

Carer's Assessments in Essex: what do carers say?

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Acknowledgements

Healthwatch Essex would like to say a huge thank you to all the carers who took the time to share their experiences with us. We appreciate the efforts of all the people who gave time during their busy caring schedule to fill out our survey, helping us to better understand their lived experience of Carer's Assessments.

Thank you also to our Healthwatch Essex Carer Ambassadors who were involved in the design of the survey, the preparation of this report, and its recommendations.

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1. Executive Summary

This report describes the findings of a survey carried out between November and December 2015 into the experiences of unpaid carers in accessing Carer's Assessments. The survey explored, from the carers' perspective, the knowledge and awareness of Carer's Assessments, as well as the experiences and expectations of outcomes. Research findings are based on 79 responses to an online survey distributed through our partnership networks, website and social media.

Key findings

- Three quarters (75%) of respondents said that they had heard about Carer's Assessments, yet less than a third (29%) had had one.
- Of those that had, less than half (46%) said they found it easy to get a Carer's Assessment, and some people reported having to reach crisis point before being offered support.
- Of those who had had a Carer's Assessment, the majority reported that they did not think, or were not sure, that having a Carer's Assessment had helped them in their role as a carer.
- Carers who had had a Carer's Assessment reported that they found the process to be lengthy, complex and confusing.
- Information or expectations about what impact an assessment might achieve may not meet with the reality experienced by carers.
- There was a lack of awareness around where to find further information, or what the benefits of having a Carer's Assessment would be.

Recommendations

- i. There needs to be active promotion of Carer's Assessments, including what they are, how to access them, and what outcomes carers can expect when they have a Carer's Assessment.
- ii. This could include raising awareness of how Carer's Assessments can benefit people who are caring for others, including those who might not consider themselves to be 'a carer' - such as through using real life examples and positive case studies.
- iii. A review of outcomes of completed Carer's Assessments should be undertaken to find out what carers actually experience in terms of outcomes or interventions which have occurred as a result. Healthwatch Essex would be well placed to undertake this further investigation.
- iv. Commissioners should seek a commitment from providers of Carer's Assessments to use carer feedback to improve the access and quality of Carer's Assessments.
- v. Commissioners should follow up on this report to find out more from carers about what prevents them from taking up Carer's Assessments and what would encourage them to take up a Carer's Assessment. Healthwatch Essex would be well placed to undertake this further investigation.

2. Background

The Care Act 2014, which came into effect in April 2015, strengthened the rights and recognition of unpaid carers in the social care system. It gave Local Authorities a legal duty to assess any unpaid carer who requests an assessment or who appears to need support. This replaced the law which said the carer must be providing "a substantial amount of care on a regular basis" to qualify for an assessment, meaning that more carers are now eligible.

Under the Care Act 2014, a Carer's Assessment must include an assessment of:

- whether the carer is able, and is likely to continue to be able, to provide care;
- whether the carer is willing, and is likely to continue to be willing, to do so;
- the impact of the carer's needs for support;
- the outcomes that the carer wishes to achieve in day-to-day life, and;
- whether the provision of support could contribute to the achievement of those outcomes.

To find out about carers' experiences of Carer's Assessments, Healthwatch Essex carried out a short online survey. We wanted to hear from as many carers as possible - carers didn't need to have had a Carer's Assessment to take part.

The survey was sent out through our membership and partnership networks, our Carer Ambassadors and through our website and social media.

It was originally due to close on the 11th December 2015, but this was extended to keep the survey open for another week allowing more carers to take part. All the responses were anonymous and we committed to getting back to respondents through posting the results on our website in January 2016.

In total 79 people responded to the survey, including 31 free text comments. Given the relatively small sample, the findings are not generalisable, but help to provide an insight which will inform future research into this area, and the commissioning and delivery of carer support services.



3. Survey findings

The survey findings were analysed and key themes were identified. Two key themes emerged: awareness and ease of obtaining assessments, and experience following an assessment.

The findings reported in this section are based on the number of respondents who answered each question, with the free text comments that accompany the relevant theme.

3.1 Awareness and ease of obtaining assessments

3.1.1 Awareness of Carer's Assessments

All 79 respondents answered the question on whether they had heard about Carer's Assessments. Three quarters (75%) of respondents said that they had heard about Carer's Assessments, which is encouraging. However a quarter (25%) said that they had not which suggests that there is still some work to do to make carers aware of their right to obtain a Carer's Assessment under the Care Act 2014.

Some respondents providing free text comments mentioned that they think people do not know their rights with regards to Carer's Assessments:

"I hear so many reports from carers that are confused and lack understanding to what they are entitled to".

"I do not think that people know their rights relating to Carer Assessments".

3.1.2 Ease of obtaining an assessment

Those that had had a Carer's Assessment were asked how easy it was to get one. Twenty six respondents answered the question, and just over half (54%) reported that they found it easy to get a Carer's Assessment. Less than half (46%) reported that it had not been easy.

Some of the comments were around having to reach breaking point, or argue their case before being able to access a Carer's Assessment:

"It was only when things reached crisis point that I was offered a Carers Assessment. I had visited GP's, hospital consultant appointments, day centres but no one offered me any support to care for my wife. They all knew how I was struggling, but not till I was on my knees did they mention this".

"I have been referred by my GP for one as I wanted help for my son who was not eligible because of the system. The systems have caused me to nearly have a break down so I am eligible".

"Despite providing 24/7 crisis care for my daughter I was not considered to be a carer. It was only after making a lot of fuss that I had a Carers Assessment".

3.2 Experience following a Carer's Assessment

3.2.1 Experience of Carer's Assessments

When asked, 'Have you had a Carers Assessment?', nearly a third (29%) of respondents said that they had, with over two thirds (71%) saying that they had not received a Carer's Assessment. Some of the respondents explained the difficulties they had experienced obtaining an assessment:

"I have had various people come out to talk to me from Essex [County Council], regarding my mum who has dementia... but no one has discussed a Carer Assessment with me".

"I was told I could not have a Carers Assessment by social care as it was only available for carers caring for someone older than my daughter".

People also mentioned some of the possible barriers which could affect people obtaining a Carer's Assessment. These focussed on people not identifying themselves as a carer because of lack of awareness, meaning they do not seek support:

"I think that part of the problem is how you can drift into becoming a carer over several years".

This confirms the findings of the Healthwatch Essex study into the lived experience of unpaid carers which found that caring relationships are often already embedded within an existing relationship, such as friendship or family. As a result, carers did not primarily identify themselves as carers but used the pre-existing relationship bond to define their identity.¹

The results from the survey suggest that despite a fairly high awareness of Carer's Assessments, not everyone has received one. This may be because carers do not see the relevance for their situation or do not expect the outcome to be helpful. They might be confused about their entitlement, or they are viewed as a negative experience with a stigma attached to having one. This suggests that further work should be undertaken to listen to carers to understand assessment take up. Furthermore, agencies providing carers support should seek to identify 'hidden carers' and promote carers services available.

¹ Guest, C., Corrigan, O., & Koffman, O. (2015) 'You really do give up your own life, once you became a full-time carer': Exploring the lived experience of carers in South Essex.

<http://www.healthwatchessex.org.uk/what-we-do/topics/carers/>

Others suggested that the guidelines and criteria for getting an assessment means they either aren't eligible or have not looked into it further:

"I was put off looking harder because of the government limits on support i.e. needing to be caring more than 30+ hours a week".

"Assessments only consider you a carer if you wash a person or toilet etc. I spend time and the person I'm caring for would not be able to get out if I didn't go with her... Like so many problems it is not considered important".

3.2.2 Experience and expectations of outcomes

The second key theme to emerge from the survey findings was around the experience and expectations of Carer's Assessments. Significantly, of those who said that they had had a Carer's Assessment, the majority of respondents reported that they did not think, or were not sure, that having a Carer's Assessment had helped them in their role as a carer (Figure 1).

This could be because information or expectations about what impact an assessment might achieve does not meet with the reality experienced by carers. It raises the question about whether the workers undertaking the Carer's Assessments understand the main problems experienced by people providing care or the options available for follow up care. It also questions whether the Carer's Assessment process is responsive enough to individual's needs, allowing creativity to find the personalised support that carers need.

Figure 1. Whether having a Carer's Assessment has helped them in their role.



People reported mostly negative outcomes from having a Carer's Assessment. These suggested that outcomes did not meet their needs, or there was a lack of communication or understanding around anticipated outcomes:

"The assessment put my mother on the radar, but achieved nothing but a few leaflets".

"[My friend] did not know that her assessment had resulted in support until she received paperwork informing her she could have a personal budget to organise respite".

"I was offered 'respite' but I didn't want this - I wanted help to care for my daughter".

Survey respondents also reported positive experiences, which confirms the findings of the Healthwatch Essex study into the lived experience of unpaid carers. This found that carers appreciated personalised support from professionals, especially when delivered with empathy and understanding.² One respondent reported a positive outcome, receiving the support that they needed:

"I was offered support and respite. Made a big difference to our lives".

The Healthwatch Essex 'carers' film also suggests that respite and support can really make a difference to the carer's experience.³ Many people perceived that a lack of funding prevented them receiving the support that was necessary, even when these needs were identified within the assessment:

"Carer's Assessments are wonderful on paper, however there is often very little money, or resources to meet all the suggestions".

"They are only useful when they are resourced for and able to meet the needs identified within them".

"My personal experience was plainly that of denying access to obviously needed assistance due to funds shortages".

An additional theme related to the timing of Carer's Assessments. These mentioned the long waiting times to be assessed, and then a wait for the identified outcomes to be actioned:

² Guest, C., Corrigan, O., & Koffman, O. (2015) 'You really do give up your own life, once you became a full-time carer': Exploring the lived experience of carers in South Essex.

<http://www.healthwatchessex.org.uk/what-we-do/topics/carers/>

³ Healthwatch Essex (2014) Voice Network, Carers video <http://www.healthwatchessex.org.uk/what-we-do/topics/carers/>

"There is a long wait between requesting a Carer's Assessment and actually getting it done. Actions agreed in Carers Assessments take longer even than the time for getting it done in the first place.

"The system seems very lengthy and complex for carers to follow especially when they are usually over tired and on their knees due to the demands of their caring role".

"My friend had to wait ages to get a Carer's Assessment. Eventually it was done over the phone but she was left very confused afterwards to know what the outcome was".

Other respondents commented on the constantly changing nature of the caring role, which means they should be re-assessed frequently as their needs as a carer changes. One person said there used to be a process for this to happen, but it had now stopped:

"A one off assessment wasn't enough as I needed follow up support for a long time".

"The carers role/situations is constantly changing. There used to be a process where a repeat assessment was carried out annually over the telephone but this useful tool seems to have been dropped".

"I was told I would have an assessment after my husband was discharged from hospital but that never happened!"

We also asked carers who had not had a Carer's Assessment their view on the value of having a Carer's Assessment. Thirty six percent (36%) said they believed that having one help them in their caring role, whereas 51% said that they were unsure. A further 13% who reported that they did not think having a Carer's Assessment would help them.

The majority of survey respondents reported that they were unsure whether having a Carer's Assessment would help them in their caring role. This suggests there is a lack of clarity on the role and purpose of assessments and that the awareness around possible outcomes and support is low, as one respondent commented:

"Would like more information on possible outcomes to help decide whether to ask for one".

In addition, a professional commented on the conflicting information given to carers about what they can expect from a Carer's Assessment, which leaves them confused and powerless about the outcomes and support they can expect to receive:

"We signpost for Carer Assessments and let them know what might happen, but quite often the SW (social worker) will tell them different conflicting things and/or not be clear. They are left confused and feel unsupported and let down, when they should be feeling more supported".

3.2.3 Finding out information

Difficulty in finding out information about Carer's Assessments also emerged as a key theme within the survey. Of those people who had not had a Carer's Assessment, 23% said they knew where to get more information about getting a Carer's Assessment, but more than half (59%) said that they did not know where to get information, or were not sure where to find this information (18%). Some of the comments demonstrated a lack of knowledge around where to find information and how to get a Carer's Assessment, however one respondent felt they would be able to find the information themselves:

"Although I do not know where to get more info, I feel that I would be capable of seeking help if needed".

"I have been in need of a Carers Assessment for quite some while... I don't know how to get one".

The lack of knowledge around where to find out further information suggests that Carer's Assessments need to be promoted more widely so that people are aware of their rights and what extra support they can expect from the assessment.

4. Conclusions

The key findings from the survey were around awareness and ease of obtaining assessments, and carers' experiences following an assessment:

4.1 Awareness and ease of obtaining assessments

Whilst most of the respondents had heard about Carer's Assessments, not many had had one. Several said they had found it difficult to access Carer's Assessments, with some suggesting they reached breaking point before being offered one. They were frustrated with the long waiting times to be assessed, and then waits for the identified outcomes to be actioned.

This confirms the findings from the Healthwatch Essex study into the lived experience of unpaid carers in South Essex which found that people's experiences of Carer's Assessments were unnecessarily bureaucratic and impersonal.⁴ It suggests that carers find formal support systems characterised by poor access, lack of continuity and often left carers feeling isolated and uncared for.

4.2 Experience following an assessment

A large number of respondents reported that they did not think, or were not sure, whether having a Carer's Assessment had helped them in their role as a carer. The main reason why carers believed they experienced negative outcomes was a lack of funding and resources.

It has previously been found by Healthwatch Essex that carers can be left feeling confused about access to and availability of help and support following an assessment. We also found that encounters with professionals that leave carers feeling dismissed and ignored can slowly erode their trust in services.⁴

⁴ Guest, C., Corrigan, O., & Koffman, O. (2015) 'You really do give up your own life, once you became a full-time carer': Exploring the lived experience of carers in South Essex.
<http://www.healthwatchessex.org.uk/what-we-do/topics/carers/>

5. Recommendations

The findings of the survey lead us to make the following recommendations:

Promotion of Carer's Assessments

- i. There needs to be active promotion of Carer's Assessments, including what they are, how to access them, and what outcomes carers can expect when they have a Carer's Assessment.

This could include raising awareness of how Carer's Assessments can benefit people who are caring for others, including those who might not consider themselves to be 'a carer' - such as through using real life examples and positive case studies.

Review what is currently being provided

- ii. A review of outcomes of completed Carer's Assessments should be undertaken to find out what carers actually experience in terms of outcomes or interventions which have occurred as a result. Healthwatch Essex would be well placed to undertake this further investigation.
- iii. Commissioners should seek a commitment from providers of Carer's Assessments to use carer feedback to improve the access and quality of Carer's Assessments.

Understand what prevents carers from taking up Carer Assessments

- iv. Commissioners should follow up on this report to find out more from carers about what prevents them from taking up Carer's Assessments and what would encourage them to take up a Carer's Assessment. Healthwatch Essex would be well placed to undertake this further investigation.

6. What next

The report will be posted on the Healthwatch Essex website so that everyone who took part will be able to see the report.

We will share the report headlines and a link to the report through our organisational networks, our social media and through local partner organisations with an invitation to carers to get in touch with us if they want to be part of further work on Carer's Assessments.

This report will be sent to Essex County Council and to providers who have responsibility for undertaking and promoting Carer's Assessments, giving them the opportunity to respond.

Why not get in touch?



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