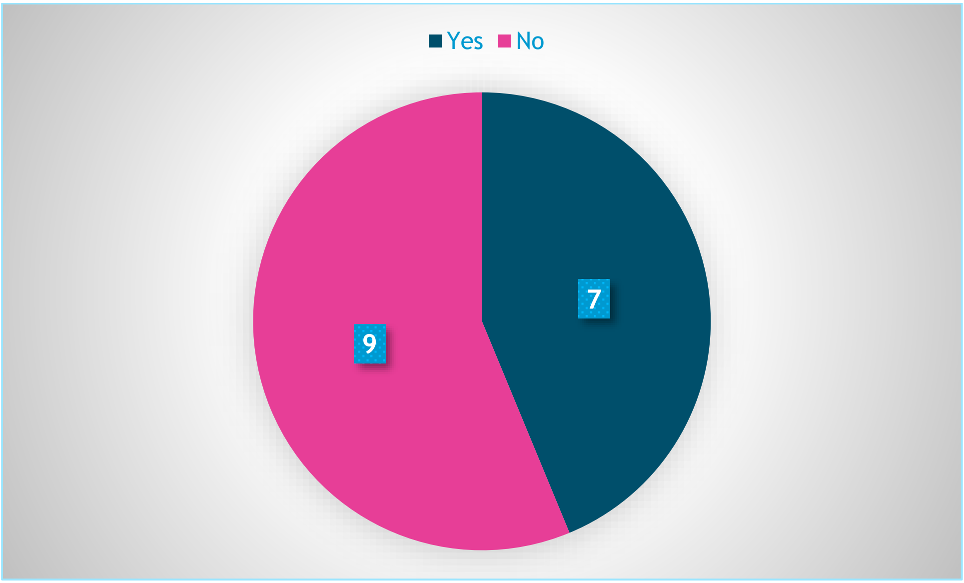

Figure 27

The cared-for respondents commented:

> *"I have attendance allowance which helps a lot to defray costs."*
>
> *"Only way I find out if any money belongs still to me is by foul means or other seemingly."*
>
> *"We have funds but a lot has been spent over the years on all the things I need."*
>
> *"I have sufficient savings."*
>
> *"I believe it will get difficult as time goes by."*
>
> *"There is never enough money to pay for cleaners, taxis, gardener, extra sittings etc etc."*

Carers were asked if their sleep is disturbed on a regular basis:

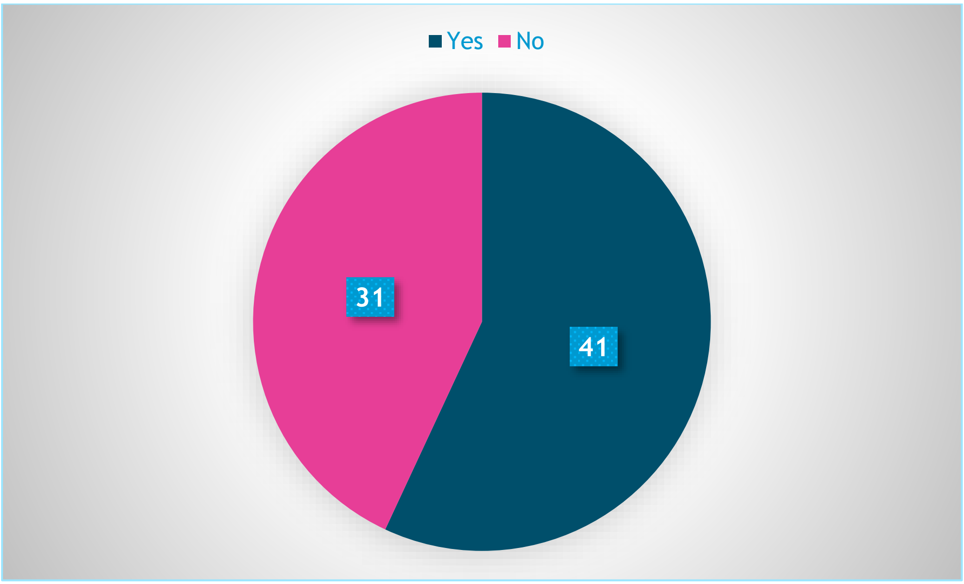

Figure 28

Carers were asked: How many times a night are you disturbed?

Most respondents are disturbed multiple times a night. Carers most commonly this would be 2-3 times, but some people could be disturbed hourly through the night.

Carers and the cared-for were asked how many nights per week were they disturbed?

Most commonly this happened seven nights a week.

Carers were also asked to describe the help you provide to your cared-for person:

> *"Toilet."*
>
> *"Assistance with toilet, drinks, help with comfort for sleeping."*
>
> *"Empty urine bottle or change sheet."*

"Toilet, a drink, reassurance."

"Getting her back to bed."

"Practically everything."

"Epilepsy & toileting."

"Emotional, practical."

"Helping to sleep and re-settle."

"All care."

"Emotional support."

"Total care."

"Assurance, pillow turn, water refill, bedding adjustment. Extra blanket."

"Whatever is needed re her health needs."

"Clean and change including bedding."

"If fallen help up. Reassure when calls or has a nightmare!"

"Everything."

"No physical help normally needed. Supervision for toileting or discomfort."

"Getting out of bed, toileting, back to bed etc."

"Full support."

"Day to day living, prompting personal care, general supervision."

"Guiding to bathroom. Mopping up spills."

"Calming reassurance."

"Help them out of bed for toilet, help to toilet."

"Calm, settle after toilet + sometimes change bed etc."

"Whatever is needed - massage, chocolate, medication, reassurance, conversation etc."

"Toileting."

"Toileting, cleaning up "mess". Moving person manually."

"I keep the bedroom door open to hear whether he has fallen or calls out. This is not every night."

"Reassurance, medication, calming, calling for medical assistance."

> *“Incontinence.”*
>
> *“Domestic help across all areas.”*
>
> *“My daughter suffers with epilepsy and is non-verbal so requires close monitoring.”*
>
> *“Physical support for toilet, bed changing, emotional support, etc.”*
>
> *“Medicine, toilet and reassurance to get back to sleep.”*
>
> *“I get woken up all night long by shouting to help to go to the toilet.”*

The cared-for person was also asked what support they needed at night, the responses were:

> *“Get ready for bed.”*
>
> *“Change incontinence pad and turn over at 10:30pm md 4am.”*
>
> *“Personal hygiene.”*
>
> *“Going to the bathroom.”*
>
> *“Making sure I'm safe.”*
>
> *“Help with drinking, pillows, anxiety, tissues, coughing, toileting and cleaning.”*
>
> *“I need help to turn over in bed.”*

Respondents were asked if the carer worked, as well as caring for the cared-for person:

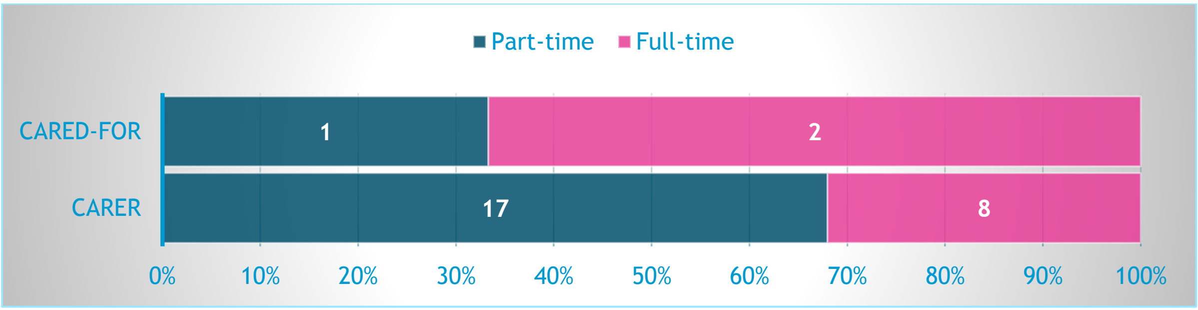

Figure 29

For six carers this involves unsociable hours.

When did the carer last have a break from caring:

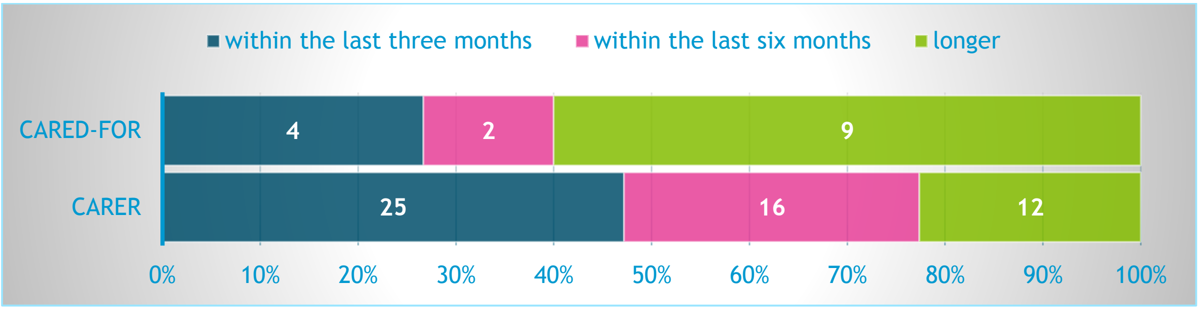

Figure 30

How long was the break for:

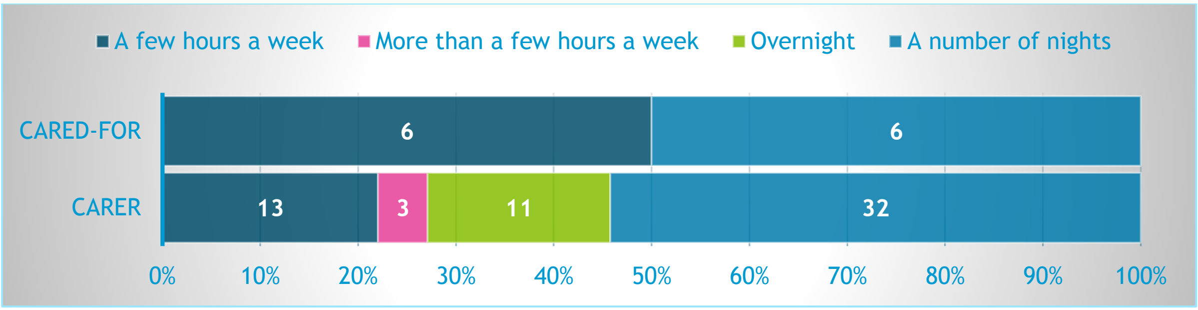

Figure 31

The respondent, whether carer or cared-for was asked which district they lived in:

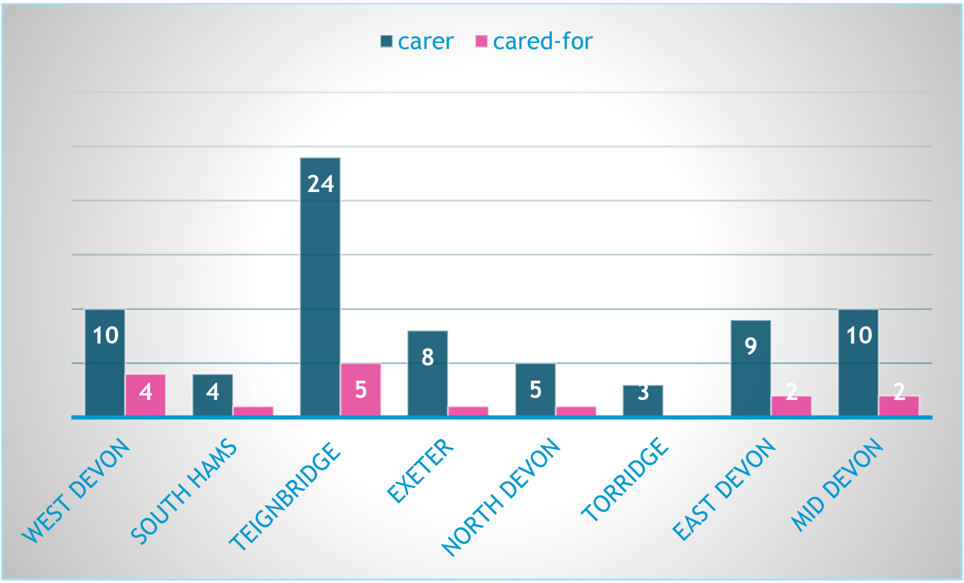

Figure 32

Respondents were asked if the carer and cared-for person live at the same address:

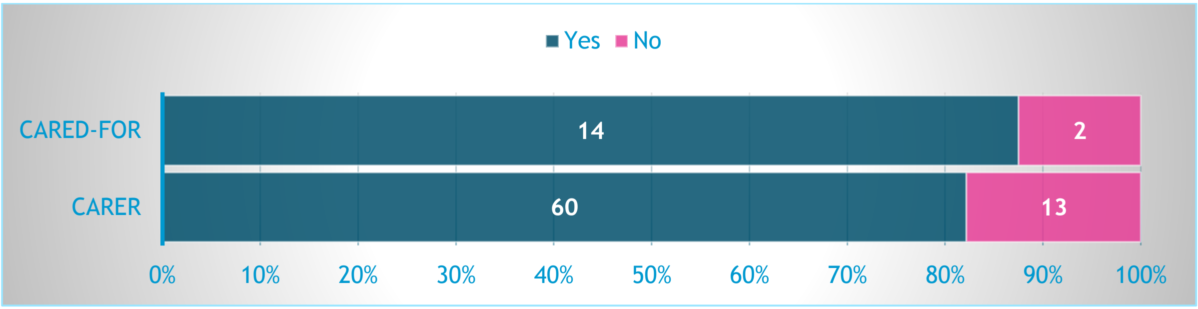

Figure 33

For those who answered ‘no’ to the above they were asked how far away they lived. 16 carers answered this question, but the comments make clear why this is higher than the responses to the above question:

The comments were:

> *“Next door.”*
>
> *“Cornwall.”*
>
> *“Also care for mother 7 miles away.”*
>
> *“Another daft question. I live with one person I care for, the other person I care for lives in Torbay.”*
>
> *“Not relevant as they are currently in supported living.”*
>
> *“Will be way at Bath Spa university from Sept 2016.”*
>
> *“Same address as one, Torbay for the other.”*

The age profile of carers relating to this survey is:

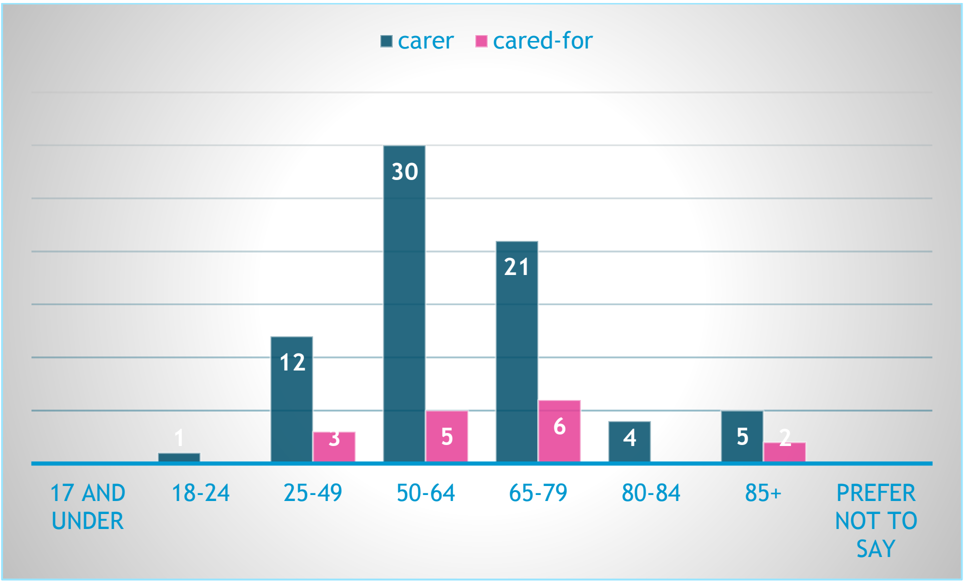

Figure 34

The age profile of the cared-for relating to this survey is:

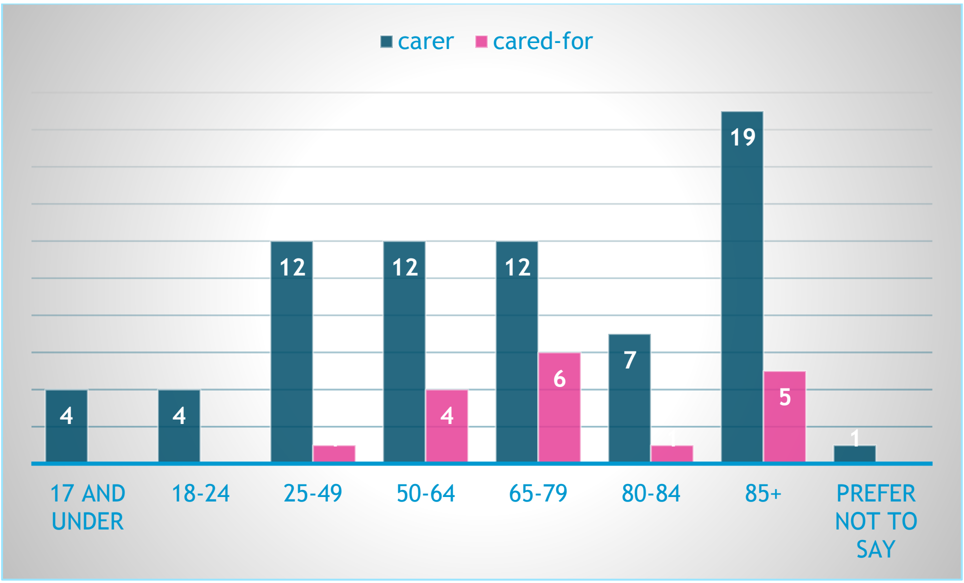

Figure 35

The gender of carers relating to this survey is:

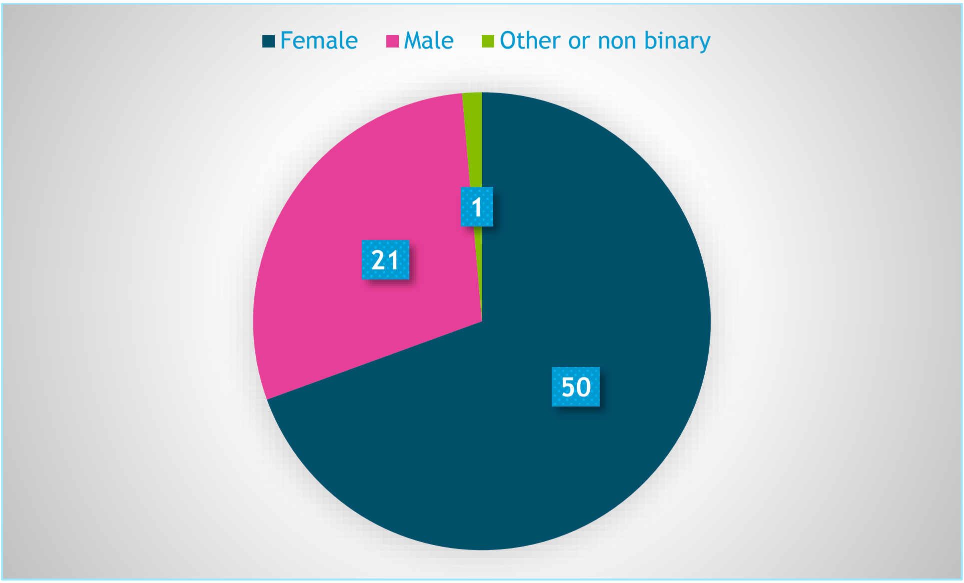

Figure 36

The ethnicity of respondents is:

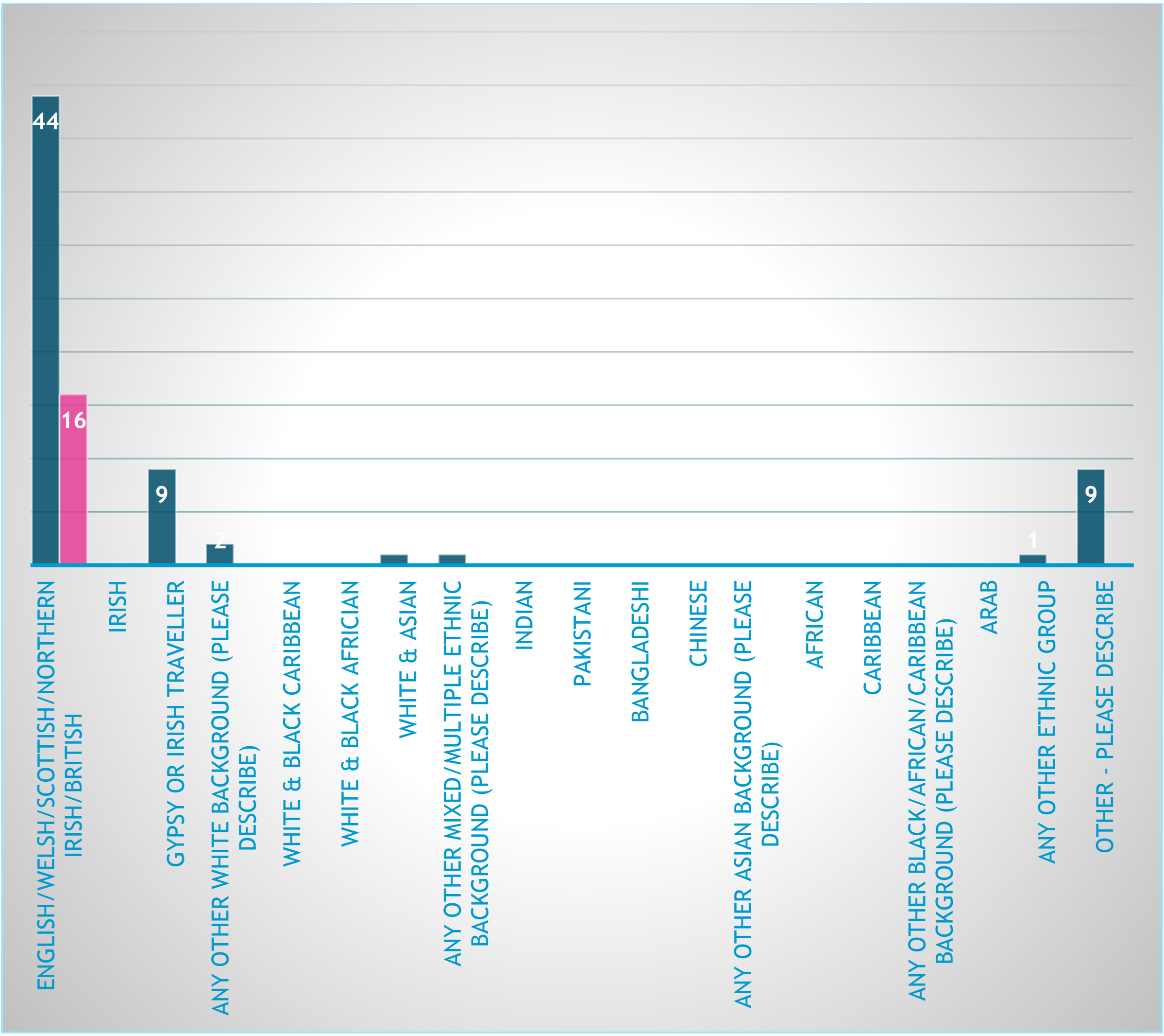

Figure 37

Although 9 ‘other’ comments were registered, only three of these relate to ethnicity, these were:

> *“Cornish Celt”*
>
> *“Anglo-Berber”*
>
> *“Cornish”*