Luminus
Home of Healthwatch Surrey

Carers Replacement Breaks

The experiences of unpaid carers and staff in Surrey

November 2023

Shining a light on what matters to people.

Carers Replacement Breaks

The experiences of unpaid carers and staff in Surrey

November 2023

If you would like a paper copy of this document or require it in an alternative format, please get in touch with us.

Contents

Introduction

Luminus (the home of Healthwatch Surrey) has gathered people's views on Surrey's Carers Replacement Breaks, which are funded by both Surrey County Council and the NHS. The service provides short term breaks to unpaid carers and is delivered by Crossroads Care Surrey.

Currently the offer to all Surrey's unpaid carers is a 'one off' 35-hour free offer, which can be taken over a 6-month period. The service is delivered in the carer's home at times and frequency agreed between the carer and Crossroads Care Surrey. The model is that after the 6 months has lapsed or the 35 hours is used, carers can choose to:

- self-fund the service to continue
- be assessed by social care to discuss funding for further breaks which may be offered
- cease the breaks as they are no longer wanted or needed.

The aim of this service is to help maintain the health and wellbeing of carers and prevent crises. In partnership with commissioners and the provider, we wanted to understand if this is working and how well the service meets carers' needs.

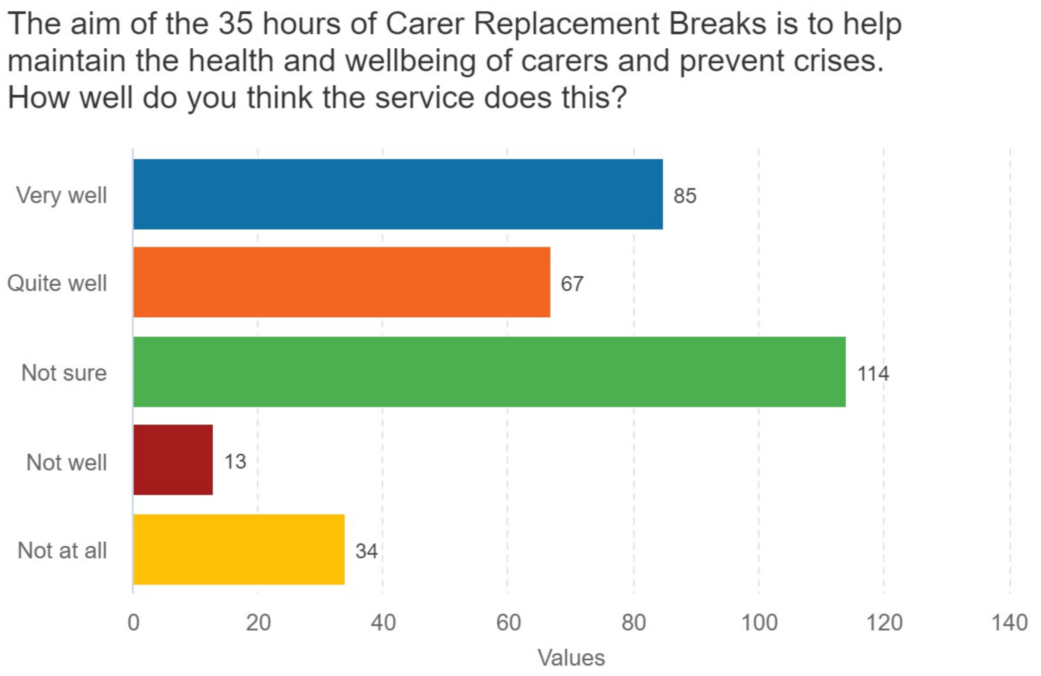
We also wanted to help provide solutions for anything that isn't working well, so we asked carers and staff to share ideas to improve the service in the future.

Key finding

The aim of this service is to help maintain the health and wellbeing of carers and prevent crises. In partnership with commissioners and the provider, Luminus wanted to understand if the service was meeting this desired aim, how well the service meets carers' needs, and what might be improved.

The headline finding from our research reveals that **just under half** of the 313 carers responding to this fundamental question felt that the service met that aim quite or very well.

Figure 1: How well does the service maintain the health and wellbeing of carers?



Further analysis of this finding can be found in the section of this report 'How well do you think the service helps to maintain the health and wellbeing of carers'.

Themes

When all survey responses were analysed, we found a number of themes.

1. Positivity about the service

1.1. Of those that **currently receive the service**, the majority reported they valued the service and it gave them a good break from caring responsibilities.

1.2. Of those who had **finished the service**, a significant proportion of respondents felt the service had met their needs and were very appreciative. There were examples where carers found it a useful way to try respite at home for free, before deciding on it becoming permanent. This was most useful for people who intended to pay privately. Carers who need social services funding would need to be assessed much earlier to ensure the funding was in place to allow a seamless transition into a funded service.

1.3. When we asked all unpaid carers what they thought the service could do differently, 28.5% commented that the service works well and nothing needs to change.

1.4. It was clear that a significant proportion of people who had received the service were very happy with it. However, respondents did not view it as a preventative service that could then be stopped until needed again.

2. Increase hours

This referred to the 35 hours of service currently available. Many respondents felt more than 35 hours should be available. This theme recurred throughout every group responding and featured in the responses to almost every question.

There was a theme in a number of responses that the limit of 35 hours is, for some, meaning that the preventative nature of the vision of the service is not working in reality. **Some carers who are aware of the limited number of hours are delaying their take-up of the service until they reach crisis or breaking point.** This may be an unintended consequence of the cap on hours, but must be addressed if the preventative nature of the service is to be fully realised.

3. Increase flexibility

3.1. This referred to the need for the service to be offered at different days and times. Examples included:

- Having the service at weekends, evenings and different times of the day
- Being able to have the 35 hours in whole days or overnight rather than 3.5 hour visits
- Having the service for different frequencies rather than once a week.

3.2. Unpaid carers on the waiting list were hoping for more flexibility in the service and some had already discovered this was not possible.

3.3. When we asked all unpaid carers what they thought the service could do differently, 19.5% commented. Most of them were under the impression flexibility of visits was not possible, a small number of respondents indicated they had been led to believe the service could be more flexible, but then this hadn't happened.

3.4. Flexibility is important if the preventative nature of the vision is to be realised, to ensure that the carer is able to maximise the hours for their own wellbeing.

4. Meeting needs

4.1. Respondents raised the importance of meeting the needs of the cared for person to effectively give the carer a break. The needs of the carer also need to be taken into account effectively. A number of areas were highlighted:

- Assessments of the unpaid carer needs to be consistent and person centred, recognising their need to continue with their other responsibilities and interests.
- The need for care staff to be consistent and effectively trained to ensure the relationship between respite carer and cared for person gives the unpaid carer confidence to leave them together. This requires the same respite carer to visit, or as few different carers as possible. This was particularly raised by respondents who care for people with dementia, mental ill health and autism.
- Perceived differences between what is available to you when paying privately and what is available if you have social services funding.
- The need for more options for respite, such as other home respite providers and residential.

4.2. Over a third of respondents who had not used the service had not done so because they felt the service would not be suitable for their circumstances.

4.3. Of the 236 responses when we asked unpaid carers what they thought the service could do differently, 13.6% respondents raised this issue.

5. What happens when the 35 hours are spent/ Advice on next steps

5.1. For a service which is meant to be preventative in nature, for carers who are in need of support and respite, clarity, forward planning and certainty about what happens when they approach the end of the service is vital. Our findings from carers who have finished the service and who are currently using the service indicate that improvements are needed – both in terms of clear information to enable planning; and timely assessments. The current consequence of delays to assessments and decisions is resulting in carers continuing with the service beyond 35 hours, meaning others on the waiting list can't enter the service.

5.2. For respondents **that had finished the service**, there seemed to have been significant challenges around the service ending. There were lots of comments about uncertainty of what would happen when the 35 hours came to an end. Many carers did not seem to have information about all the options available to them. Assessments and decisions happened between 7 and 10 weeks into the service so there was a lot of anxiety and in some cases the service continued until a decision was reached.

5.3. Of those **currently using the service**, a significant percentage of respondents were going to pay privately once the 35 hours of Carers Replacement Breaks finished. This was mostly continuing with Crossroads Care Surrey but could have included using other agencies as it wasn't specified. 5 respondents had had social services funding confirmed. They did not specify if this was with Crossroads Care Surrey. 9 respondents had had a discussion but no decision, 3 mentioned the service would continue. This meant the service would continue beyond the 35 hours because of a delay in deciding next steps.

5.4. Indications were that some respondents had stopped having any respite because they were not aware of being able to have an assessment to continue or to elect to self-fund it.

5.5. Some unpaid carers mentioned the challenge of having to pay for the service to continue after the 35 hours had finished and felt the service was expensive. In some cases this meant when the service ended they no longer had respite.

6. Better promotion of the service

There is a need for better promotion of the service, and to ensure the information clarifies what is provided, level of flexibility, what needs can be met and who is eligible.

6.1. **Carers waiting for the service** were not always clear exactly what the offer was and information about the service may have led them to believe it was more flexible than the reality.

6.2. Understanding of the offer in advance of starting the service was inconsistent amongst carers that had received the service, with people not fully understanding the 35 hour allocation until their first meeting with Crossroads Care Surrey.

6.3. As a number of carers have not used the service because things do not feel 'bad' enough, information should include what other respite is available and where Carers Replacement Breaks fits. The preventative nature of the service needs to be communicated more clearly.

6.4. For some, finding out about the survey was the first time they had heard of the service. We received a number of calls from people wanting more information and to be referred. These were passed to Crossroads Care Surrey or Action for Carers where appropriate. Some respondents felt information should be more proactive, for example when a GP registers someone as a carer, this should trigger a contact from an organisation like Action for Carers.

6.5. Overwhelmingly respondents found out about the service from professionals. This would suggest that any activity to increase awareness of the service amongst unpaid carers should have a significant focus on increasing awareness amongst professionals that come into contact with unpaid carers.

7. Waiting list

7.1. Those currently waiting for the service seem to have been waiting for longer than those that are currently receiving the service. 14 people had waited longer than a year. For those currently receiving the service, the majority of respondents had waited less than 3 months.

7.2. Respondents who are parent carers seem to have had more challenges getting a service. Their responses tended to give more detail about their circumstances and described difficulties getting social care assessments and waiting longer to get a service that met the needs of their cared for person and gave the required consistency and flexibility.

Recommendations

1. Positivity about the service

There is an opportunity for further analysis of the feedback and triangulation with Crossroads Care Surrey data to understand who the service works best for, to enable better targeting of the offer.

2. Increase hours

Further work needs to happen with carers to understand what the ideal number of hours would be.

This also needs to be seen in the context of better promotion of the service and understanding where it fits in the range of respite services available.

3. Increase flexibility

Further codesign work needs to happen with carers to develop solutions for:

- Having the service at weekends, evenings and different times of the day
- Being able to have the 35 hours in whole days or overnight rather than 3.5 hour visits
- Having the service for different frequencies rather than once a week.

4. Meeting needs

Service codesign needs to be done with carers of people with complex needs to develop the right offer.

5. What happens when the 35 hours are spent/ Advice on next steps

Options on next steps needs to be discussed much earlier in the offer.

6. Better promotion of the service

Information needs to include:

- The range of respite options – Crossroads Care Surrey is often portrayed as the only service
- Preventative nature of service
- Clarity on what the offer really is and how flexible it can really be
- Options on next steps as soon as possible
- To ensure it is targeted at professionals as this is the route to hearing about the service for most people.

7. Waiting list

Better information and sooner discussion of next steps will impact positively on waiting lists Service codesign needs to happen with parents of children and young adults with complex needs and carers of adults with complex needs.

Methodology

We utilised a range of methods to capture the views of carers and staff.

An online survey ran from 7 August to 2 October 2023 (further requests were received to contribute after this date and these contributions were recorded via other means). The survey was shared widely via carers' organisations and their newsletters to carers.
550 people opened the survey, 381 people completed it, 169 partially completed it.

To meet the needs of those who are digitally excluded, all our promotional material included an email and telephone contact to contribute to the survey in alternative ways and provide support.

We spoke to 19 carers over the phone and 24 via email. Where they needed additional advice or support, we referred them to the appropriate organisation.

Visits either online or virtual to carers groups:
- Carers forum for parents caring for adults with mental ill health online 17 July 2023
- National Autistic Society Parents of adults with autism Carers group online 2 August 2023
- Action for Carers Hub meeting, Shepperton 2 August 2023
- Action for Carers Hub meeting, Addlestone 9 August 2023
- Action for Carers Parent Carer Support Group meeting, Hersham 24 August 2023
- Action for Carers Hub meeting, Epsom 5 September 2023.

We also held a number of bespoke online focus groups for carers:
Discussion groups for Crossroads Care Surrey carers, held online:
- 6:30 pm Monday 18 September 2023
- 2:00 pm Wednesday 20 September 2023
- 11:00am Saturday 23 September 2023.

We also held solution focussed discussion groups for anyone who indicated in the survey they wanted to be involved. All were held online at 6pm and included staff from Luminus and Surrey County Council:
- Monday 9 October 2023
- Tuesday 10 October 2023
- Monday 16 October 2023
- Tuesday 17 October 2023.

Survey findings

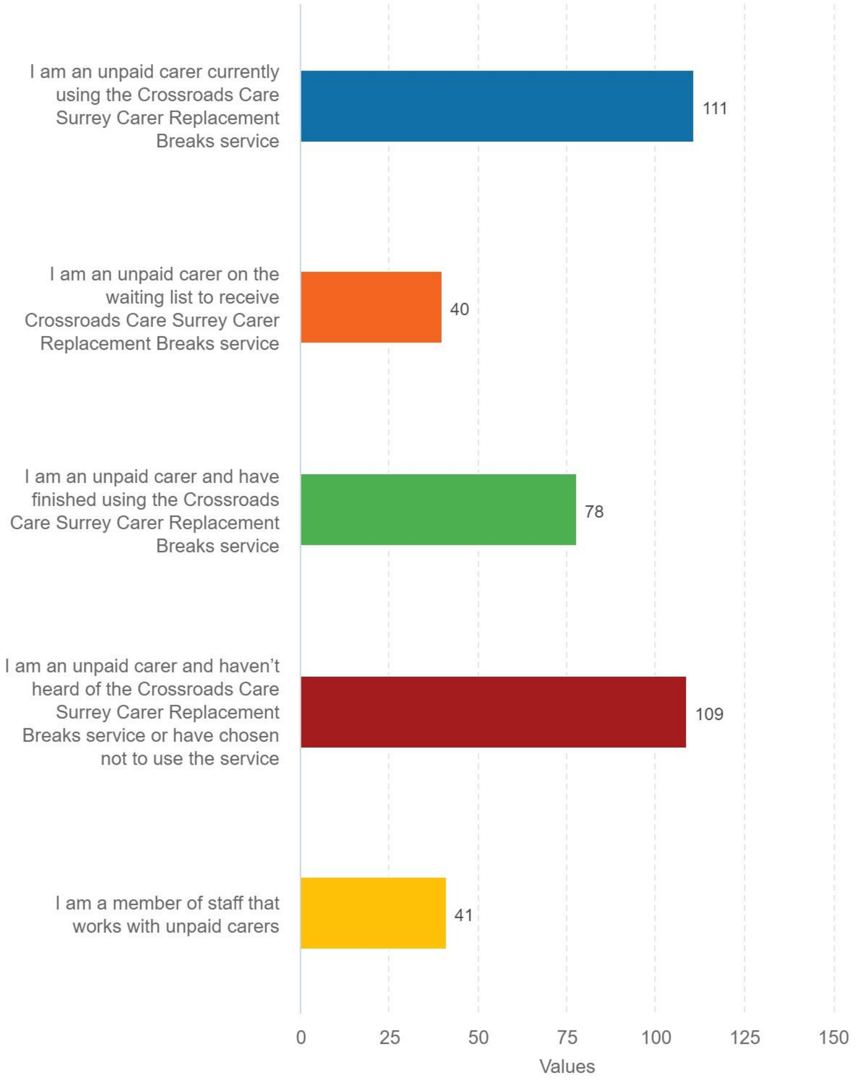
Numbers that completed the survey:

- Total: 550
- Completed: 381
- Partially completed:169.

Who responded?

We asked people how they described their situation. We wanted a range of perspectives from people who were using the service, waiting for the service, had finished using the service, and those who had not heard of it or chosen not to use it. We also wanted to hear from staff who worked with carers to utilise what they observed or heard from carers. Figure 2 below shows the number of completed responses from each group.

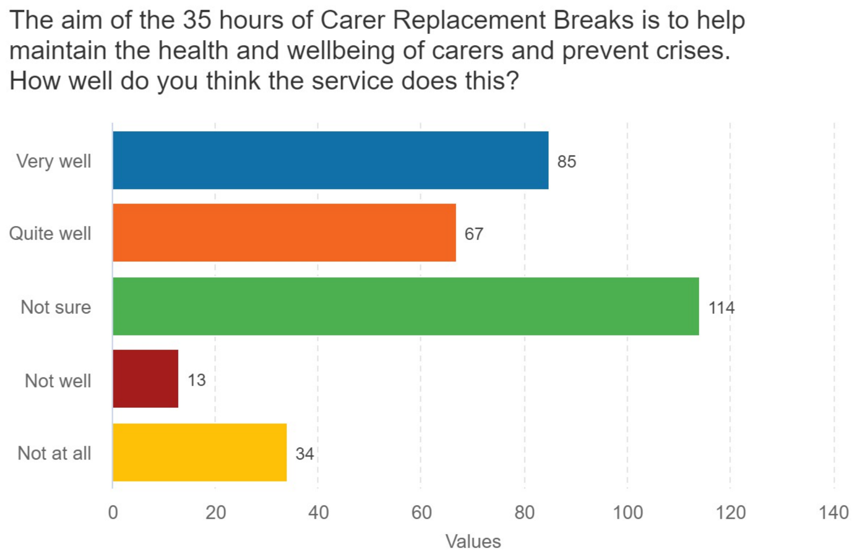
Figure 2: Please choose the description that fits you best



How well the service helps to maintain the health and wellbeing of carers

We asked everyone who had identified themselves as an unpaid carer how well the Carers Replacement Breaks service helped to maintain the health and wellbeing of carers. 313 carers responded, their views are summarised in figure 3 below.

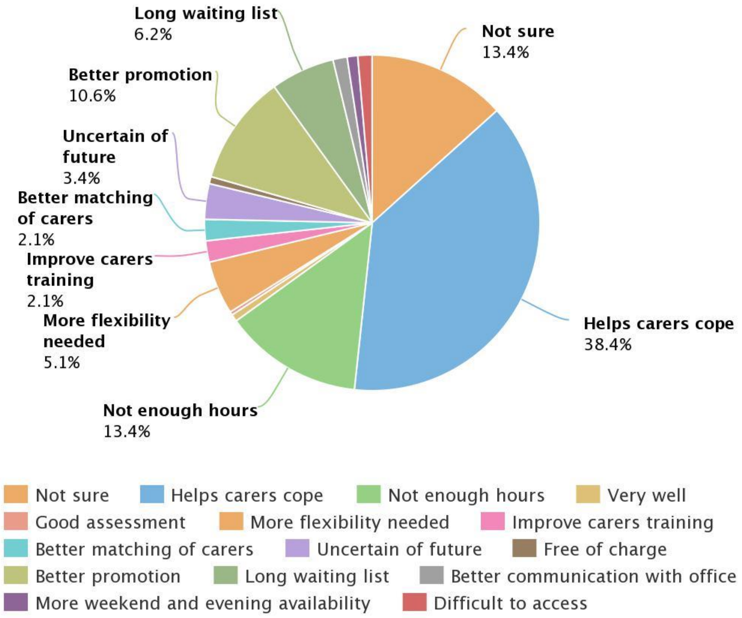
Figure 3: How well does the service maintain the health and wellbeing of carers



We asked respondents to give more detail on why they thought this. 279 carers responded, their comments are summarised in figure 4 on the next page. Some comments had more than one theme within them so the percentages do not map precisely to the numbers of respondents.

- 112 comments felt the service helps carers cope with their caring responsibilities
- 39 were not sure
- 39 comments felt there should be more than 35 hours available
- 31 comments stated it needed better promotion
- 18 felt there was a long waiting list
- 15 wanted more flexibility such as different lengths of visits, frequency and availability in the evenings and weekends.

Figure 4: Why do you think this?



Number of comments per theme:

- 112 - helps carers cope
- 39 - not sure
- 39 - not enough hours
- 31 - better promotion
- 15 - more flexibility needed
- 18 - long waiting list
- 10 - uncertain of future
- 6 - improve carers training
- 6 - better matching of carers
- 4 - better communication with office
- 4 - difficult to access
- 3 - more weekend and evening availability
- 2 - free of charge
- 2 - very well
- 1 - good assessment.

Examples are below, more examples can be found in Appendix 3.

Helps carers cope

> "Frees the carer of the worries albeit temporarily. One feels mentally refreshed after every session. Besides the individuals do an excellent job, selfless sacrifice."
>
> "The carer is lovely and reassuring."

"Very professional and caring"

"She is kind caring & empathetic towards my husband...and I trust her to take care of him while I'm out."

Not enough hours

"I found it stressful having a carer with whom my husband could not relate and therefore worried about him while I was away, which somewhat defeats the object. When I reported this to Crossroads, I felt that they were not interested. If carers need a break, surely 35 hours is a drop in the ocean!"

"The Crossroads staff and service are fantastic but I struggled knowing that my 35 hours would end and I'd be stuck at home again. I worried counting down my afternoons of freedom."

"Because it's only a temporary fix. I need something more permanent."

"35 hours is nothing in the life of a carer. I thought 35 hours a month would have been reasonable but a one off support is an insult."

Flexibility

"It would be nice to be able to get a full respite break of a week or weekend to make a real difference"

"The service was not flexible enough to keep going with my mum. An alternative volunteer was not found and we are still waiting for some support."

"Might be good if you have transport and can go further afield I have train card but not enough time in 3.5 hours to go anywhere."

Next steps

"Social care assessments seem to be dependent on waiting for families to be in crisis or safeguarding issues to be present before agreeing to help. Waiting lists are long."

"It has been good to have the service for a free period before I have to pay privately"

"Carers who have no choice but to work full time as my husband who I am a carer for and is not entitled to anymore help financially. I feel that carers like myself are being penalised due to working full time."

Meeting needs

"Couldn't meet need for son with autism"

"It hasn't started as yet and I feel like I've had to jump through multiple hoops to just be recognised. I feel extremely tired of fighting the fight at this stage, always looking, asking, requesting for support to provide a better life for the person I care for. While he has only been living at home full time for 1 year, as a parent & carer of a young adult, it's become more difficult than having a child."

Conclusions

Key themes arose from asking carers how well the service maintains the health and wellbeing:

- The service works well and helps carers cope
- More than 35 hours should be available
- There should be flexibility in how long and how frequently the service is available
- There needs to clarity on what will happen after the 35 hours is used
- The service needs to be able to cope with more complex needs such as autism
- The service needs to be better promoted
- The service can have a long waiting list.

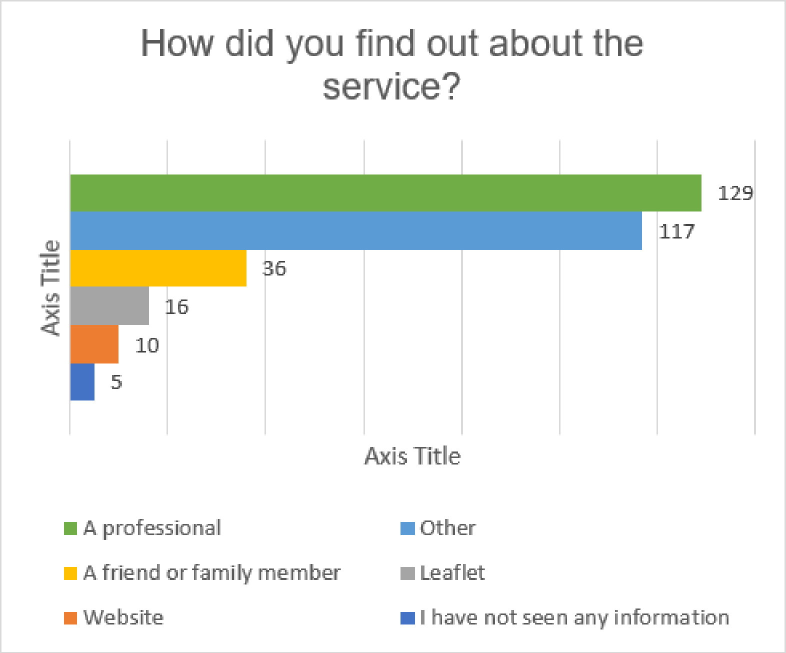
Finding out about the service

We wanted to understand how people had found out about the service. We found the responses from the three groups we asked very similar and so have combined the results.
The three groups were:

- Unpaid carers currently using the service
- Unpaid carers on the waiting list for the service
- Unpaid carers who have finished using the service.

We did not ask people who had not used the service, or staff, how they found out about the service.
The results from the three groups are summarised in figure 5 below.

Figure 5: How did you find out about the service? Combined results.



For the 117 respondents that gave further details for ‘other’ these were predominantly 3 sources of information:

- Action for Carers
- NHS staff such as those in GP practice, hospitals or condition specific support services such as Dementia Nurses
- Council and social services.

The detailed feedback can be found in Appendix 1.

Conclusion

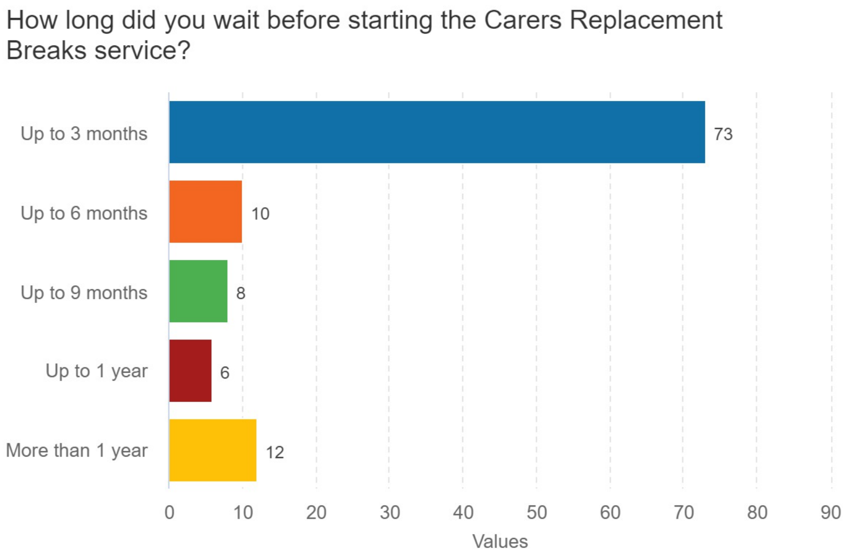
Overwhelmingly respondents found out about the service from professionals. This would suggest that any activity to increase awareness of the service amongst unpaid carers should have a significant focus on increasing awareness amongst professionals that come into contact with unpaid carers.

Unpaid carers currently receiving the service

Waiting times

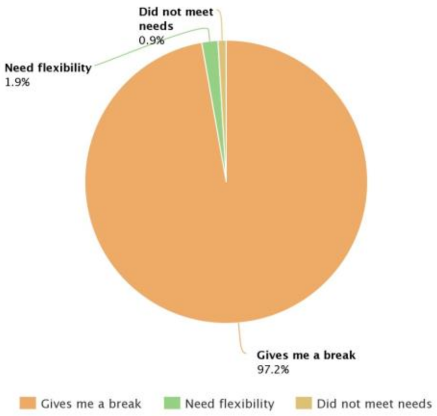
111 respondents identified themselves as unpaid carers currently receiving the service. We asked them about their experiences. Firstly, we asked how long people had waited to start the service. All 111 responded, figure 6 summarises the responses. Encouragingly, the majority of respondents had waited less than 3 months.

Figure 6: How long unpaid carers currently receiving the service had to wait



How it meets need

Figure 7: How the Carers Replacement Breaks service meets your needs



110 carers responded, giving feedback in their own words.

Number of comments per theme:

- 105 - gives me a break
- 2 - need flexibility
- 1 – did not meet needs.

As can be seen above, responses were overwhelmingly positive, referring to the break the service gives them from their caring role. Some examples of responses are below, more examples can be found in Appendix 3.

> "A morning off a week from my caring role revitalises & helps immensely."
>
> "If it wasn't for Crossroads my husband and I would very rarely be able to leave the house together. We've been able to attend medical appointments, see friends, relax with a coffee and visit garden centres. Before Crossroads I was rarely able to leave the house at all and I developed severe vitamin D deficiency as a result (though this is now managed with medication). I am the main carer for my 98 year old bed bound mother. It takes the pressure off me for a while and it's wonderful knowing that she can engage with someone other than me in such an enjoyable way."
>
> "This is a life-line where I can leave the house feeling easy and know I'm leaving my husband in good company."

There were individual comments that raised other issues:

Need flexibility

> "Crossroads can only come twice a month with the ad hoc additional evening. I would dearly like overnight support but this is unavailable. We haven't had any overnight respite for over a year."
>
> "It is excellent to have 3.5 hours free time every week for 10 weeks and I hope this will continue after the 10 weeks. Friday afternoon was the only time available when it started but I would much prefer another day (Tuesday or Wednesday) when I would have other activities to take part in."

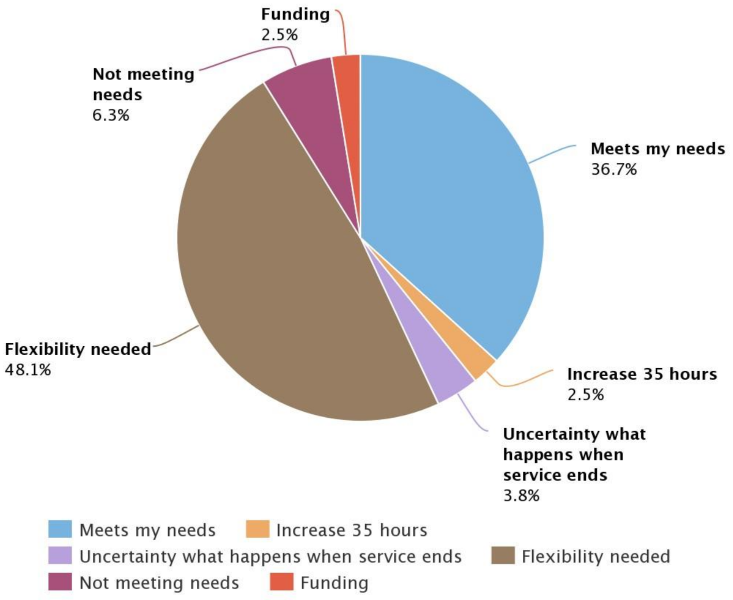
Did not meet needs

> "I feel I did not benefit much from them. As there was no feedback from the carer and she didn't really do what was discussed. So I didn't benefit from any break."

How it doesn’t meet need

80 respondents talked about how they felt the service doesn’t meet their needs. 29 responses reiterated that the service did meet their needs. Responses are summarised below in figure 8.

Figure 8: How the Carers Replacement Breaks service DOESN'T meet your needs



Number of comments per theme:

- 38 - flexibility needed
- 29 - meets my needs
- 5 - not meeting needs
- 3 - uncertainty what happens when service ends
- 2 - increase 35 hours
- 2 – funding.

Where respondents felt their needs were not being met, the main theme was the need for more flexibility. This included the times being offered not being best suited to the needs of the carer, the need for a different frequency of visits and having more choice for days and times, including weekends and evenings. Examples are below, more examples can be found in Appendix 3.

> “Times a bit off .10 consecutive weeks when I only need twice a month.”
>
> “The only way it doesn’t meet my needs is if I need a one off break to go to an appointment and I don’t want to take my husband. It cannot do this.”

> "Would like to be able to have a longer period of time occasionally, e.g. save up sessions and have a whole day."
>
> "Would like more flexibility rather than same time and day each week for 10 weeks but want to keep carer so will go along with it."

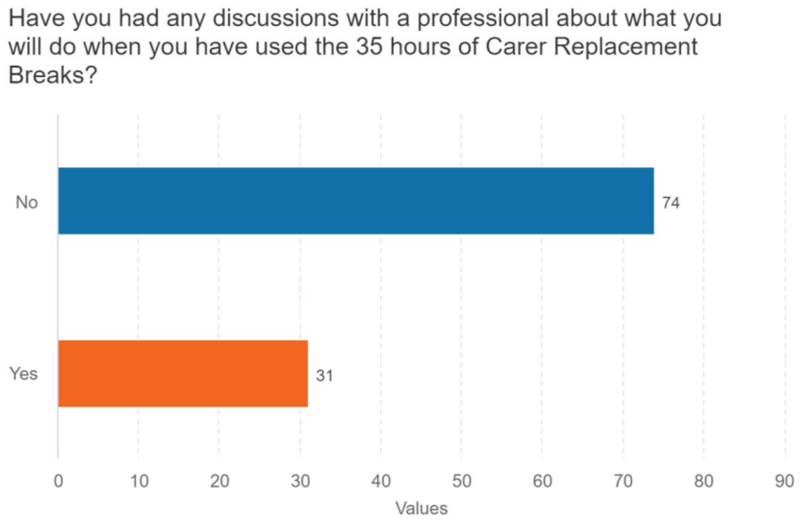
Conclusions

A significant number of respondents reiterated what did work for them when answering this question. The main theme where needs were not being met was around the need for more flexibility in how the service is delivered. There were also comments on the uncertainty around what would happen after the 35 hours, difficulties funding and the need for the service to be for more than 35 hours.

Clarity on what will happen after the 35 hours of service

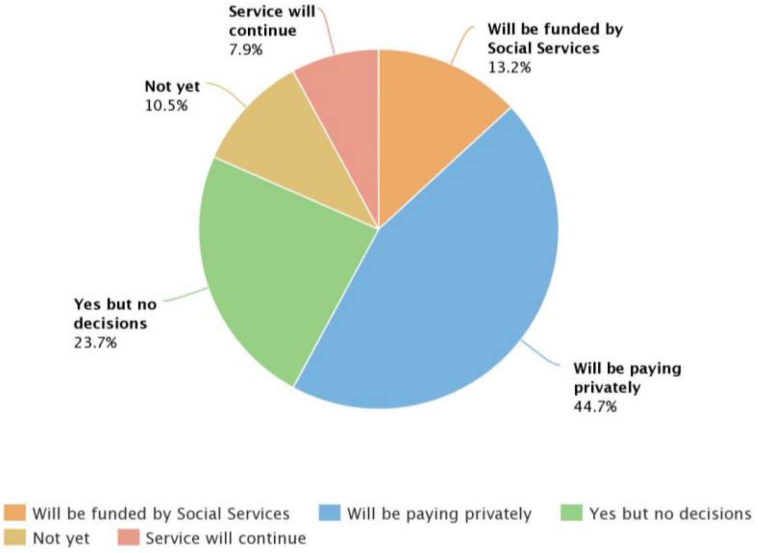
We wanted to understand how much carers understood about what would happen once the Carers Replacement Breaks service finished. Figure 9 summarises how many respondents had had a discussion about this.

Figure 9: How many unpaid carers currently receiving the service had had discussions about the service finishing



We asked those that had responded yes to give more detail on what had been discussed. 40 people responded even though only 31 had said yes. 4 carers stated they had not yet had discussions. The other responses are summarised in figure 10 below.

Figure 10: What has been discussed when the service ends with carers currently receiving the service



Number of comments per theme:

- 17 - will be paying privately
- 9 - yes but no decisions
- 5 - will be funded by social services
- 4 - not yet
- 3 - service will continue.

Examples are below, more examples can be found in Appendix 3.

> "Had discussion about being self funding which was agreed, I know I'm outside of the limits where I could get help. Currently have no input from social services."
>
> "Social services have said that they will have to undertake an assessment to see what is required."
>
> "What professional? We had a visit from a trainee adult social care person who visited us and told us we need to start paying. This is the only conversation we had."

Conclusions

There were a number of important themes in these responses which recur throughout our findings.

Paying privately

A significant percentage of respondents were going to pay privately once the 35 hours of Carers Replacement Breaks finished. This was mostly continuing with Crossroads Care (Surrey) but could have included using other agencies as it wasn’t specified.

Funding from social services

5 respondents had had social services funding confirmed. They did not specify if this was with Crossroads Care Surrey.

Services continuing pending decision

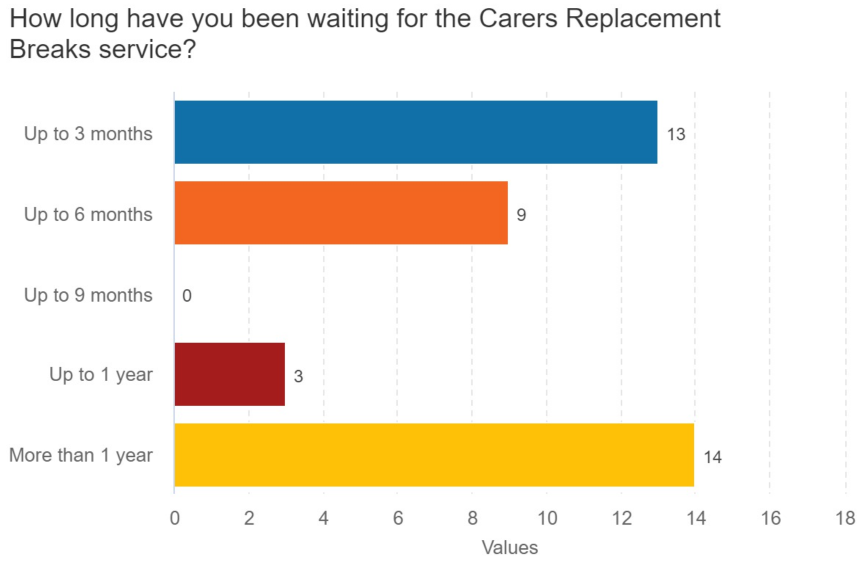
9 respondents had had a discussion but no decision, 3 mentioned the service would continue. This meant the service would continue beyond the 35 hours because of a delay in deciding next steps.

Unpaid carers on the waiting list to receive Crossroads Care Surrey Carer Replacement Breaks service

Waiting times

40 respondents identified themselves as unpaid carers on the waiting list for Carers Replacement Breaks. We asked how long they had been waiting. The responses were different for this group, in that the highest number of responses was that they had waited more than a year. Figure 11 below summarises the responses.

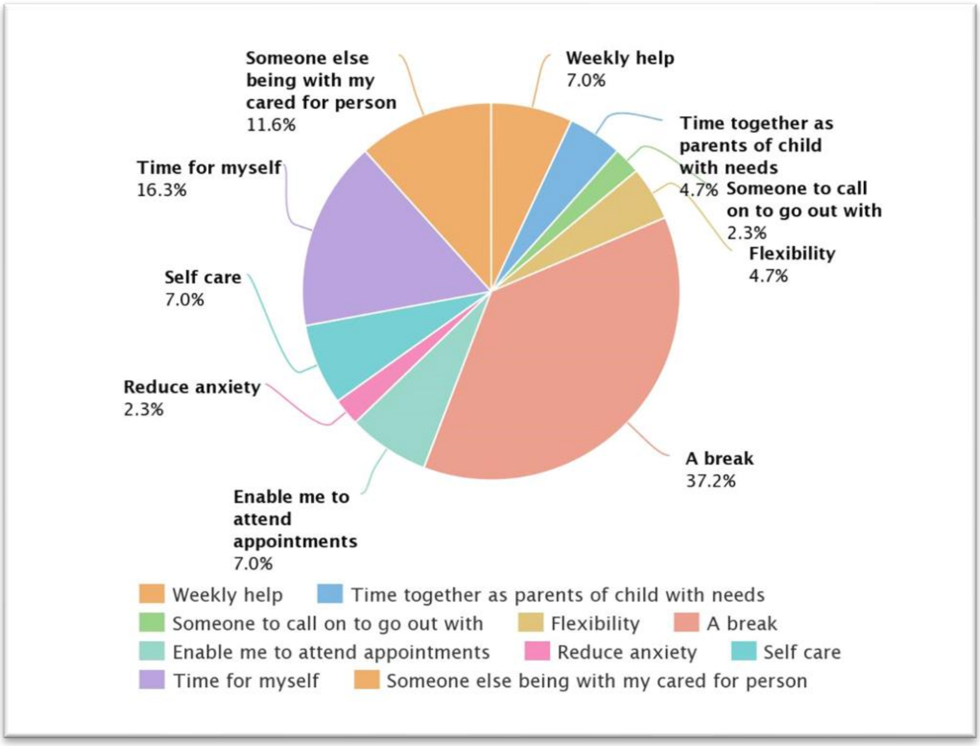
Figure 11: How long carers have been waiting to start receiving the service so far



How are you hoping the service can help you?

We asked how carers were hoping the Carer Replacement Breaks service will help them. 40 people responded and these are summarised in figure 12 on the next page.

Figure 12: How carers were hoping the Carer Replacement Breaks service will help them



Number of comments per theme:

- 16 - a break
- 7 - time for myself
- 5 - someone else being with my cared for person
- 3 - weekly help
- 3 - enable me to attend appointments
- 3 - self care
- 2 - time together as parents of child with needs
- 2 - flexibility
- 1 - someone to call on to go out with
- 1 - reduce anxiety.

The responses included the benefits of the service we would expect to see. But there were examples that highlighted a need for flexibility in the provision.

> "An ideal solution for us would be an ad hoc arrangement. Mum needs someone to help her be more independent and be able to buy things without depending on me all the time. Perfect example is birthday and Christmas presents - where I am the only one who can get stuff for her, so she is never able to get something for me and this upsets her. Mum sometimes likes to go out, but when she feels up

to it I am sometimes busy with the grandchildren or other commitments. It would be great if she had someone she could call on to take her to events/ church or just out for a cup of tea.”

“To look after our autistic son one afternoon at the weekend. Times are fixed (9-12 or 1-4 I think?) and he is at college during the week. We have now been waiting over a year since we contacted Crossroads - I call every couple of months but not luck yet…”

“1) I need to rest and not always be ‘switched on’ to having to be the person on call - but I’ve discovered it won’t
2) peace of mind that on the one weekend a month I’d want to not be going over and doing stuff that someone else would keep her company.”

“I need help with my young daughter just to give respite to me and my family especially at weekends as she needs 1 to 1 care and attention. I am a full time working mum that has an older daughter too whom I am not able to give my full attention to as my younger child has demanding care needs. Just someone to play with her or read books take her to the park would help tremendously a few hours a week.”

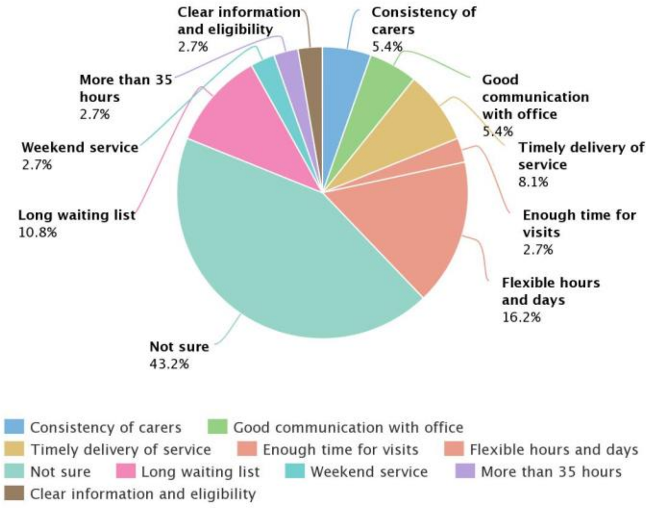
What have you discovered is not available?

We asked carers whether there were things that they hoped the Carers Replacement Breaks service would offer but had discovered it won’t. Of the 37 respondents:

- 16 were not sure
- 6 had discovered hours and days were not flexible
- 4 mentioned a long waiting list and 3 raised timely delivery service where the outcome was they had waited for a long time.

The full breakdown is in figure 13 on the next page:

Figure 13: Things that carers hoped the Carers Replacement Breaks service would offer, but have discovered it won't



Number of comments per theme:

- 16 - not sure
- 6 - flexible hours and days
- 4 - long waiting list
- 3 - timely delivery of service
- 2 - consistency of carers
- 2 - good communication with office
- 1 - enough time for visits
- 1 - weekend service
- 1 - more than 35 hours
- 1 - clear information and eligibility.

Examples are below, more examples can be found in Appendix 3.

> "The current service is focused on 2.5 hours per week - every week. This would be a waste for mum as she wouldn't be able to utilise it for the things she really needs support in."
>
> "I was offered 3 hours every Wednesday afternoon with no choice. From the literature it seems it is under discussion with the carer."
>
> "Information was overwhelming - I still have no complete understanding of what is offered and what is not offered."
>
> "Been on the waitlist for 9 plus years, which is really unfair and no use to a parent who needs it."

Conclusions

Those currently waiting for the service seem to have been waiting for longer than those that are currently receiving the service. 14 respondents had been waiting more than a year. People are not always clear exactly what the offer is and information about the service may lead them to believe it is more flexible than the reality. Unpaid carers were hoping for more flexibility in the service and some had already discovered this was not possible.

Respondents who are parent carers seem to have had more challenges getting a service. Their responses tended to give more detail about their circumstances and described difficulties getting social care assessments and waiting longer to get a service that met the needs of their cared for person and gave the required consistency and flexibility.

Unpaid carers that have finished using the Crossroads Care Surrey Carer Replacement Breaks service

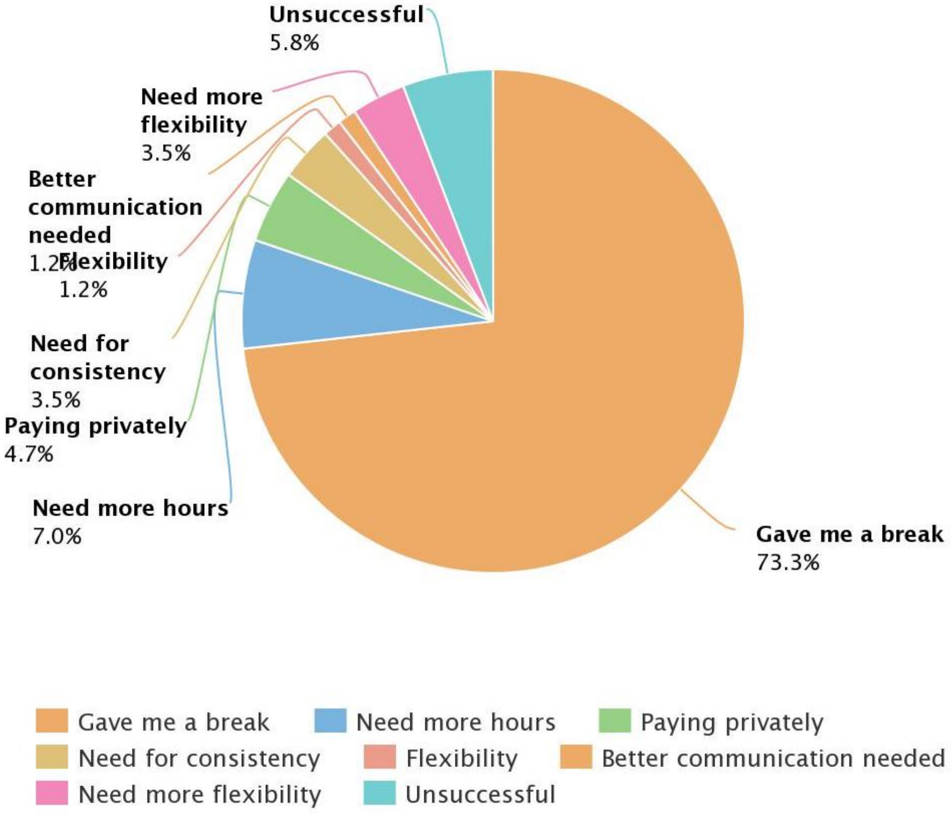
78 respondents identified themselves as having finished using the service. Because the introduction of Carer Replacement Breaks as a preventative service has been fairly recent, we asked respondents to confirm how long ago they had received the service. Out of 77 responses only 5 had received the service over 2 years ago.

How it met needs

77 respondents told us how they felt the service met their needs. Some comments had more than one theme within them so the percentages do not map precisely to the numbers of respondents. Although the question asked for what had worked, more than a quarter of comments were about what did not work. The results are summarised in figure 14 below.

- 63 comments confirmed the service succeeded in giving them a break
- 6 stated they needed more hours (the service needed to continue for longer)
- 5 said it had been unsuccessful.

Figure 14: How the service met carers needs who have now finished the service.



Number of comments per theme:

- 63 - gave me a break
- 6 - need more hours
- 5 - unsuccessful
- 4 - paying privately
- 3 - need more flexibility
- 3 - need for consistency
- 1 - flexibility
- 1 - better communication needed.

Examples are below, more examples can be found in Appendix 3.

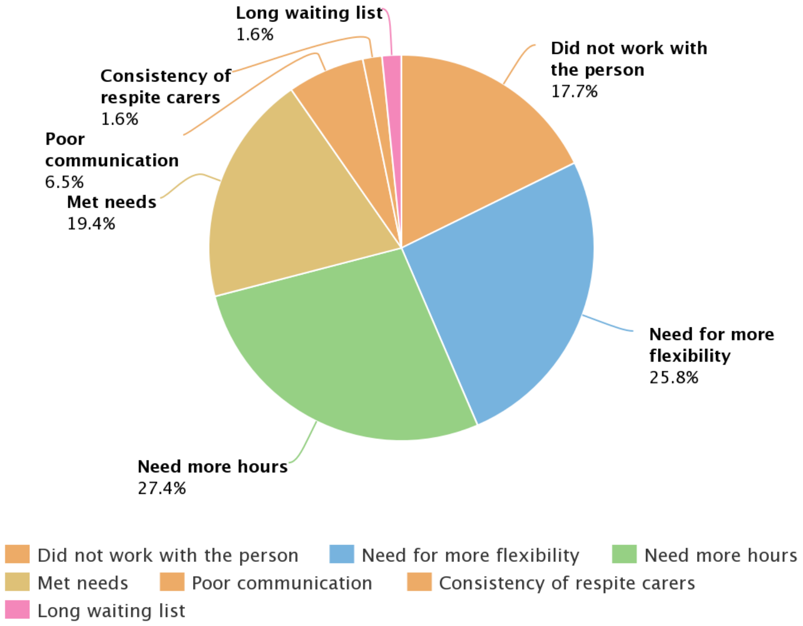
> "I was able to take some me time and time for myself. I also have health issues."
>
> "Crossroads enabled me to have a free afternoon for several weeks, which was invaluable. I was so appreciative to have this time to myself and the carers showed such kindness and respect. Thank you!"
>
> "Very helpful visit from the initial and follow-up assessors that came to visit."
>
> "Having a regular time slot each week was very helpful. We appreciated the efforts made to meet our need in 1 - changing the day to a Friday each week, and 2 - changing carer."
>
> "It helped a little had no idea it was so limited no one told me till it ended I was totally shocked."

How it didn't meet needs

62 respondents told us how the Carers Replacement Breaks service DIDN'T meet their needs. Some comments had more than one theme within them so the percentages do not map precisely to the numbers of respondents. Although we asked for things that didn't work, 12 comments state the service met their needs. Figure 15 on the next page summarises the results.

- 17 comments wanted more than 35 hours
- 16 comments wanted more flexibility in days and times, many mentioned the need for weekend and evening availability
- 11 comments stated the service didn't work for the person they cared for.

Figure 15: How the service didn't meet the needs of carers who had finished the service



Number of comments per theme:

- 17 - need more hours
- 16 - need for more flexibility
- 12 - met needs
- 11 - did not work with the person
- 4 - poor communication
- 1 - consistency of respite carers
- 1 - long waiting list.

Examples are below, more examples can be found in Appendix 3.

> "I was not very happy with the carer sent to be with my husband as he did not engage very well or show interest in anything that he might do with my husband during the times he was at our home. Each week I tried to think of things that they might do together, but the carer was not interested and spent a lot of time on his phone. I think 35 hours is not a very long spell for breaks and would appreciate if this could be repeated at some time in the future (with a different carer!)."

> "The visiting carers were different each week, and were unable to communicate with him. He became annoyed and upset and bored. I wanted someone to take him out for a walk or out in a car for a walk and a cup of tea but this didn't happen. I had to keep explaining to the visitor carers what to do and the situation broke down every time I tried to concentrate on what I was doing."

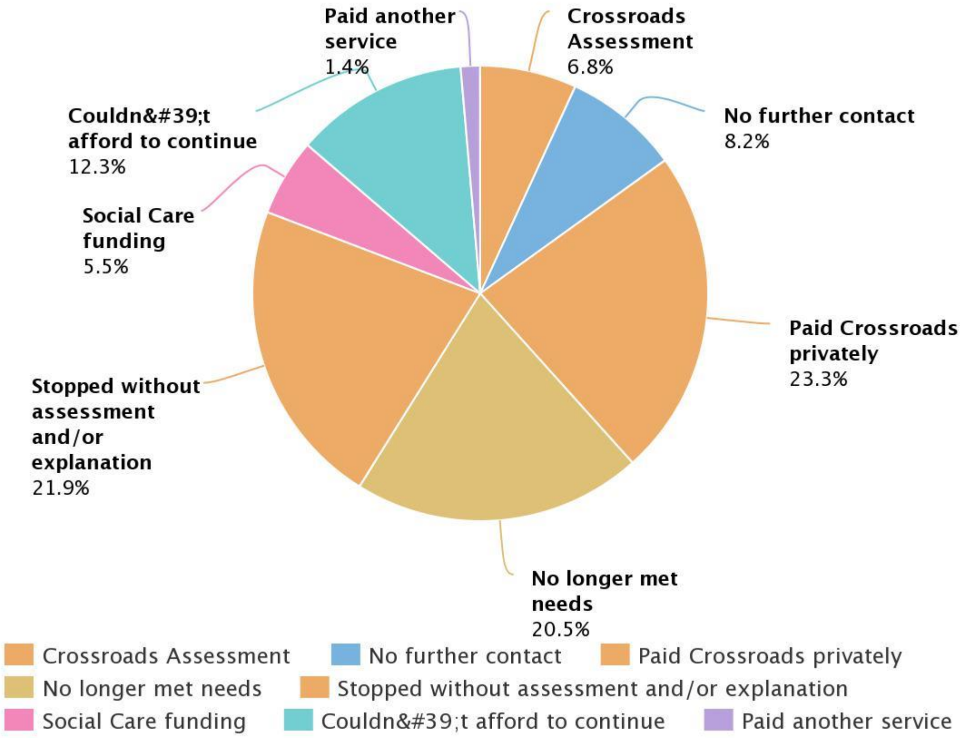
> "The rigid 9.30 a.m. or 2.30 p.m. slots whereas the cover would be nice over lunch period so that I can meet friends to eat. Also the 4 days' notice not to have a care worker seems rather unfair when my mother was suddenly taken ill and we cancelled immediately but paid for session anyway."

What happened when the service ended

75 carers responded to the question; 'When you came to the end of your 35 hours of Carer Replacement Breaks, what happened?' Many responses did not give enough detail to fully understand what did and did not take place, so themes have only been applied where it felt reasonable to do so. Figure 16 on the next page summarises the results.

- 17 comments said they decided to carry on the Crossroads Care Surrey service and pay privately (1 comment paid for another agency)
- 16 comments stated the service stopped without a satisfactory explanation or assessment
- 15 respondents' circumstances had changed so they no longer needed the service anyway
- 9 couldn't afford to continue and seemed to say they had no service
- 6 just lost contact with Crossroads Care Surrey
- 4 comments mentioned social care funding to continue having the service.

Figure 16: What happened when the service finished



Number of comments per theme:

- 17 - paid Crossroads privately
- 16 - stopped without assessment and/or explanation
- 15 - no longer met needs
- 9 - couldn't afford to continue
- 6 - no further contact
- 5 - Crossroads assessment
- 4 - social care funding
- 1 - paid another service.

Examples are below, more examples can be found in Appendix 3.

> "Just finished ...said no more available till next year... heard nothing since."
>
> "Was offered further care but would have to pay. I did not think that the rates offered were competitive and had not enjoyed the experience as much as I might as each time the carer came I worried about what my husband was going to do. I do not remember being offered further assessment for any more free ongoing breaks."
>
> "We continued to use the service, paying for it ourselves."
>
> "Just told you have used up your allocation. NO mention of being able to be reassessed!! Never knew this."
>
> "I only had a 2 hour session. It would clearly not meet my need, so the lady said I should get in touch again if I ever need 2 hours off each week. I thanked her and that was the end of it. Now I leave my husband, which is a risk, but I attach an alarm button around his neck."
>
> "I was left with no options."

Conclusions

It should be noted that a significant proportion of respondents felt the service had met their needs and were very appreciative. There were examples where carers found it a useful way to try respite at home for free before deciding on it becoming permanent. This was most useful for people who intended to pay privately, carers who would need social services funding would need to be assessed much earlier to ensure continuation.

Understanding of what the service offered was inconsistent, with people not fully understanding the 35 hour allocation until their first meeting with Crossroads Care Surrey. Given that earlier in this report we highlight the valuable role other professionals play in directing carers to the service, they should be a focus for up to date and accurate information.

Key themes where the service did not meet needs were:

- Carers wanted more than 35 hours.
- Carers wanted more flexibility in days and times, many mentioned the need for weekend and evening availability.
- Concerns over the suitability of the Crossroads Care Surrey staff for their cared for person, particularly if they had complex needs such as autism and dementia.
- A significant number of carers continued with the service by paying privately for it.
- There were a number of carers who did not continue with the service because they did not or could not pay for it privately. They mentioned this has left them in a challenging situation.
- Few respondents received social services funding to continue the service.

There seemed to be significant challenges around the service ending. There were lots of comments about uncertainty of what would happen when the 35 hours came to an end. Carers did not seem to have information about all the options available to them.

Assessments and decisions seem to happen quite late in the process so either there was a lot of anxiety or the service continued until a decision was reached.

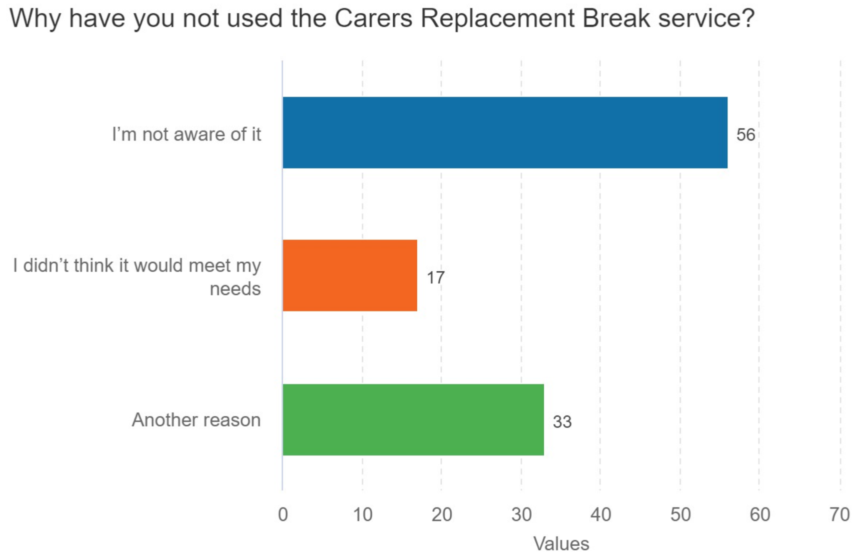
Unpaid carers who haven’t heard of the Crossroads Care Surrey Carer Replacement Breaks service or have chosen not to use the service

Reasons why carers have not used the service

109 respondents identified themselves as an unpaid carer who either hadn’t heard about the Carers Replacement Breaks service or had decided not to use it.

We asked them why they had not used the service, 106 responded and are summarised in figure 17 below.

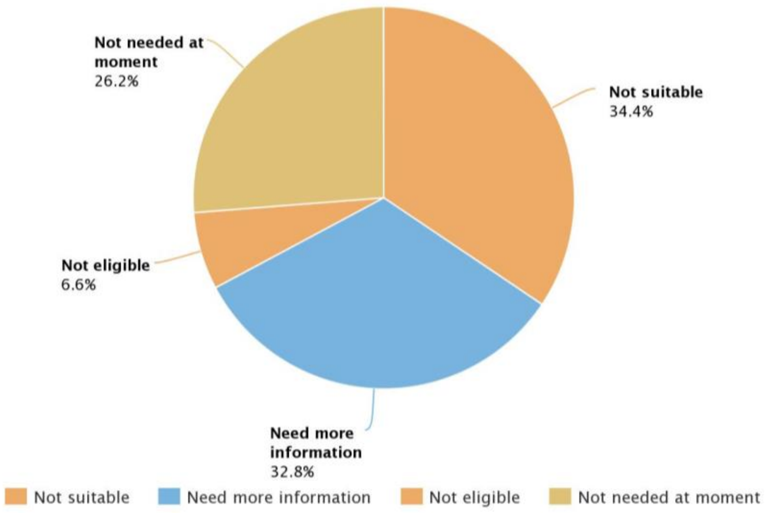
Figure 17: Reasons why unpaid carers have not used the service



We asked carers to tell us more. 65 carers responded and the results are summarised in figure 18 below.

- 21 respondents felt the service was not suitable and could not meet their needs or the person they cared for did not want respite at home
- 20 carers needed more information to understand the offer
- 16 felt their situation did not require respite at that time
- 4 people had been told or believed they were not eligible.

Figure 18: Why carers have not used the service



Number of comments per theme:

- 21 - not suitable
- 20 - need more information
- 16 - not needed at moment
- 4 - not eligible.

Examples are below, more examples can be found in Appendix 3.

> "I have heard of Crossroads but not in relation to young autistic adults (I am a carer to one). I have always associated Crossroads with older people. None of the professionals I speak to have ever mentioned this service to me."
>
> "This survey is the first time I have heard of this. Depending on what is offered, it may be of use to me but without any information, I cannot make an informed decision."
>
> "I reached out at breaking point and was denied access to this service."
>
> "I need longer spells of respite than was offered and in a more adhoc way."
>
> "I was told funding was being cut and staff reduced so I organised some private help."
>
> "I was kindly offered a couple of hours a week but it would be harder to explain about me going out than it was worth it currently."

Conclusions

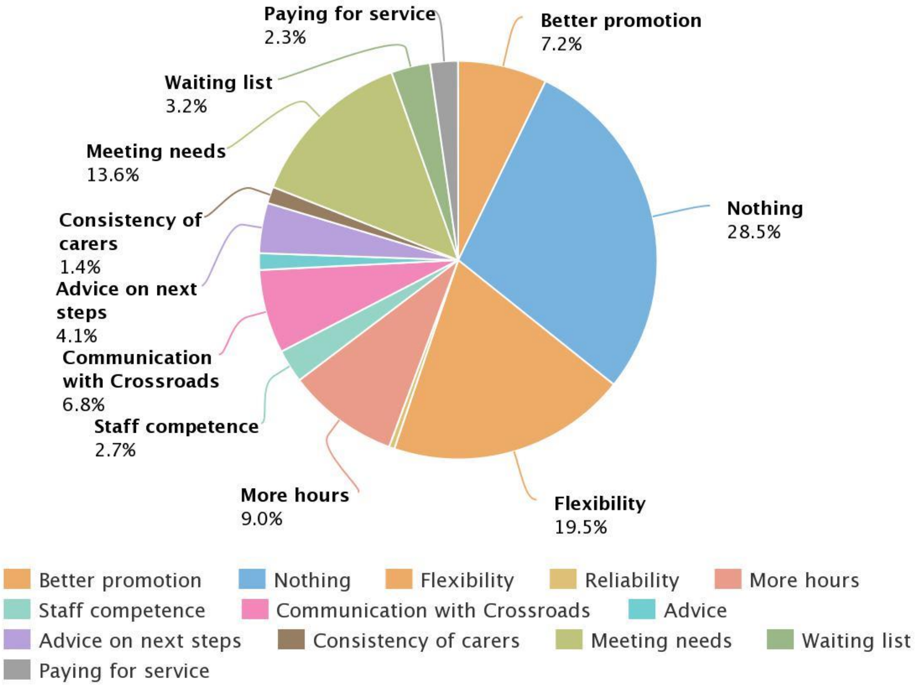
Over a third of respondents who had not used the service had not done so because they felt the service would not be suitable for their circumstances.

There is a clear need for better promotion of the service, and to ensure the information clarifies what is provided, level of flexibility, what needs can be met and who is eligible. As a quarter of respondents have not used the service because things do not feel ‘bad’ enough, information should include what other respite is available and where Carers Replacement Breaks fits. The preventative nature of the service needs to be communicated more clearly.

What do unpaid carers think the Carers Replacement Breaks service should do differently?

236 respondents gave their views. A small amount stated they could not comment and so could not be included, some responses covered more than one theme. The analysis in figure 19 below reports the number of times different themes were raised in responses.

Figure 19: What do unpaid carers think the Carers Replacement Breaks service should do differently?



Number of comments per theme:

- 63 - nothing
- 43 - flexibility
- 30 - meeting needs
- 20 - more hours
- 16 - better promotion
- 15 - communication with crossroads
- 9 - advice on next steps
- 7 - waiting list
- 6 - staff competence 5 paying for service
- 3 - consistency of carers
- 3 - advice
- 1 - reliability.

Responses can be grouped into themes. Examples are below, more examples can be found in Appendix 3.

Nothing needs to change

There were 63 comments that the service works well and nothing needs to change. Some responses provided more detail:

> "The service is fantastic."
>
> "I cannot speak highly enough of the carers we have had."
>
> "I am very pleased with the current carer. She is very friendly and patient and kind."

Flexibility

This referred to the need for the service to be offered at different times - examples included:

- Having the service at weekends
- Having the service in the evenings
- Being able to have the 35 hours in whole days rather than 3.5 hour visits
- Having the service for different frequencies rather than once a week.

There were 43 comments and most of them were under the impression this was not possible, a small number of respondents indicated they had been led to believe the service could be more flexible, but then this hadn't happened.

There were a small number of comments where the service had to change at the last minute, e.g. due to staff sickness. The comments indicated that there was a frustration that unpaid carers were expected to be flexible in these circumstances when the service wasn't being as flexible as they expected. One comment raised the concern that when they cancelled at late notice due to the cared for person being unwell, they still had to pay for the visit.

> "It would be more beneficial to have say 2 days off with an overnight stay to help with my health and wellbeing."
>
> "It wasn't made clear to me that my 35 hours could be taken in any way other than weekly half days."
>
> "I would have liked to have known that the 35 hours can be spread out over 6 months rather than taken in 10 consecutive weeks of 3.5 hours per week. I would probably still have taken a weekly break, but the information would have been good."

Meeting needs

This was a key issue, highlighted by 30 respondents and echoed in other themes. A number of areas were identified:

- Assessments of the unpaid carers need to be consistent and person centred, recognising their need to continue with their other responsibilities and interests.
- Assessments of the cared for person need to have an understanding of the impact of their condition. This was particularly raised by respondents who care for people with dementia, mental ill health and autism.
- The need to return to the previous service where respite care was ongoing.
- The current service not undertaking certain activities, such as taking the cared for person out in a car.
- Perceived differences between what is available to you when paying privately and what is available if you have social services funding.
- The need for more options for respite, such as residential.

> "I think there is a general tendency (not just here) to forget that the elderly have the same desire for interaction and connection as everyone else."
>
> "The carers have struggled to cope with the complex needs of my wife."
>
> "I understand that resources are limited and have to be shared but I think further individual assessments and discussions about mental and physical needs may help to allocate staff accordingly."
>
> "Train the carers how to handle different types of dementia. Ensure there is continuity. Carers need to be mature and confident."
>
> "There appears to be no joined up thinking between social services and Crossroads. Because we are self funding social services don't keep us on their radar and Crossroads appear also to fail in following up with their cases."
>
> "Carers could help with gardening and assistance with help to take the person you care for for walks and activities."

Increase hours

This referred to the 35 hours of service currently available. 20 comments referred to this and all of them suggested the number of hours should be increased.

> "Care in the evening to allow the carer top go to the theatre, out for dinner, attend a club/hobby. A regular pattern of replacement care not just the 35 hours."

> "I don't think this should be a one-off help, carers continuously work and have their ward in their focus, and they do this for years, not just once a year."

Better promotion

16 responses felt the service should be better promoted. For some, finding out about the survey was the first time they had heard of the service. We received a number of calls from people wanting more information and to be referred. These were passed to Crossroads Care Surrey or Action for Carers where appropriate.

Some respondents felt information should be more proactive, for example when a GP registers someone as a carer, this should trigger a contact from an organisation like Action for Carers.

Advice on next steps

9 respondents indicated it had not been made clear to them what would happen at the end of the 35 hours of respite care. Indications were that some respondents had stopped having any respite because they were not aware of being able to have an assessment to continue or to elect to self-fund it.

> "If they can't provide the care give you the option to source it yourself."
>
> "I would have been happy to fund the breaks if this could have meant a continuing service."
>
> "Properly assess a person already receiving care before any decision is made as to whether to continue the service."
>
> "We had no follow up assessment."
>
> "Social services took over 2 months to come and confirm diagnosis, was lovely when they arrived. Action for Carers gave phone numbers to ring and helped with Blue Badge, will talk to Admiral Nurses re future care needs for husband."

Waiting list for the service

There were 7 comments that the waiting time for the service was too long.

> "Carers should not have to wait so long to access help."
>
> "Just wish I could have had this service sooner. It took a long time to get someone."
>
> "Provide regular updates on waiting times."

Staff skills

There were 6 comments with concerns about how well members of staff went about the respite care. Some comments were about Crossroads Care Surrey carers not seeming to have the skills to engage with people with more complex needs such as dementia.

Paying for the service

5 comments mentioned the challenge of having to pay for the service to continue after the 35 hours had finished.

> "I feel the amount we have to pay for 3.5 hours is extremely expensive."
>
> "It needs to be available for longer, the amount of money I'm having to spend is really difficult."
>
> "The hourly rate is quite expensive so if this was cheaper, we could have more hours per week."

Advice

3 comments cited the need for more general advice and guidance.

> "Provide direct guidance of where support can be obtained that match my circumstances."
>
> "Offering sessions that carers can attend when they have their respite sessions."
>
> "The assessment took a long time and was thorough, were going to redo whole process if he came out of hospital, felt protracted although carers were nice. Was going to have to wait 12 weeks for carer to start. Felt that you were locked in to using Crossroads and may not have opportunity to look at other options for respite at home. Do we need more agencies offering the same service to try to meet needs. Historically I have used Claridge House on a reduced rate negotiated by Action for Carers for a couple of nights, but even that wasn't really long enough although it was very good. It was very challenging to get information, didn't feel supported except by Action for Carers, didn't know about lots of useful services like community matrons. No joined up thinking. Struggled to even get GP to come out. Feel carers aren't supported and not enough to help carer."

Consistency of carers

3 respondents mentioned the need for the same carer each time, or at least as few different carers as possible. It also echoed the need for staff to be competent and that the needs of the person receiving the respite to be met.

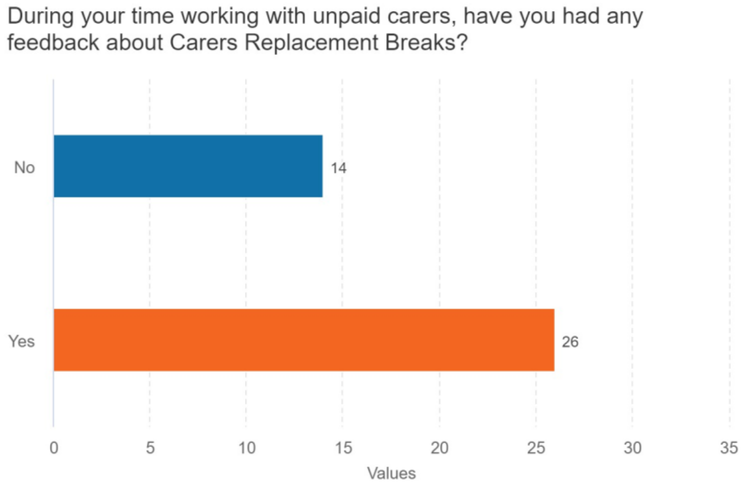
> "I also struggle if the carer gets changed at the last minute for someone I haven't met before. I do ideally like to have the first couple of sessions to get to know the person in my home."
>
> "At the time, we would've been happy, accepting fewer hours, but over a longer period, with a view that should it work, we might consider paying privately for it to continue. For people with dementia, it is important that the relationship is built up. It took my mum several months to adapt to the carer we now pay for privately. She actually takes both mum and dad out together which gives my dad a break in that, although still with my mum, he has someone different to talk to and different places to go to each week. This flexible approach has been important to us."
>
> "Make sure carers are consistent and that they are trained and follow the care plan and wishes of the carer and cared for person."

Staff that work with unpaid carers

Feedback on the service from unpaid carers

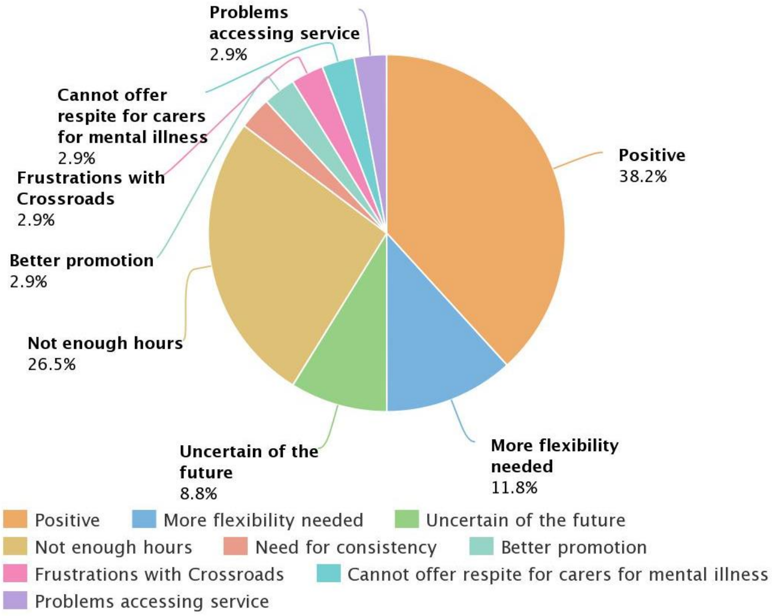
We asked staff about feedback they had had from unpaid carers about the service. 41 respondents identified themselves as staff, 40 responded about the feedback they had had as shown in figure 20 below.

Figure 20: feedback staff had had from unpaid carers about the service



27 Respondents gave us more detail about the feedback they have had from unpaid carers, s detailed in figure 21 below:

Figure 21: What feedback staff have had about the service



Number of comments per theme:

- 13 - positive
- 9 - not enough hours
- 4 - more flexibility needed
- 3 - uncertain of the future
- 1 - need for consistency
- 1 - better promotion
- 1 - frustrations with crossroads
- 1 - cannot offer respite for carers for mental illness
- 1 - problems accessing service.

Examples are below, more examples can be found in Appendix 3.

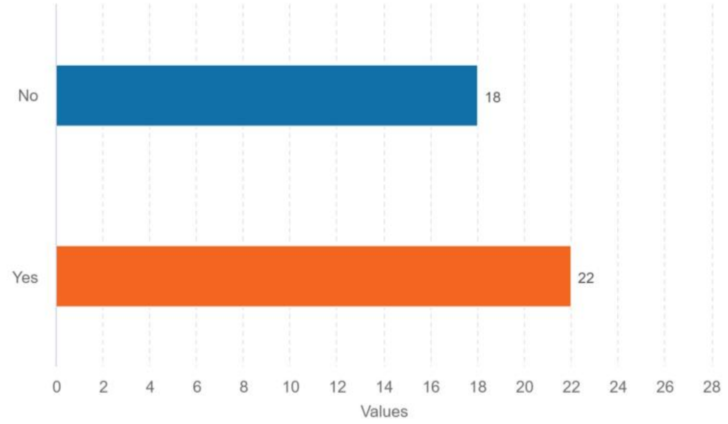
> "Very much appreciated in most cases essential."
>
> "Current service is not working and does not meet all Carers needs for a break. Carers would like to have a variety of ways to take a break and flexibility to take a break when they need. Some need this regularly at set times, some need this ad hoc and some need to cover holidays."
>
> "I have spoken to a number of carers who were without exception distressed and upset that their Crossroads service was coming to an end. Particularly those caring for someone with dementia."

> "When I explained the rationale for the change in service several carers said that if they had only been offered 35 hours at the start of their service they would have declined. It takes time and trust for people with dementia (and their carers who need to feel reassured to leave them) to feel comfortable with a care worker and by the time a trusting relationship had been formed, the service would end, leaving both the person being cared for and the carer distressed."
>
> "Carers of people with dementia have reported that it's not worth having the 35 hours of support from Crossroads because by the time the care worker has built up a relationship with the cared for person, the service ends. It can be distressing for both the carer and the cared for person."

Impact on other carers services

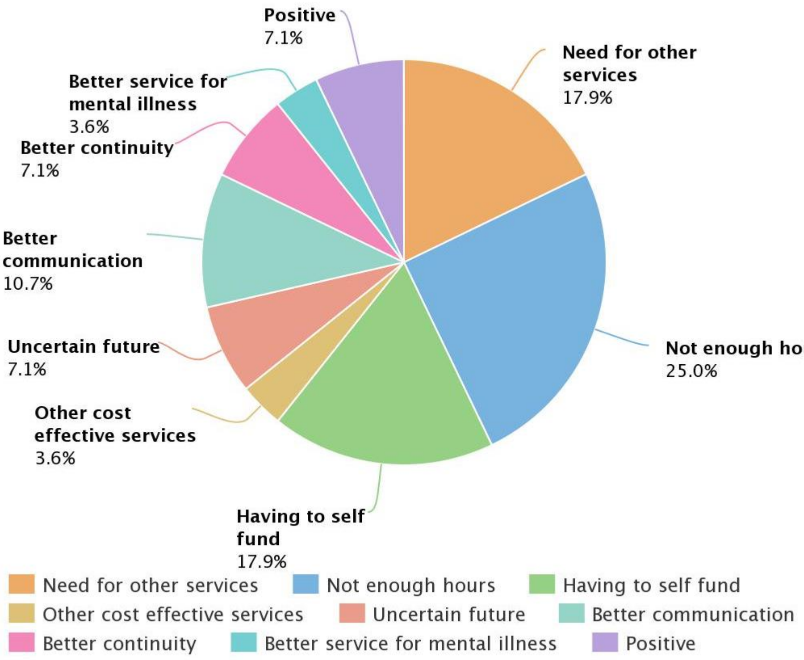
40 staff respondents told us whether the Carers Replacement Breaks offer had had any impact on their own service, as shown in figure 22 below.

Figure 22: Has the offer had any impact on your service?



23 respondents gave additional details on the impact which are summarised in figure 23. Impacts were predominantly negative.

Figure 23: Impacts on other services



Number of comments per theme:

- 7 - not enough hours
- 5 - having to self-fund
- 5 - need for other services
- 3 - better communication
- 2 - better continuity
- 2 - uncertain future
- 2 - positive
- 1 - other cost effective services
- 1 - better service for mental illness.

Examples are below, more examples can be found in Appendix 3.

> "Carers are feeling low in mood and express their displeasure more often. The cared for person is often having to pay for a service themselves to allow their carer a break. Carers often don't feel comfortable about this."
>
> "It takes time to build a relationship. It takes time for a spouse/partner to trust us with their loved one especially if they have been the only person caring for them for years the time restraint of 35 hours does nothing to help this as it all seems so rushed now."
>
> "We have had to deal with a lot of unhappy carers - some have been very distressed by the changes."

> “I tend not to refer people now, if people are in a position to self fund I will direct them to private agencies for this type of support. If people cannot self fund then I would direct them to Adult Social Care but in my experience they are more likely to fund personal care than companionship/supervision which is what many people with dementia need. Often unpaid Carers need support in the ‘early stages’ when the person with dementia may have little insight and understanding about why their Carer needs a break, however Adult Social Care tend in my experience to think that someone has less need when ‘they are only in the early stages’. This means that many Carers are now left with no support options whatsoever.”

How the Carers Replacement Breaks service could be changed or enhanced to make a positive difference to carers’ lives

We asked staff for ideas on how the Carers Replacement Breaks service could be changed or enhanced to make a positive difference to carers’ lives. 27 people responded and the comments are grouped into themes below. These themes reflect themes arising earlier in this report. Examples are below, more examples can be found in Appendix 3.

Coordination and planning

> “Tailored to specific needs.
> Regular familiar Carer Support Workers where possible providing continuity of care.
> Flexible time slots.”

> “1. To have a variety of ways a Carer can take a break.
> 2. To have a Carers Direct payment for a fixed amount to use in the way they choose to give them choice and control.
> 3. To have a list of providers that can offer a few hours, half a day, all day or overnight or ad hoc replacement care.
> 4. To have providers who specialise in ASD, Mental Health, Dementia, Challenging behaviours, young adults with disabilities, specialists who can support people with sensory impairments, offer services where English is not first language.”

> “Engage with other providers who can offer the above.”

> “More dementia day care facilities - only one I know of is in Haslemere and they are often oversubscribed and hard to reach for many carers.”

> “Transport for carers is essential - more thought needs to go into this.”

Meeting needs

> “For carers of people with mental illness a service which offers replacement care would be invaluable and equitable.

The type of replacement care service ideally would look like:

- Emotional replacement care – i.e. a trained person to be booked for a day / half day/ few hours to sit with the cared-for to supervise any suicidal risk.
- Emotional replacement care - needs to offer staff who are skilled and trained in managing cared-for who has unusual behaviours e.g. delusions, responding to unseen stimuli, bi-polar manic garrulous state, or catatonic depression.
- Emotional replacement care- for the trained person to be the "point of contact" for the cared-for to call if distressed, needing emotional reassurance, social contact, motivational support. To be available to meet with the cared-for at a time of crisis.
- Emotional replacement care- needs to be consistent so that the cared-for person knows who they are and doesn't get a random person supporting them. Time needs to be spent building rapport and trust to enable replacement care to work."

"Just to keep the continuity of care as much as possible…"

Flexibility

"By providing more flexibility. Offering all service users weekend breaks."

"Be more flexible with the 35 hours."

"Carer breaks to be more flexible - ongoing support to be provided by the same person/s (as regularly as is possible) to give reassurance to the carer and cared for person."

Increase hours

"From my experience, 35 hours is not enough for the carers. They need continued support to be able to carry on caring."

"35 hours not adequate for most carers - this to be increased."

"Need more than 35 hours."

"I don't understand the 35 hour limit. You give people support for 10 weeks and then we disappear. How does this help them? They need a regular break every week to be of any benefit."

Increase choice

"Think about using other companies/providers."

"There needs to be more variety, especially for carers of people with dementia."

"Prior to the pandemic, there were far more options for day care - many of which haven't re-opened."

"There need to be more providers who can manage challenging behaviour - often if they can't the person is returned to their carer. Carers often wonder how they are expected to manage when professionals can't. This has lead to carer breakdowns in a number of cases I'm aware of and resulted in the cared for person being permanently placed. With the right support and frequency of breaks, this could be avoided."

"Low cost options/subsidised breaks for carers would enable them to take a meaningful break. We know that carers are often living on low incomes and do not prioritise spending money on themselves. To be supported to take a weekend away would make a huge difference. Carers could be supported to utilise charities like Carefree. Perhaps a carer direct payment could be agreed once a year to support with the cost of the admin fee and transport?"

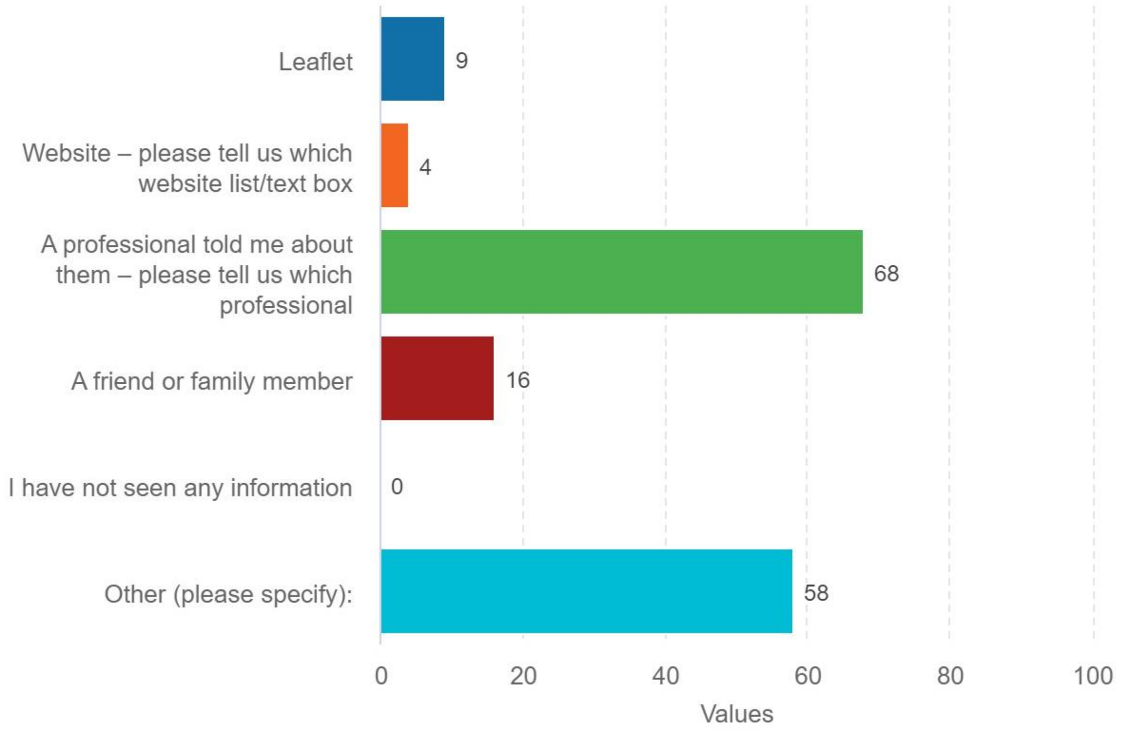
Appendices

Appendix 1 How did you find out about the service?

Unpaid carers currently using the Crossroads Care Surrey Carer Replacement Breaks service

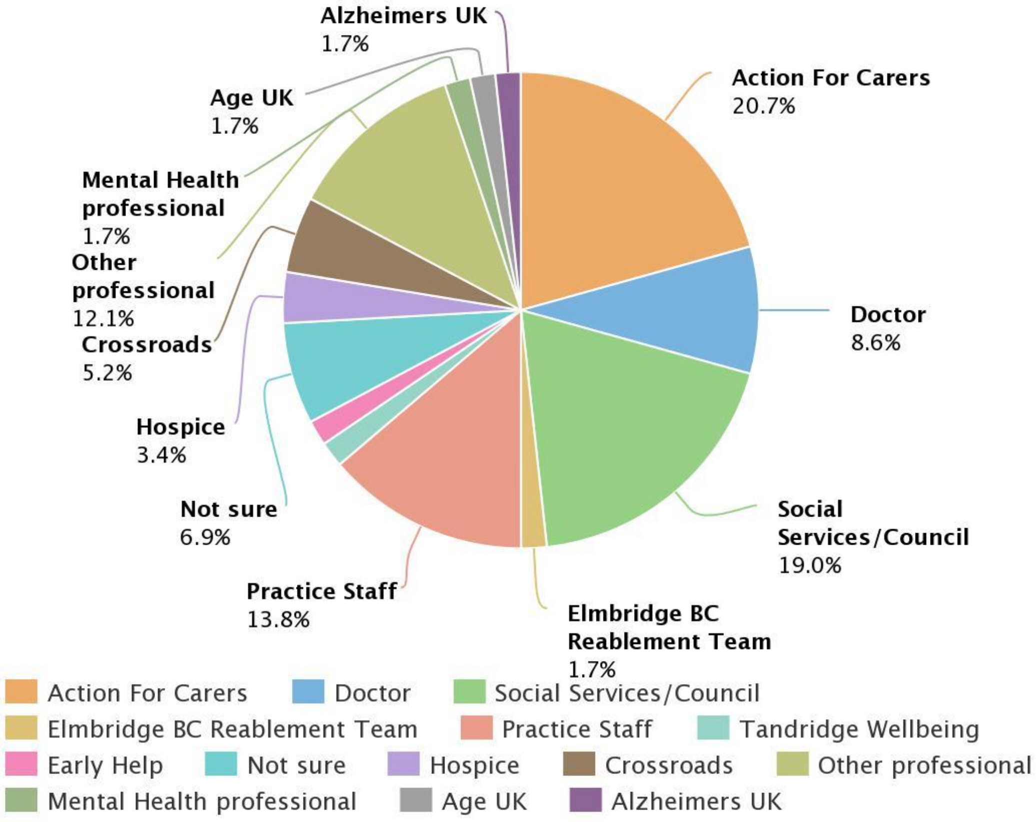
We wanted to understand how people found out about the service. For unpaid carers currently using the Crossroads Care Surrey Carer Replacement Breaks service, Figure 24 shows how they found out about the service.

Figure 24: How did unpaid carers currently receiving the service find out about it?



Where 58 responded 'other', figure 25 breaks down where they had heard about the service:

Figure 25: Other places unpaid carers currently receiving the service had found out about it



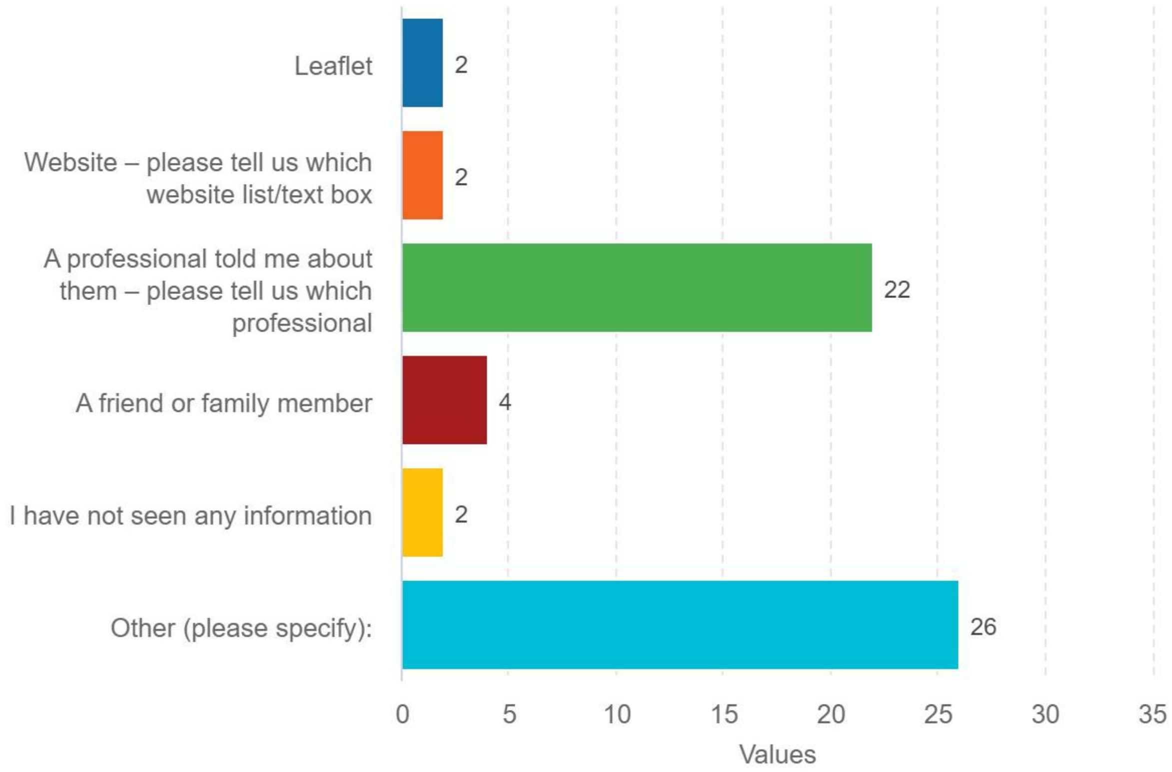
Number of comments per theme:

- 12 - Action for Carers
- 11 - Social Services/Council
- 8 - Practice staff
- 7 - Other professional
- 5 - Doctor
- 4 - not sure
- 3 - Crossroads
- 2 - Hospice
- 1 - Elmbridge BC Reablement Team
- 1 - Tandridge Wellbeing
- 1 - Early Help
- 1 - Mental health professional
- 1 Age UK
- 1 Alzheimer's UK.

Unpaid carers on the waiting list to receive Crossroads Care Surrey Carer Replacement Breaks service

For unpaid carers on the waiting list to receive Crossroads Care Surrey Carer Replacement Breaks service, figure 26 below breaks down the ways they heard about the service.

Figure 26: How unpaid carers on the waiting list for the service found out about it



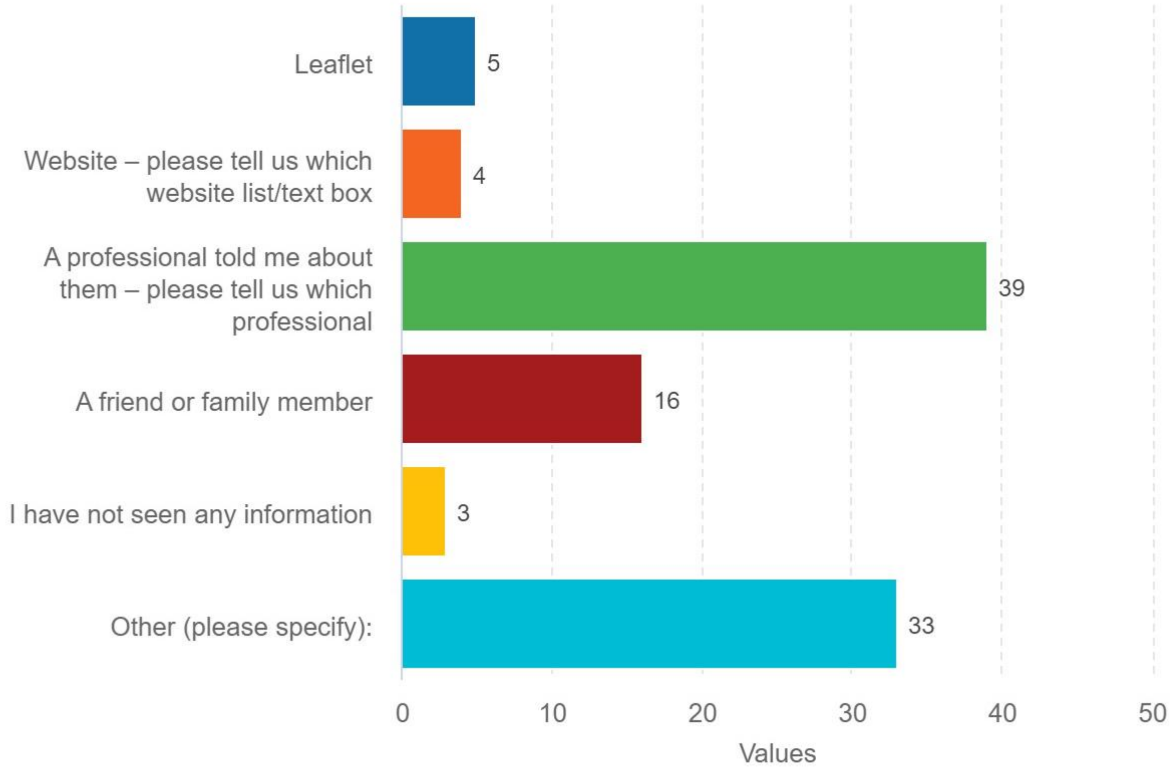
For those that said 'other' this broke down into:

- 7 had Crossroads Care Surrey previously
- 3 Action for Carers
- 2 NHS
- 2 Council
- 2 can't remember
- 1 CMHT Nurse
- 1 West Sussex Carers Group
- 1 Dementia Navigator
- 1 another carer
- 1 GP
- 1 Internet search
- 1 Social Worker
- 1 email.

Unpaid carers who have finished using the Crossroads Care Surrey Carer Replacement Breaks service

For unpaid carers who have finished using the Crossroads Care Surrey Carer Replacement Breaks service, figure 27 shows how they found out about it:

Figure 27: How unpaid carers who have finished using the service found out about it



The 33 that chose 'other' broke down like this:

- 6 had Crossroads Care Surrey previously
- 4 Social services
- 3 Action for Carers
- 2 Hospital consultant
- 2 Council
- 2 can't remember
- 2 GP practice staff
- 2 Dementia Navigators
- 1 East Surrey Hospital
- 1 Dementia Connect
- 1 Frimley Park Hospital
- 1 Dementia Support
- 1 another carer
- 1 Rapid Response Team
- 1 Walton Community Hub

- 1 leaflet
- 1 Caterham Hospital
- 1 internet search.

Appendix 2 Information about respondents

The following figures provide information about the respondents.

Figure 28: How long have you been a carer?

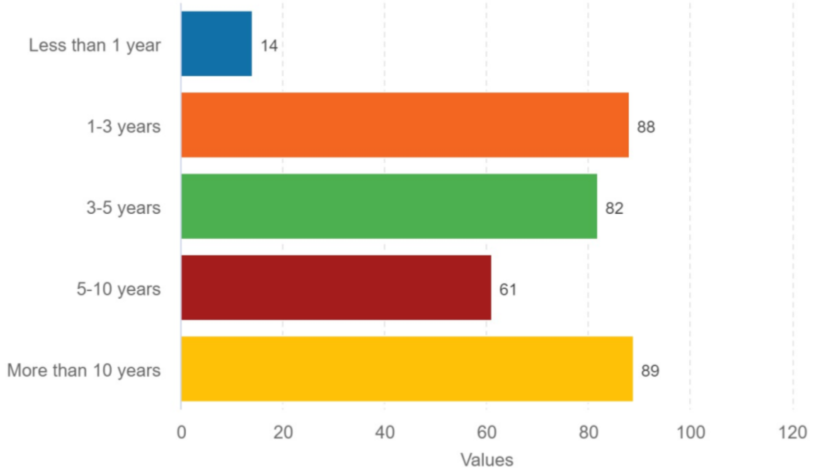


Figure 29: What are the main needs of the person you care for?

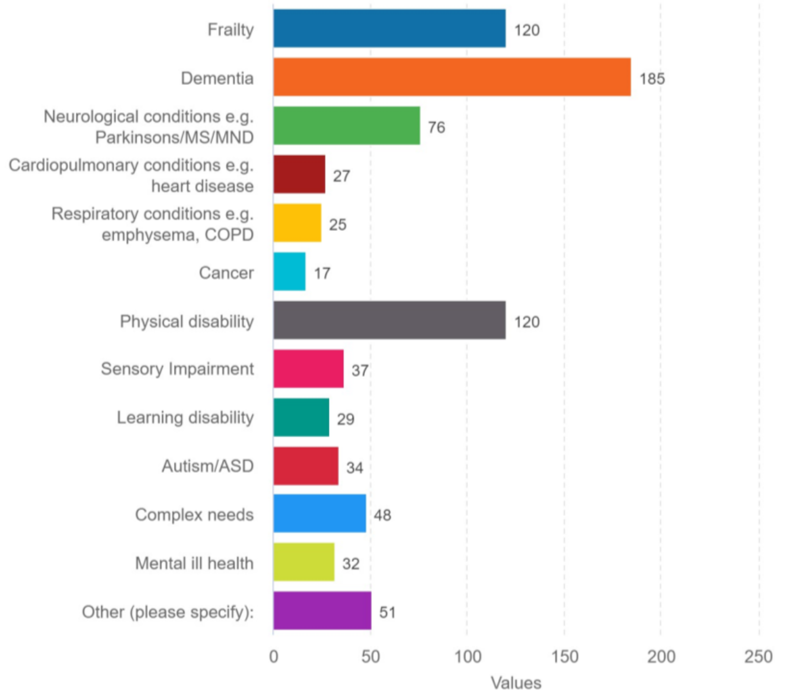


Figure 30: Please tell us your age group

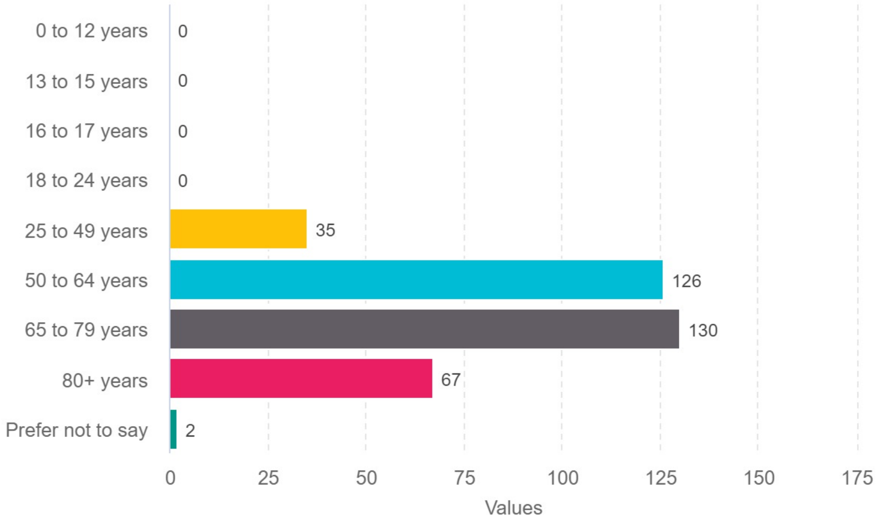


Figure 31: Please tell us your gender

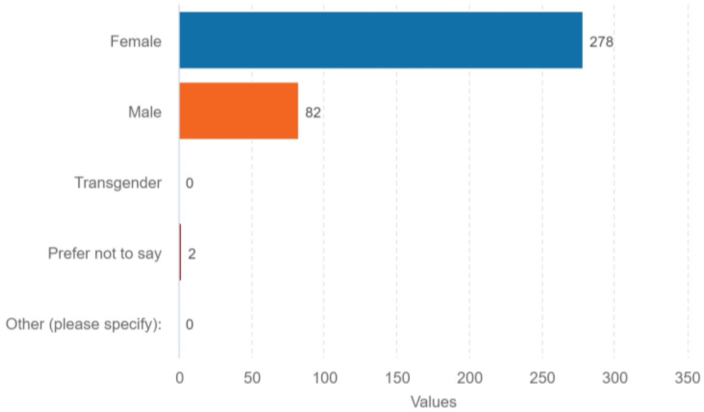


Figure 32: Pick the area that best describes where you live

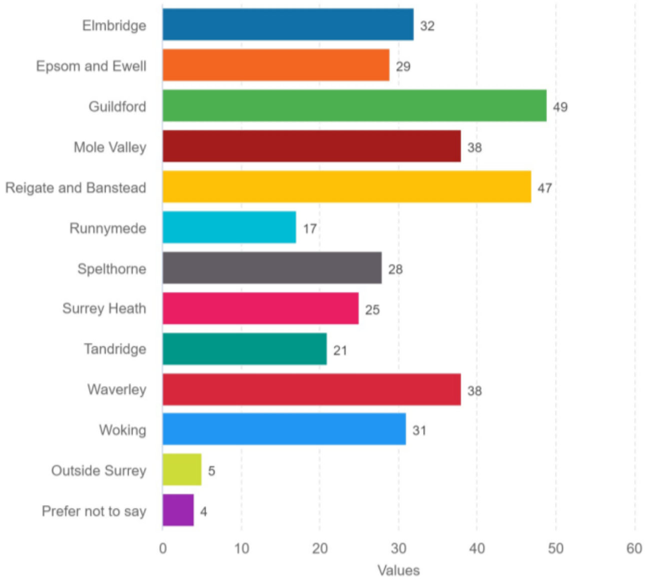


Figure 33: Please tell us which ethnicity you identify as

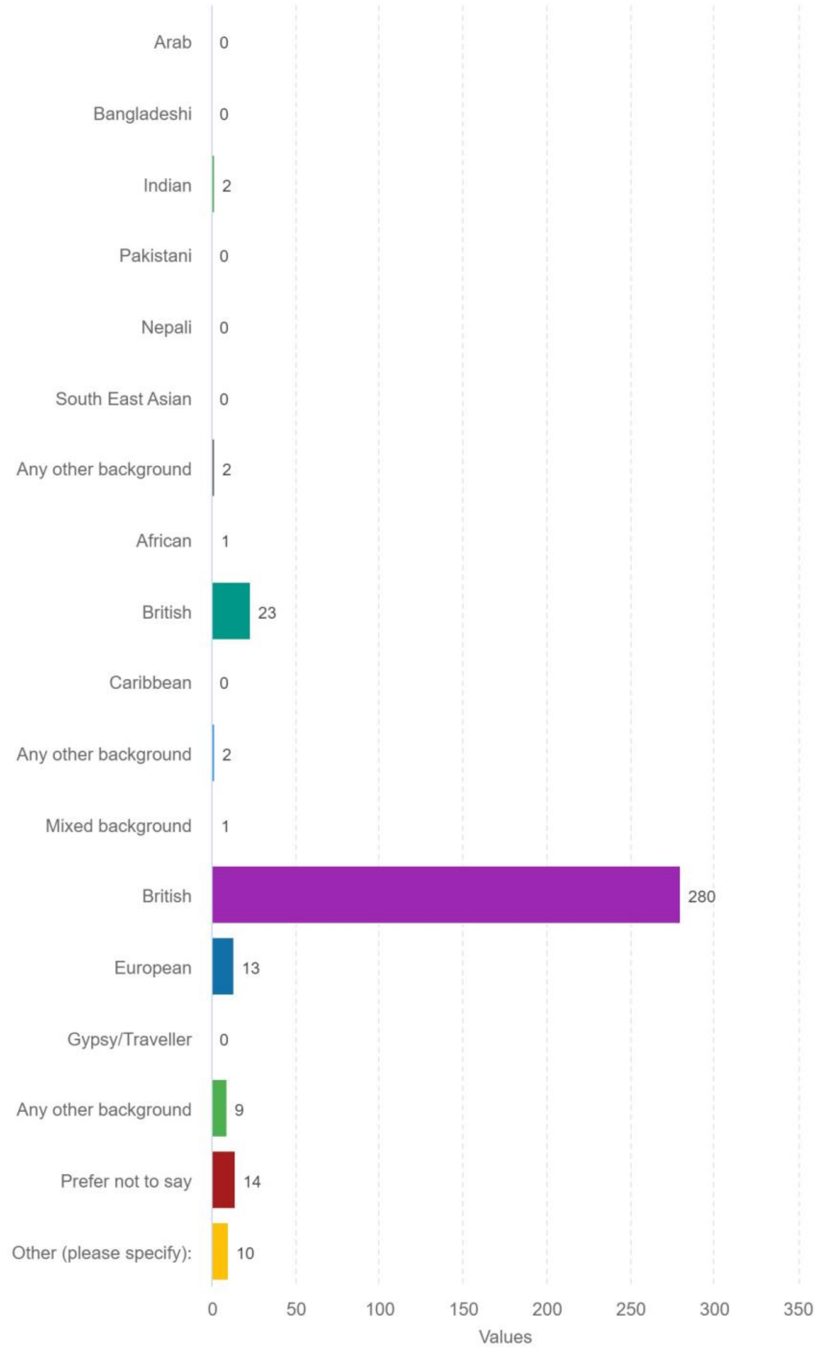


Figure 34: Do you have a disability?

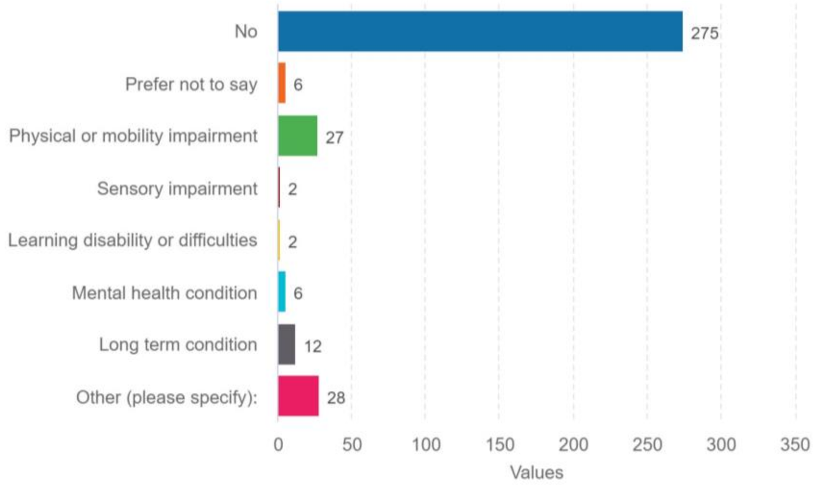
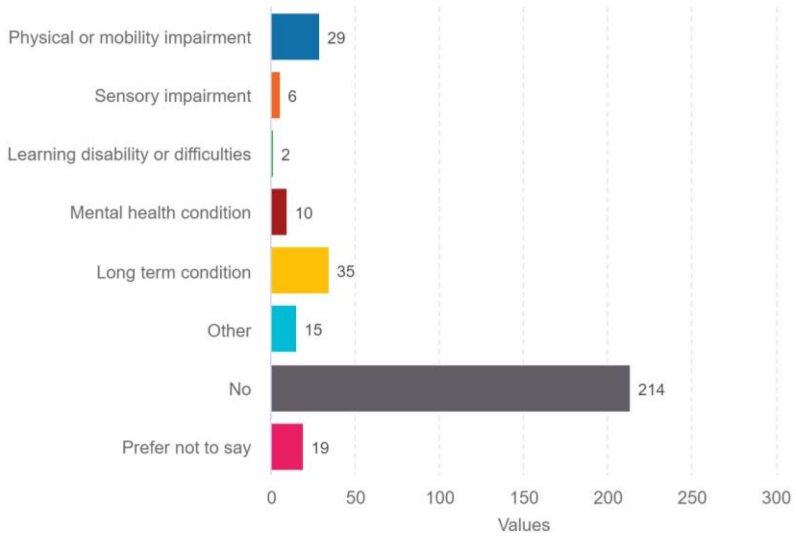


Figure 35: Do you have a long term condition?



Appendix 3 Fuller quotes from respondents

Unpaid carers currently receiving the service

How it meets need

“A morning off a week from my caring role revitalises & helps immensely.”

“If it wasn’t for Crossroads my husband and I would very rarely be able to leave the house together. We’ve been able to attend medical appointments, see friends, relax with a coffee and visit garden centres. Before Crossroads I was rarely able to leave the house at all and I developed severe vitamin D deficiency as a result (though this is now managed with medication). I am the main carer for my 98 year old bed bound mother. It takes the pressure off me for a while and it’s wonderful knowing that she can engage with someone other than me in such an enjoyable way.”

“This is a life-line where I can leave the house feeling easy and know I’m leaving my husband in good company.”

“I so appreciate the service I receive from Crossroads, the carers are kind and professional and I am at ease leaving them with my husband when necessary. My husband has Alzheimer’s and various health issues and I am finding life looking after him very challenging and welcome the friendly face and someone to talk to each week. We do not have family or friends nearby so feel very isolated as now do not have a car as my husband was the driver in the family.”

“Sometimes the Crossroads carer is the only person I have to talk to all week.”

“Allows my partner to work extra hours at work to build up being able to take time off to help with hospital appointments especially those up London without us losing too much money. It gives me a chance to get certain housework done as I know my child is safe.”

“My wife has dementia and the carer comes in 3.5 hours per week, they are able to do everything my wife needs and I can go out and do the shopping etc. I’m very pleased with our carer from Crossroads.”

“Good referral process from mental health team.”

“Just met the carer this week, very happy with them at that initial meeting.”

“Very thorough assessment, good match of carer to needs.”

“It is such a relief to be able to have a few hours rest knowing that my husband will be looked after. I care for him 24/7 and sometimes feel totally exhausted and overwhelmed.”

“My mother cannot be left alone - as determined by her psychiatrist - I am her only carer. She is very high needs, (Rockwood 7) and does not like to go out. The 3.5 hours a week that I have allow me to go out and collect prescriptions and do some food shopping etc. Also as I am with her constantly, it does give me some much needed respite once a week.”

“Just gives me a break from my husband who has mixed dementia, and mobility problems, prone to falling in the past, and I can go out, knowing that he is well cared for in my absence.”

“This service has meant that we have been able to spend time with our other daughter, providing support for her at an important time in her life. It has also provided time to spend on our relationship which has been neglected over the years as a carer.”

“Very well. I could not do without it. I feel the sitters are totally trustworthy. They are on time and I rely on them for my appointments when they can be made on the days when sitters are due.”

“The quality of the service is excellent. having the same experienced, properly trained carer who understands my disabled autistic young son and knows the family is a huge support to all of us.”

“My son is currently unemployed and has ASD/ADHD he finds is difficult to go to places like the gym on his own I was taking him myself but it was proving stressful for both of us and I felt overwhelmed by my caring role at this time.”

“Having a support worker from Crossroads has been very beneficial to me as a carer and my son too.”

“It has reduced my stress and stopped me worrying so much about my son just sitting in his room alone while I’m at work.”

“Having the support work has worked well and I’m hoping to carry on using Crossroads once the 35 hours have ended but we can’t do this without the support of social services and my son is still waiting to be assessed by the Surrey’s transition team.”

“It helps to take the strain from myself and my dad who take it in turns to supervise mum (with dementia). It was difficult to manage as I work full time and dad has his own care needs.”

“As I am unable to leave my husband on his own other than for a very short period of time it means that I am able to attend my once a week art class, otherwise I don’t go out and have to do all my shopping online.”

“Enables me to have stress free time, knowing that my husband is safe and well cared for.”

“Very happy with carer, does speech therapy exercises with husband, helps manage anxiety, will take out for short walks.”

“It enables me to join a walking group and attend a choir and visit friends.”

“Being a carer is just a hard slog most of the time - it is nice to be recognised and to receive some financial assistance to do something nice, just for you for a change.”

“It gives me time to myself to just be me and sometimes to meet friends. This enables me to continue being patient and reduces my stress level. Also the carer has formed a good relationship with my wife so I can go out with complete confidence in her, this enables me to completely switch off my carers role for 3.5 hours.”

“The quality of the service is excellent. having the same experienced, properly trained carer who understands my disabled autistic young son and knows the family is a huge support to all of us.”

“My son is currently unemployed and has ASD/ADHD he finds is difficult to go to places like the gym on his own I was taking him myself but it was proving stressful for both of us and I felt overwhelmed by my caring role at this time.
Having a support worker from Crossroads has been very beneficial to me as a carer and my son too.
It has reduced my stress and stopped me worrying so much about my son just sitting in his room alone while I’m at work.
Having the support work has worked well and I’m hoping to carry on using Crossroads once the 35 hours have ended but we can’t do this without the support of social services and my son is still waiting to be assessed by the Surrey’s transition team.”

> "I was told I would have to wait sometime before getting a carer for free so I decided to pay for their service"

There were individual comments that raised other issues:

Need flexibility

> "Crossroads can only come twice a month with the ad hoc additional evening. I would dearly like overnight support but this is unavailable. We haven't had any overnight Respite for over a year."

> "It is excellent to have 3.5 hours free time every week for 10 weeks and I hope this will continue after the 10 weeks. Friday afternoon was the only time available when it started but I would much prefer another day (Tuesday or Wednesday) when I would have other activities to take part in."

Did not meet needs

> "I feel I did not benefit much from them. As there was no feedback from the carer and she didn't really do what was discussed. So I didn't benefit from any break."

How it doesn't meet need

> "Times a bit off .10 consecutive weeks when I only need twice a month."

> "The only way it doesn't meet my needs is if I need a one off break to go to an appointment and I don't want to take my husband. It cannot do this."

> "Would like to be able to have a longer period of time occasionally, e.g. save up sessions and have a whole day."

> "Would like more flexibility rather than same time and day each week for 10 weeks but want to keep carer so will go along with it."

> "When doctors or hospital appointments are unavailable on the days when the sitters are due."

> "The benefit of the break is limited as it is only available during office hours. I work from home so generally I can't go and take advantage of a real break. I would love this to be available in the evenings or at weekends but can understand why that's not popular with your carers."

> "Doesn't provide overnight care. Doesn't provide more that two carers who are busy with other support work and who aren't replaced during periods of sickness or holidays."

> "Would like to change the times, daughter now goes to youth club, lack of awareness of wider issues around daughters needs at times."

Other comments included:

> "Crossroads Care has met my expectations and more."
>
> "The carer that came to mum didn't seem to want to take mum out so I felt the visit did not benefit myself or mum as neither of us got out of it what we hoped and we're told would happen."
>
> "I think the problem is once the 35 hours have ended we will have to stop until my son has been assessed by Surrey transition team which is a real shame for both him and me."
>
> "Not a lot of flexibility around term time as child in school. A lot of unknowns around after 6 months especially as my child has developed a strong bond with Crossroads worker."
>
> "Administration of medication protocol/boundaries should be explained straightaway to the unpaid carer & client, followed by opportunity to discuss where necessary."
>
> "Would like carer to be more house proud, help with keeping house tidy during time there. May not be aware they should be doing this."
>
> "I have asked for text messages as I wear hearing aids. This does not happen also as I work in environment that answering a phone can be difficult. To leave voice mail I sometimes cannot listen to until shift finishes."

Clarity on what will happen after the 35 hours of service

> "Had discussion about being self-funding which was agreed, I know I'm outside of the limits where I could get help. Currently have no input from social services."
>
> "Already paying for care in mornings and evenings but starting to get more care. Have info from Action for Carers."
>
> "Social services have said that they will have to undertake an assessment to see what is required."
>
> "What professional? We had a visit from a trainee adult social care person who visited us and told us we need to start paying. This is the only conversation we had."

Unpaid carers on the waiting list to receive Crossroads Care Surrey Carer Replacement Breaks service

How are you hoping the service can help you?

> "An ideal solution for us would be an ad hoc arrangement. Mum needs someone to help her be more independent and be able to buy things without depending on me all the time. Perfect example is birthday and Christmas presents - where I am the only one who can get stuff for her, so she is never able to get something for me and this upsets her. Mum sometimes likes to go out, but when she feels up to it I am sometimes busy with the grandchildren or other commitments. It would be great if she had someone she could call on to take her to events/ church or just out for a cup of tea."
>
> "To look after our autistic son one afternoon at the weekend. Times are fixed (9-12 or 1-4 I think?) and he is at college during the week. We have now been waiting over a year since we contacted Crossroads - I call every couple of months but not luck yet..."
>
> "1) I need to rest and not always be "switched on" to having to be the person on call - but I've discovered it won't
> 2) peace of mind that on the one weekend a month I'd want to not be going over and doing stuff that someone else would keep her company."
>
> "A couple of short visits a couple of days a week."
>
> "I need help with my young daughter just to give respite to me and my family especially at weekends as she needs 1 to 1 care and attention. I am a full time working mum that has an older daughter too whom I am not able to give my full attention to as my younger child has demanding care needs. Just someone to play with her or read books take her to the park would help tremendously a few hours a week."

What have you discovered is not available?

Some examples of comments made were:

> "The current service is focused on 2.5 hours per week - every week. This would be a waste for mum as she wouldn't be able to utilise it for the things she really needs support in."
>
> "I was offered 3 hours every Wednesday afternoon with no choice. From the literature it seems it is under discussion with the carer."
>
> "Information was overwhelming - I still have no complete understanding of what is offered and what is not offered."

> "Been on the waitlist for 9 plus years, which is really unfair and no use to a parent who needs it."
>
> "Absolutely ridiculous time to wait for help. I know I am not the only parent who has been waiting this length of time and still waiting. The rules of how you can use the hours are not very flexible either."
>
> "Yes the hours are fixed and weekends appear very difficult to staff. It would have been helpful to use the hours in a different way e.g. my son needs help at a club once a week but that would require 5 hours This is not possible even when we offered to fund the additional 2 hours a week."
>
> "Help after school on a Friday. She finishes school early and I needed some help on a Friday specifically from 3-6pm but was told that there are no carers available to help at that time as not convenient for them."

Unpaid carers that have finished using the Crossroads Care Surrey Carer Replacement Breaks service

How it met need

Some examples of comments were:

> "I was able to take some me time and time for myself. I also have health issues."
>
> "Crossroads enabled me to have a free afternoon for several weeks, which was invaluable. I was so appreciative to have this time to myself and the carers showed such kindness and respect. Thank you!"
>
> "Very helpful visit from the initial and follow-up assessors that came to visit."
>
> "Having a regular time slot each week was very helpful. We appreciated the efforts made to meet our need in 1 - changing the day to a Friday each week, and 2 - changing carer."
>
> "It helped a little had no idea it was so limited no one told me till it ended I was totally shocked."
>
> "The breaks were invaluable, enabling me to go to shops, dentist etc. while I could not leave my husband safely alone. He enjoyed the company of excellent carers."
>
> "It didn't. I was an unpaid carer for my mum and had no opportunity to have time off. At the time I started using Crossroads, they sent a lady to us for three hours one afternoon a week. This was little enough but to find out that the new service was only 35 hours in total was devastating. It is totally inadequate and based

solely on making reporting data look better. Look how many carers we've helped this year.' When actually you haven't really helped any."

"During the time I received your services which amounted to 4 hours every week, I was able to attend a bridge club. My husband was not able enough to be left for any length of time. Since the cessation of your services I have had to lodge my husband in a nursing home. In order to pay the fees of the home I must sell our property and downsize. So you can see that the cessation of your services has had a drastic effect on our lives."

"Really helpful in that it helped me stay in my job and juggle supporting my mum and dad. I was registered as carer for mum who needed me to take her out a lot and the break helped in that the carer support worker was able to take her shopping in her car (I don't drive)."

"It was a useful guide to the fact that I would be needing carers after the Breaks ended. In the event I signed up with Crossroads Surrey and am finding them very satisfactory."

"It was such a relief to be able to leave the house for a few precious hours, knowing that if there was a crisis, somebody would be there to help".

"I am housebound with my husband who is totally blind, frail now, and has diabetes with the related kidney and heart issues. I cannot leave him alone he has had three heart episodes to date, and prompt medical attention has saved him. Somebody must always be here. It was so good to walk out the door and relax knowing he was looked after and I did not have to worry. Made a big difference to my mental health, and something I looked forward to knowing your carer would meet his needs if necessary."

"I only heard from this service to say I was on a waiting list. My husband has now died and over 5 years I never received any break from Crossroads."

"I was offered 10 weeks of 3.5 hours on a Monday afternoon, which when you rely on public transport is not good."

"I was not made aware I could take this any other way."

"Would have preferred to have been given 5 days over a period of time."

"It demonstrated that having a care professional come to the house regularly works for both me (the carer) and for the person I care for."

How it didn’t meet needs

“I was not very happy with the carer sent to be with my husband as he did not engage very well or show interest in anything that he might do with my husband during the times he was at our home. Each week I tried to think of things that they might do together, but the carer was not interested and spent a lot of time on his phone. I think 35 hours is not a very long spell for breaks and would appreciate if this could be repeated at some time in the future (with a different carer!)”

“Both carers were unsuitable “matches” for my mum - a quiet and gentle (though very ‘with-it’) lady. Although very pleasant, they were both very strong personalities and appeared unable to simply ‘listen’. As such, my mum was unable to meet her needs for social interaction (i.e. partake in a two-way conversation or talk about her life / interests). I witnessed the second carer talking “at” my mum as I arrived home each time, and my mum said it was pretty much like that all the way through. This was unbearable for my mum and in the end we cut the time of the visit down and down each week, and I couldn’t really relax whilst away.”

“The visiting carers were different each week and were unable to communicate with him. He became annoyed and upset and bored. I wanted someone to take him out for a walk or out in a car for a walk and a cup of tea but this didn’t happen. I had to keep explaining to the visitor carers what to do and the situation broke down every time I tried to concentrate on what I was doing.”

“The rigid 9.30 a.m. or 2.30 p.m. slots whereas the cover would be nice over lunch period so that I can meet friends to eat. Also the 4 days’ notice not to have a care worker seems rather unfair when my mother was suddenly taken ill and we cancelled immediately but paid for session anyway.”

“I work 4 days a week and there was no availability on my day off which would have given me a break. Now we have finished the funding mum doesn’t go any more to chair yoga as she can’t get out of the flat by herself. I feel bad about that as I can’t help her.”

“We asked for 2 days split hours were told no we had to have whole three hours on day only. Then carer did not do anything with mum just sat there. Lady on holiday and had op no one to replace. No one told us when carer was coming or return our calls. Not a good service at all.”

“It was only 35 hours total and never consulted on the finish.”

What happened when the service ended
Some examples of comments were:

> "Just finished ....said no more available till next year.... heard nothing since."
> "Was offered further care but would have to pay. I did not think that the rates offered were competitive and had not enjoyed the experience as much as I might as each time the carer came I worried about what my husband was going to do. I do not remember being offered further assessment for any more free ongoing breaks."
>
> "We continued to use the service, paying for it ourselves."
>
> "Just told you have used up your allocation. NO mention of being able to be reassessed!! Never knew this."
>
> "I only had a 2 hour session. It would clearly not meet my need, so the lady said I should get in touch again if I ever need 2 hours off each week. I thanked her and that was the end of it. Now I leave my husband, which is a risk, but I attach an alarm button around his neck."
>
> "I was left with no options."
>
> "Unfortunately my father decided that he didn't want anyone coming to sit with him, so we had to cancel early. Mum and I were frustrated, but you can reason with an obstinate person with dementia. Glen was great though and I am just sorry we couldn't continue."
>
> "I have battled with Surrey ever since my son came to live at home for appropriate support - we now receive 14 hours per week, way less than other parents I am in contact with. Surrey gave 8 hours to a company who supported Tom for 8 hours one day a week - that was the replacement of the hours that Crossroads provided. The balance of the hours is supposed to be fulfilled by another company but they have never been able to provide someone for the full 6 hours they are supposed to supply."
>
> "We complained about service and it was ended. They did not really want to assist us any further."
>
> "I didn't and haven't had a break or any respite from caring for my loved one, since the 28th June, or any time without caring for my loved one."

> "I was told that further visits could be arranged, but I would have to pay for them. At the time I was already paying quite a bit for carers for my father. Since then, my father has sadly died, and my mother's Alzheimer's has progressed so leaving her is a real concern."

Unpaid carers who haven't heard of the Crossroads Care Surrey Carer Replacement Breaks service or have chosen not to use the service

Reasons why carers have not used the service

Examples of comments included:

> "I have heard of Crossroads but not in relation to young autistic adults (I am a carer to one). I have always associated Crossroads with older people. None of the professionals I speak to have ever mentioned this service to me."
>
> "This survey is the first time I have heard of this. Depending on what is offered, it may be of use to me but without any information, I cannot make an informed decision."
>
> "I reached out at breaking point and was denied access to this service."
>
> "I need longer spells of respite than was offered and in a more ad hoc way."
>
> "I was told funding was being cut and staff reduced so I organised some private help."
>
> "I was kindly offered a couple of hours a week but it would be harder to explain about me going out than it was worth it currently."
>
> "I have not heard of this before and not been informed by my daughter's social worker or as part of my carers assessment, which is extremely disappointing"
>
> "My mum has dementia, and last year my dad was in hospital with bowel cancer. I was concerned that my dad wouldn't be well enough to cope when he came out of hospital, so looked into various options of support for them. One of which was Crossroads Care. However, my understanding at that time was that it was 3.5 hours a week for 10 weeks and I felt that my parents would need longer term support than this. It therefore didn't feel appropriate to introduce them to a carer for 10 weeks and then for that service to finish and have to either find a new carer or stop the service completely. My mum's dementia wasn't going to improve and it felt it didn't feel sensible to introduce her to someone only for that finish and then have to introduce a new carer at the end of it with potentially a different

service. In the end, we paid privately for someone who continues to support them once a week to this day."

"Tried to use service some time ago, couldn't recruit member of staff with right skills for son with autism."

"Had issues with consistency of careers coming to offer respite."
"Not yet at breaking point."

"My husband does not think there is anything wrong with him Very difficult he also is losing his sight does not want anyone else but me worn out."

"I don't currently use the service as I don't think my husband is 'bad' enough."

"I need 'one off' support when I go out for a longer day…Crossroads service is too prescriptive for my needs."

How well the service helps to maintain the health and wellbeing of carers
Some examples of comments were:

Helps carers cope

"Frees the carer of the worries albeit temporarily. One feels mentally refreshed after every session. Besides the individuals do an excellent job, selfless sacrifice."

"The carer is lovely and reassuring."

"Very professional and caring"

"She is kind caring & empathetic towards my husband…and I trust her to take care of him while I'm out."

"I know mum has stimulation, another face to see, not just me. See has fun, things to talk about . I have an afternoon off and worry free as I'm off duty with mum."

"Always having the same carer each visit. The staff are reliable and caring."

"The documents that you need to complete in conjunction with administration prior to the start of the service give a sense of reassurance that you can go out and safely leave mum with a competent carer."

"Once the carer started and mum felt safe and happy with the carer, it immediately lifted a burden from my shoulders."

"When you care for someone with Vascular Dementia it's a full time job caring for them day and night. I sometimes only get 3-4 hours sleep so it is great to hand him over to the carer so I can mentally relax for an afternoon and just do what I want to."

"I have been very pleased with the speed of the assessment and how quickly a support worker was found/started supporting my son."
"The service has supported me as a carer and reduced some of my stress for now."

"Your carers have calm confidence, and my husband looked forward to their visits."

"I haven't used it, but e.g. 12 sessions of just under 3 hours would free me up to attend a whole years' meetings of an association I belong to. That would be brilliant."

Increase hours

"I found it stressful having a carer with whom my husband could not relate and therefore worried about him while I was away, which somewhat defeats the object. When I reported this to Crossroads, I felt that they were not interested. If carers need a break, surely 35 hours is a drop in the ocean!"

"The Crossroads staff and service are fantastic but I struggled knowing that my 35 hours would end and I'd be stuck at home again. I worried counting down my afternoons of freedom."

"Because it's only a temporary fix. I need something more permanent."

"35 hours is nothing in the life of a carer. I thought 35 hours a month would have been reasonable but a one off support is an insult."

"I don't know how it resolves but the offer is so limited to those fixed hours and mornings/afternoons and for 10 weeks only. It's not very flexible."

"It doesn't take into account people like me as a carers who have to care in the evenings or on my day off or at weekends. For those caring 24 hours a day I should imagine it's a godsend but not enough to really help on a long term basis."

"It is a very welcome break from the stress and strain of daily life, but 35 hours in total is nothing compared to a lifetime of caring. Not everyone can afford the self-funding, and even though I can I have to limit what I spend on 'me' as my husband's needs increase almost daily and we have to divert our funds to his needs"

"Crossroads offer a great service. However 35 hours is not sufficient to meet the wellbeing needs of most carers. There needs to be continuity. It is borderline cruel for the funding providers to believe it okay to provide some support for a few weeks and then remove that support. Carers need ongoing support. The stress and issues they face do not go away after 10 weeks. Fortunately Crossroads recognise this when it come to unpaid carers of children. However we do not know how long the support will continue for with all the funding cuts. We are still quite worried about losing our Crossroads carer."

"The service was great, but the problem of the stress on carers does not stop after 35 hours. I tried to get my husband into a day centre, one day a week, but they wouldn't take him. So 3.5 hours a week is the only break I get."

Flexibility

"It would be nice to be able to get a full respite break of a week or weekend to make a real difference."

"The service was not flexible enough to keep going with my mum. An alternative volunteer was not found and we are still waiting for some support."

"Might be good if you have transport and can go further afield I have train card but not enough time in 3.5 hours to go anywhere."

"In an ideal world, the service would be more flexible. It would allow a full day's break one week, or two consecutive days, and maybe just a couple of hours the next. But obviously that would mean staffing levels and scheduling abilities would be unlimited. Which is why I think the service did as well if not better than I expected for a free service from a charity / not for profit organisation."

Next steps

"Social care assessments seem to be dependent on waiting for families to be in crisis or safeguarding issues to be present before agreeing to help. Waiting lists are long."

"It has been good to have the service for a free period before I have to pay privately."

"Carers who have no choice but to work full time as my husband who I am a carer for and is not entitled to anymore help financially. I feel that carers like myself are being penalised due to working full time."

Meeting needs

> "Couldn't meet need for son with autism."
>
> "It hasn't started as yet and I feel like I've had to jump through multiple hoops to just be recognised. I feel extremely tired of fighting the fight at this stage, always looking, asking, requesting for support to provide a better life for the person I care for. While he has only been living at home full time for 1 year, as a parent & carer of a young adult, it's become more difficult than having a child."

What do unpaid carers think the Carers Replacement Breaks service should do differently?

Responses can be grouped into themes:

Nothing needs to change

There were 63 comments that the service works well and nothing needs to change. Some responses provided more detail:

> "The service is fantastic."
>
> "I cannot speak highly enough of the carers we have had."
>
> "I am very pleased with the current carer. She is very friendly and patient and kind."

Flexibility

This referred to the need for the service to be offered at different times - examples included:

- Having the service at weekends
- Having the service in the evenings
- Being able to have the 35 hours in whole days rather than 3.5 hour visits
- Having the service for different frequencies rather than once a week

There were 43 comments and most of them were under the impression this was not possible, a small number of respondents indicated they had been led to believe the service could be more flexible, but then this hadn't happened.

There were a small number of comments where the service had to change at the last minute, e.g. due to staff sickness. The comments indicated that there was a frustration that unpaid carers were expected to be flexible in these circumstances, when the service wasn't being as flexible as they expected. One comment raised the concern that when they cancelled at late notice due to the cared for person being unwell, they still had to pay for the visit.

> "It would be more beneficial to have say 2 days off with an overnight stay to help with my health and wellbeing."

> “It wasn’t made clear to me that my 35 hours could be taken in any way other than weekly half days.”

> “I appreciate whatever they can offer. I think I would have liked 35 hours respite home or full day say 9 hours x 4”

> “My son is able to attend a club when supported. I would love for a holiday club or weekend club (even 2 hours) for my son to attend so he can have consistency and structure and I can work. I am happy to pay for this.”

> “I would have liked to have known that the 35 hours can be spread out over 6 months rather than taken in 10 consecutive weeks of 3.5 hours per week. I would probably still have taken a weekly break, but the information would have been good.”

Meeting Needs

This was a key issue, highlighted by 30 respondents and echoed in other themes. A number of areas were identified:

- Assessments of the unpaid carers need to be consistent and person centred, recognising their need to continue with their other responsibilities and interests.
- Assessments of the cared for person need to have an understanding of the impact of their condition. This was particularly raised by respondents who care for people with dementia, mental ill health and autism.
- The need to return to the previous service where respite care was ongoing.
- The current service not undertaking certain activities, such as taking the cared for person out in a car.
- Perceived differences between what is available to you when paying privately and what is available if you have social services funding.
- The need for more options for respite, such as residential.

> “I think there is a general tendency (not just here) to forget that the elderly have the same desire for interaction and connection as everyone else.”

> “The carers have struggled to cope with the complex needs of my wife.”

> “I understand that resources are limited and have to be shared but I think further individual assessments and discussions about mental and physical needs may help to allocate staff accordingly.”

> “Train the carers how to handle different types of dementia. Ensure there is continuity. Carers need to be mature and confident.”

“I understand that if your loved one has care funded by Surrey County Council you would not be eligible as a carer for these breaks. So really its only self-funders or people who don’t get any support other than from informal carers who are eligible. I only found this out when recommending to a friend whose mum has homecare visits funded by Surrey CC through an agency. I think that’s disgraceful - just because SCC fund someone’s care the carer isn’t eligible for a bit of respite! Its not like 4 calls a day to someone is respite for a carer they do all the care in between. This is actually a bit of a scandal when you think about it.”

“I don’t think that Crossroads care for disabled young adults anymore so the care no longer is offered.”

“Access training available for people with autism”

“Make sure carers are consistent and that they are trained and follow the care plan and wishes of the carer and cared for person.”

“It is more about social services being more responsive and having alternatives and choice, had problems with the system for 40 years. Struggled to get support for years, had to make serious complaints to the council.”

“There should be an increase in the funding for carers of disabled children and teenagers. Unpaid carers are often juggling the needs of other children, sometimes even elderly parents too. Younger carers in their 30s, 40s and 50s are more impacted by the current cost of living crisis. There are many agencies out there for elderly and dementia. Sadly there is virtually nothing for unpaid carers of under 18s.”

“Offer respite care in a certified care home.”

“Listen to what people really need!!”

“There appears to be no joined up thinking between social services and Crossroads. Because we are self funding social services don’t keep us on their radar and Crossroads appear also to fail in following up with their cases.”

“Carers could help with gardening and assistance with help to take person you care for for walk and activities.”

Increase hours

This referred to the 35 hours of service currently available. 20 comments referred to this and all of them suggested the number of hours should be increased.

> "Care in the evening to allow the carer top go to the theatre, out for dinner, attend a club/ hobby. A regular pattern of replacement care not just the 35 hours."
>
> "I don't think this should be a once-off help, carers continuously work and have their ward in their focus, and they do this for years, not just once a year."
> "It needs to be available for longer, the amount of money I'm having to spend is really difficult."
>
> "Not having tried this format, I may not understand it properly, particularly with regard to the possibility of extending the time offered, as the limited time was what put me off signing up for it."

Advice on Next Steps

9 respondents indicated it had not been made clear to them what would happen at the end of the 35 hours of respite care. Indications were that some respondents had stopped having any respite because they were not aware of being able to have an assessment to continue or to elect to self-fund it.

> "If they can't provide the care give you the option to source it yourself"
> "I would have been happy to fund the breaks if this could have meant a continuing service."
>
> "Properly assess a person already receiving care before any decision is made as to whether to continue the service."
>
> "We had no follow up assessment."
>
> "Social services took over 2 months to come and confirm diagnosis, was lovely when they arrived. Action for Carers gave phone numbers to ring and helped with Blue Badge, will talk to Admiral Nurses re future care needs for husband"
>
> "I feel more feedback from the visits and also some sort of conversation afterwards as I was led to believe there would be a chat and some advice given but it did not happen."
>
> "I was grateful for the 10 weeks of respite I had but as soon as the respite finished one is back to square one, trying to cope and do the best you can as a carer and to be the best person to be a carer of whom you are caring for and being a carer to a loved one is in itself stressful, energy zapping and sometimes frustrating ,so more respite is needed in my case."

Waiting List for the service

There were 7 comments that the waiting time for the service was too long.

> "Carers should not have to wait so long to access help."

> "Just wish I could have had this service sooner. It took a long time to get someone."

> "Provide regular updates on waiting times."

Paying for the service

5 comments mentioned the challenge of having to pay for the service to continue after the 35 hours had finished.

> "I feel the amount we have to pay for 3.5 hours is extremely expensive."

> "It needs to be available for longer, the amount of money I'm having to spend is really difficult."

> "The hourly rate is quite expensive so if this was cheaper, we could have more hours per week."

Advice

3 comments cited the need for more general advice and guidance.

> "Provide direct guidance of where support can be obtained that match my circumstances."

> "Offering sessions that carers can attend when they have their respite sessions."

> "The assessment took a long time and was thorough, were going to redo whole process if he came out of hospital, felt protracted although carers were nice. Was going to have to wait 12 weeks for carer to start. Felt that you were locked in to using Crossroads and may not have opportunity to look at other options for respite at home. Do we need more agencies offering the same service to try to meet needs. Historically I have used Claridge House on a reduced rate negotiated by Action for Carers for a couple of nights, but even that wasn't really long enough although it was very good. It was very challenging to get information, didn't feel supported except by Action for Carers, didn't know about lots of useful services like community matrons No joined up thinking Struggled to even get GP to come out Feel carers aren't supported and not enough to help carer."

Consistency of carers
3 respondents mentioned the need for the same carer each time, or at least as few different carers as possible. It also echoed the need for staff to be competent and that the needs of the person receiving the respite to be met.

> “I also struggle if the carer gets changed at the last minute for someone I haven't met before. I do ideally like to have the first couple of sessions to get to know the person in my home.”

> “At the time, we would’ve been happy, accepting fewer hours, but over a longer period, with a view that should it work, we might consider paying privately for it to continue. For people with dementia, it is important that the relationship is built up. It took my mum several months to adapt to the career we now pay for privately. She actually takes both mum and dad out together which gives my dad a break in that, although still with my mum, he has someone different to talk to and different places to go to each week. This flexible approach has been important to us.”

> “Make sure carers are consistent and that they are trained and follow the care plan and wishes of the carer and cared for person.”

Staff that work with unpaid carers

Feedback on the service from unpaid carers

Comments included:

> “Very much appreciated in most cases essential”

> “Current service is not working and does not meet all Carers needs for a break. Carers would like to have a variety of ways to take a break and flexibility to take a break when they need. Some need this regularly at set times, some need this ad hoc and some need to cover holidays.”

> “I have spoken to a number of carers who were without exception distressed and upset that their Crossroads service was coming to an end. Particularly those caring for someone with dementia.”

> “When I explained the rationale for the change in service several carers said that if they had only been offered 35 hours at the start of their service they would have declined. It takes time and trust for people with dementia (and their carers who need to feel reassured to leave them) to feel comfortable with a care worker and by the time a trusting relationship had been formed, the service would end, leaving both the person being cared for and the carer distressed.”

“Replacement care offered by care agencies was often provided by a number of different care workers calling and this confused the cared for person. A number of carers had little confidence and were unable to leave the home. Forgoing their opportunity to have a break away from the home.”

“Very negative. They find there are limited, if any, options available. They say they are no longer able to book respite in care homes in advance, making it impossible for them plan or take holidays. The changes to the Crossroads contract has been very negative as they can’t even have a couple of hours to themselves during the week.”

“Long-term clients have been disappointed that the support given has been stopped and newer clients are grateful for some help although they seem to be waiting until they are desperate and in real need before starting the service as they realise they only get 35 hours.”

“Carers Replacement Breaks are an absolute life saver for unpaid carers and their mental health.”

“Lots of carers as declining the service because it’s only funded for 35 hours and they want to wait until they are desperate as only can have the service once.”

“That the service from Crossroads has been invaluable. It allows our unpaid carers time off to catch up with jobs, either indoors or out, catch up with friends and family, rest, or generally be themselves again.”

“Carers of people with mental illness are declined replacement breaks because the service says they cannot offer replacement care for mental illness carers.”

“Carers need an ongoing break, something they know is a regular arrangement so they can plan having a break.”

“Many carers like to have the same person to provide the break and support their loved one - this gives them confidence that the person they care for is being left with someone who can anticipate their needs and who has been able to build up a relationship with both the carer and the cared for person. It also means that the carer doesn’t have to keep repeating themselves when explaining the care the cared for person needs.”

“Carers of people with dementia have reported that it’s not worth having the 35 hours of support from Crossroads because by the time the care worker has built

> up a relationship with the cared for person, the service ends. It can be distressing for both the carer and the cared for person."
>
> "Carers often feel guilty about taking a break and feel better if the person they care for also finds the replacement care worthwhile and stimulating. Sitting indoors seems to be the main option, which can be off putting. If the cared for person is taken out, this can enable the carer to have some time at home alone. Carers don't always want to go out to achieve a break!"
>
> "That the current offer seems pretty pointless, it seems to be aimed at families whose caring role is time limited whereas for 99% of people it is an ongoing issue. The 35 hours on offer does not address their needs, to say that people will be directed to Adult Social Care for a Carers Assessment if they still require a service beyond the 35 hours seems ridiculous, I would expect people to have this before Crossroads involvement. For people with dementia (which is where the majority of my experience lies) consistency is one of the most important aspects, why introduce someone who will then be removed - it makes no sense."
>
> "The offer from Surrey County Council is not long enough, currently at 35 hours, unpaid carers are using it like a savings account. Instead of using the offer as a preventative element, it is being used as a crisis offer."

Impact on other carers services
Comments included:

> "Carers are feeling low in mood and express their displeasure more often. The cared for person is often having to pay for a service themselves to allow their carer a break. Carers often don't feel comfortable about this."
>
> "It takes time to build a relationship. It takes time for a spouse/partner to trust us with their loved one especially if they have been the only person caring for them for years the time restraint of 35 hours does nothing to help this as it all seems so rushed now."
>
> "The continuity of care is important with clients and carers, they get used to trust and feel comfortable, and after the 10 weeks that can change after having a valuable service which is needed very much."
>
> "We have had to deal with a lot of unhappy carers - some have been very distressed by the changes."

> "It has created more work for our teams, having to find care agencies to provide ongoing breaks - the care agencies are not used to providing breaks, they can't guarantee the same worker and if they are having difficulty covering care calls, because of sickness in their organisation, the carer breaks seem to be the first calls that get cancelled."
>
> "Because of the cost implications of paying for a package of care to have a break (where replacement care is required), many carers have decided to go without and struggle on."
>
> "There was huge miscommunication from Crossroads at the start of the 35 hour contract, which was confusing for staff and very time consuming. This also added to the stress on carers. They were receiving the wrong information in a way that was causing concern."
>
> "I tend not to refer people now, if people are in a position to self-fund I will direct them to private agencies for this type of support. If people cannot self-fund then I would direct them to Adult Social Care BUT in my experience they are more likely to fund personal care than companionship/supervision which is what many people with dementia need. Often unpaid Carers need support in the "early stages" when the person with dementia may have little insight and understanding about why their Carer needs a break, however Adult Social Care tend in my experience to think that someone has less need when 'they are only in the early stages'. This means that many Carers are now left with no support options whatsoever."

How the Carers Replacement Breaks service could be changed or enhanced to make a positive difference to carers' lives

We asked staff for ideas on how the Carers Replacement Breaks service could be changed or enhanced to make a positive difference to carers' lives. 27 people responded and the comments are grouped into themes below. These themes reflect themes arising earlier in this report.

Coordination and Planning

> "Tailored to specific needs."
>
> "Regular familiar Carer Support Workers where possible providing continuity of care."
>
> "Flexible time slots."
>
> "1. To have a variety of ways a Carer can take a break.
> 2. To have a Carers Direct payment for a fixed amount to use in the way they choose to give them choice and control.

3. To have a list of providers that can offer a few hours, half a day, all day or overnight or ad hoc replacement care.
4. To have providers who specialise in ASD, Mental Health, Dementia, Challenging behaviours, young adults with disabilities, specialists who can support people with sensory impairments, offer services where English is not first language."

"Engage with other providers who can offer the above."

"More dementia day care facilities - Only one I know of is in Haslemere and they are often over subscribed and hard to reach for many carers."

"Transport for carers is essential - more thought needs to go into this."

"Carer break payments are one off for all carers, despite how much care they are providing. I feel those who are providing 24 hour care, 7 days a week, should be afforded more long term support. Especially those caring for someone with dementia as this is mentally and physically draining."

"As far as I can see, the assessments are working well, and my unpaid carers are being offered the opportunity to 'top up' payment for our service. However, some are finding this procedure very confusing. Surely this could be made an easier process for some of our more elderly or non-tech savvy unpaid carers. I fear many have lost our service as they do not understand the process?"

"If this is about Surrey no longer supporting "self-funding" unpaid Carers then they need to be upfront about it and concentrate their efforts and funding on those who meet their funding criteria whilst recognising the stresses and strains which can present for Carers who are 'only in the early stages'."

"I think the clients should be assessed also on the estimated length of time that they would need care support. (I am not sure if this is already done?) There could be two client pools: 1. Long term clients (10+ weeks system) 2. Short term clients (10 week system or less).
Short term clients: Most likely to be individuals that require end of life care. The process for this would be the same as current - 10 weeks allocated initially and then reassessed on completion.
Long term clients: Most likely to be fit for clients with any learning disabilities, autism, children, and individuals with non life threatening conditions. This allows true relationship building between clients and carers which is a very significant aspect of providing care and allows for trust to be formed over time. This may also reduce stress for the unpaid carer - knowing the support we offer will not be taken away when it may still be needed."

"From a carers standpoint: I believe the current client allocation system is flawed. Currently there are carers travelling all over Surrey to different clients, yet there is most likely a carer who is situated much closer to said clients. A massive quality of life change for Crossroads Carers would be to receive clients closer to their living arrangements. For this to be done smoothly though, all current clients would need to be removed and client allocation would need to start from scratch again. Yes, this would put the business at a temporary standstill. This change does slightly contradict my earlier suggestion of keeping clients and carers together for relationship building, but I believe the future benefits of making this change would outweigh the negative implications. Travel cost reimbursement would go down due to carers having to travel less of a distance to get to their clients. There would likely be less carers arriving late or being stuck in traffic due to having less of a distance to travel. I would also assume that the mental wellbeing of carers would become more positive - knowing you have less travel to and from clients. Also this would provide the opportunity to encourage positive habits within the business, such as walking/cycling to clients (as long as they do not require car access), which is good for both the carers health and the environment."

Meeting needs

"For carers of people with mental illness a service which offers replacement care would be invaluable and equitable.
The type of replacement care service ideally would look like;
Emotional replacement care- i.e. a trained person to be booked for a day / half day/ few hours to sit with the cared-for to supervise any suicidal risk.
Emotional replacement care- needs to offer staff who are skilled and trained in managing cared-for who has unusual behaviours e.g.; delusions, responding to unseen stimuli, bi-polar manic garrulous state, or catatonic depression.
Emotional replacement care- for the trained person to be the 'point of contact' for the cared-for to call if distressed, needing emotional reassurance, social contact, motivational support. To be available to meet with the cared-for at a time of crisis.
Emotional replacement care- needs to be consistent so that the cared-for person knows who they are and doesn't get a random person supporting them. Time needs to be spent building rapport and trust to enable replacement care to work."

"Just to keep the continuity of care as much as possible…"

"Direct payments to enable carers to choose who provides the care."

"Carers need a robust respite service for themselves. Every eligible carer should have respite hours on their support plan."

Flexibility

> "By providing more flexibility. Offering all service users weekend breaks."
>
> "Be more flexible with the 35 hours."
>
> "Carer breaks to be more flexible - ongoing support to be provided by the same person/s (as regularly as is possible) to give reassurance to the carer and cared for person."

Increase hours

> "From my experience, 35 hours is not enough for the carers. They need continued support to be able to carry on caring."
>
> "35 hours not adequate for most carers - this to be increased."
>
> "Need more than 35 hours."
>
> "I don't understand the 35 hour limit. You give people support for 10 weeks and then we disappear. How does this help them? They need a regular break every week to be of any benefit."
>
> "I think that 3.5 hours break per week for an unpaid carer is a small amount of time, but significant for them. I would like to see this break continue indefinitely or until the circumstances changed. If there had to be a limit on hours I think 175 hours (or just under a year) would be more beneficial as 35 hours is not really long enough."
>
> "I think the offer of up to 35 hours for a carer break through the current offer is not worthwhile. I have not met a carer who uses the 35 hours and doesn't need any more support. Often by the time carers are trying to access carer break services, they have been caring for a long time and are reaching crisis point. The offer needs to be something that can be ongoing and specialised."
>
> "Don't stop us going in at 35 weeks continue the service until they no longer need the support."
>
> "Carers to stay longer then there 10 weeks."
>
> "The service would benefit by having the offer increased. This would provide continuity of service, reduce referral levels back to SCC and support a preventative approach."

Increase choice

“Think about using other companies/providers.”

“There needs to be more variety, especially for carers of people with dementia.”

“Prior to the pandemic, there were far more options for day care - many of which haven’t re-opened.”

“There need to be more providers who can manage challenging behaviour - often if they can’t the person is returned to their carer. Carers often wonder how they are expected to manage when professionals can’t. This has lead to carer breakdowns in a number of cases I’m aware of and resulted in the cared for person being permanently placed. With the right support and frequency of breaks, this could be avoided.”

“Low cost options/subsidised breaks for carers would enable them to take a meaningful break. We know that carers are often living on low incomes and do not prioritise spending money on themselves. To be supported to take a weekend away would make a huge difference. Carers could be supported to utilise charities like Carefree. Perhaps a carer direct payment could be agreed once a year to support with the cost of the admin fee and transport?”

“Reliable replacement care/respite needs to be available, and not always in a care home setting.”

Contact us

Contact us through any of the channels below.
We’d love to hear from you:

Web: luminus-cic.uk
Telephone: 01483 301448
Text: 07592 787 533 (SMS only)
Email: info@luminus-cic.uk

Our address is:
Luminus, GF21 Astolat, Coniers Way, Burpham, Guildford, Surrey, GU4 7HL