What’s it like to be a carer?

A summary of Healthwatch England’s research and recommendations
About us

We are the independent national champion for people who use health and social care services. We’re here to find out what matters to you and to help make sure your views shape the support you need.
The role of local Healthwatch

There is a local Healthwatch in every area of England. They speak to local people to find out what people like and what could be improved with those running services.

They also provide information and advice about publicly-funded health and care services.
What we did
What people told us - the key themes

1. Information and advice for carers is not easy to find.

2. Professionals don’t always identify carers and their specific support needs.

3. Some carers don’t know what a carer’s assessment is, or how to access one.

4. Carers struggle to access support that meets their needs.
How many carers are accessing support services?
What kind of support services are carers getting?
When do carers access assessments or ask for support?

There are a lot of people who just get on and manage, with very little or no help whatsoever. It can be very difficult and hard to know where to go.

Carer Speaking to Healthwatch Gateshead, January 2018

How is the average carer supposed to find out about a carer’s assessment? Nobody tells you anything. I’ve had a social worker for years and it’s not been mentioned.

Carer speaking to Healthwatch Gateshead, January 2018
How many days are carers waiting for assessments and services?

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<thead>
<tr>
<th>Year</th>
<th>Assessment</th>
<th>Services</th>
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<tbody>
<tr>
<td>2015/16</td>
<td>35</td>
<td>31</td>
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<td>2016/17</td>
<td>29</td>
<td>28</td>
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Do councils have the data they need to effectively support carers?

- Very few councils held the information we requested.
- Only 23% held data on how long carers had waited for an assessment.
- 16% kept a record of how long carers were waiting for their agreed care plan to start.
- 48% of councils told us that they ‘did not know’ how many carers were resident in their area.
- The majority of those that could provide an answer referenced the 2011 census.
Why is this a problem?

- People tend to put off asking for help, and only approach their council at a point of ‘crisis’. Councils cannot manage demand effectively or offer interventions that are timely.

- There is a widespread lack of awareness among carers about what their rights and entitlements are. Councils cannot target information, or signpost effectively.

- Councils do not know how many carers are resident in their local area, or the level of need. This means councils cannot properly plan or commission strategically to get the best outcomes for the populations they serve.

- The data we do have suggests that there is a significant and growing level of unmet need. This will have a significant social impact.
Our key recommendations

1. Councils should start routinely collecting service user level data on waiting times for carers assessments and services, so that they can develop an accurate picture of local system pressure and make an evidence based case for additional resource to manage those pressures.

2. NHS Digital, at the direction of the Department for Health and Social Care, should start collecting and publishing this data from councils on waiting times for carer’s assessments and for support services to be provided.

3. The Department of Health and Social Care should develop guidance for councils on fulfilling their statutory information and advice services in an accessible and consistent manner.

4. Councils, along with their local Clinical Commissioning Groups (CCG), should work to understand the number of carers in their local area, and develop a profile of their level of need. Support services should be planned and commissioned around this data, focussing on addressing current gaps in provision and unmet need.
Any questions