healthwatch

What's it like to be a carer?

Healthwatch England policy briefing

October 2018

What is it like to be a carer?

Conversations that the Healthwatch Network has had with 5,000+ carers over the past two years, as well as research and data we've gathered, shows that people don't always get the support they need.[1]

They have difficulty accessing the assessments to which they are entitled and councils often don't have the systems in place to understand the number of carers in their area, or the support they require.

As we approach the publication of the government's Social Care Green Paper, it's vital that carers' needs are considered a priority. This briefing summarises our research into the support available for carers, and their experiences, to shape the green paper process and to improve the accessibility and quality of support for carers.

Key messages

- We know that the number of carers is increasing and that they are doing more than ever.
- The Care Act sets out the rights carers have to assessments as well as information and advice. However, our research suggests that carers are not always aware of this, and only start looking for help when they reach a 'crisis' point. Any delay in accessing support at this point has an adverse effect on their health and wellbeing.
- Data we collected from councils shows that carers have to wait an average of 57 days for services once they request support. This, in and of itself, is not an overly long wait, the problem is that people are only requesting support when they have already reached crisis.
- We also found that many councils (48%) do not know how many carers are in their area, very few councils (30 or 23%) were able to say how long carers were waiting for services.
- We recommend that government puts in place steps to resolve these issues in the forthcoming green paper, including addressing council level data collection, strategic commissioning and Care Act implementation.

[1] We submitted a Freedom of Information request to every council with social care responsibility in England in March 2018. All the data we collected relates to the financial year 2016-17.

Setting the context

There are **7 million carers** in the UK

1.2 million carers spend **50 hours** or more a week performing their care duties

2 million people become a carer each year, equivalent to **6,000 a day**

61% of carers say that their physical health has been affected as a result of their responsibilities

72% say their mental health has been negatively affected

The Care Act 2014 sets out the rights of support for adult carers. It says that all councils in England must provide an assessment of the support need of any adult with caring responsibilities. Those with eligible needs should receive support from their local council.[3]

Without unpaid carers, our already over stretched and fragile social care sector would likely collapse. Carers are entitled to, and deserve, proper support and recognition for the long hours that they work. However, while councils and the social care sector continue to face rising demand and pressure, carers struggle to access that support.

Carers are a vital and growing part of our social care system, and we can't afford to overlook them.

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[2]The Department of Health and Social Care, *Care and Support Statutory Guidance,* 2015 https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance

[2] Carer's UK, *Facts and Figures* https://www.carersuk.org/news-and-campaigns/press-releases/facts-and-figures

[2] Office for National Statistics, Census Data 2011 https://www.ons.gov.uk/census/2011census

[2] Carer's UK

[2] Carer's UK, *The State of Caring, 2017* https://www.carersuk.org/for-professionals/policy/policy-library/state-of-caring-report-2017

[3] The Department of Health and Social Care, *Care and Support Statutory Guidance,* 2015 https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance

To produce this report, we spoke to 5,447 carers from 27 different local areas across England. Kate's was just one of these.

Kate's story

Kate's husband, Pete*, was diagnosed with Parkinson's Disease at 75. He later developed cancer and Parkinson's Dementia, leaving him with limited mobility and cognitive impairment and making Kate his full-time carer.

Being self-funded, Kate was left to find the information she needed on her own and, in her own words, discovered a lot of it "by accident". At the time of Pete's diagnosis, Kate told us that she was given a handful of leaflets and an appointment for six months' time. This left Kate feeling stressed and confused with very little idea of how where to go or what to do next.

As Pete's condition got more severe, like many other carers, Kate needed a break and found herself thinking "What about me?". Kate herself needed support and someone to talk to about her situation. During one of Pete's hospital appointments, Kate was referred to Carers First who told her about a Day Centre. Twice a week the Day Centre allowed Kate to focus on everyday tasks like shopping and housework, and gave her some well-deserved time to herself.

"A Day Centre meant that I could have a bit of me time, as a full-time carer you can't get much of that."

Kate also discovered a 'carers cafe', a group set up to help carers to get together and share their experiences and exchange advice. Speakers on relevant topics are also organised .

Many carers often have moments of feeling helpless. For Kate, it occurred at the end of Pete's illness as his health deteriorated due to an infection. Being doubly incontinent, Pete relied on Kate to change him and make him comfortable. The evening before his admission to hospital, Pete couldn't provide any assistance and Kate physically couldn't do it alone.

"Things always seem to be worse late at night, you feel even more cut off and helpless."

Phoning the emergency number for social services, Kate was referred to a duty social worker who said that there was no possibility of anyone coming out to help her that evening. Distressed, Kate phoned the out of hours GP and then 111 asking for help. 111 informed Kate about the Impact Team, a team of NHS community nurses, and sent a couple to help her soon after midnight, six hours after her original call.

"If the social services team had only known about the Impact Team I could have had a solution four phone calls and several hours sooner. There doesn't seem to be any joined-up thinking."

Unfortunately, Pete's condition deteriorated even further whilst in hospital, to the extent it was not feasible for Kate to take him home. Once again, she was left to fend for herself, with no discharge meeting or care plan she found a suitable nursing home for Pete, who sadly passed away ten days later.

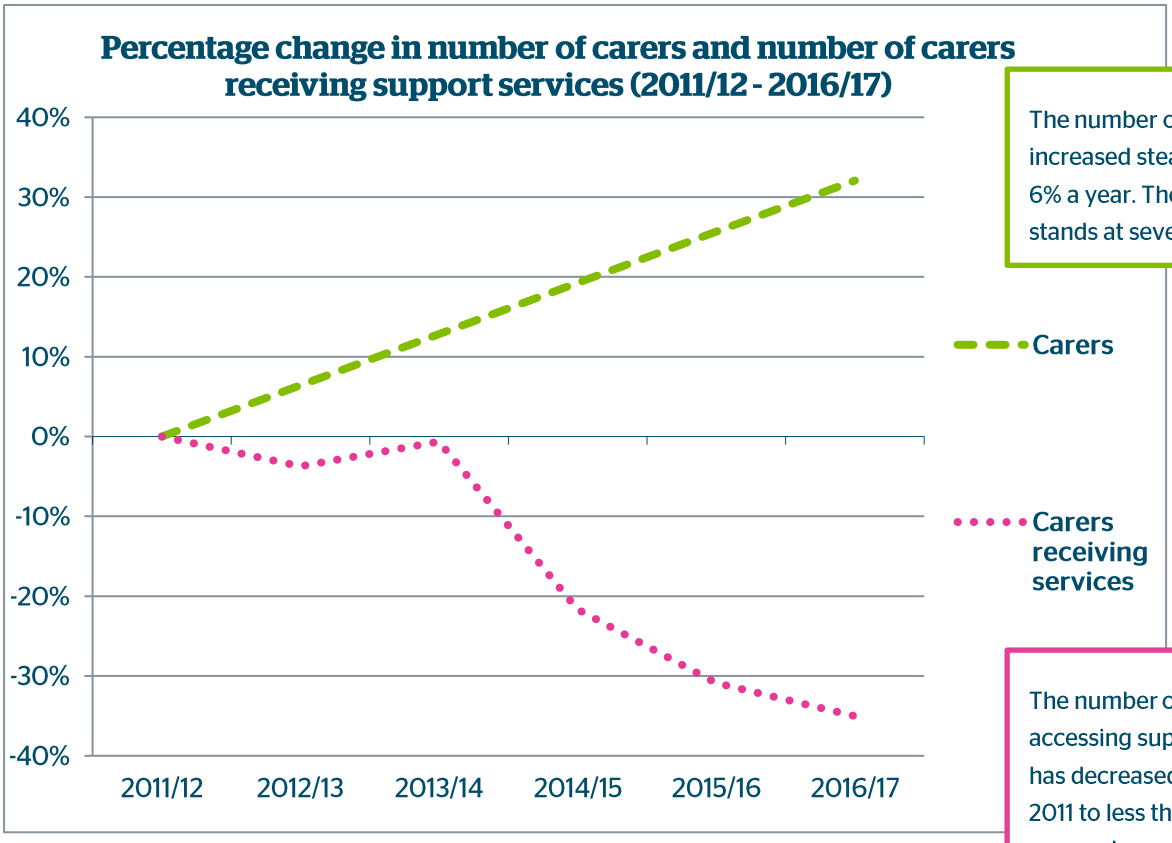
Support available to carers

Many people have told us about the difficulties they have faced in accessing support from their local council. Carers often report that support is only available once they reach crisis and little is done to try and prevent them reaching that crisis point.

> **"What could they say to keep me going? 'We have emergency respite'. Just knowing it's there would help."**
>
> Carer speaking to Healthwatch North Tyneside, July 2017

> **"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

The data shows that the number of carers accessing support has fallen steadily over recent years. This is despite the growing level of need and the introduction of the Care Act in 2015, which should have helped drive support to more carers.



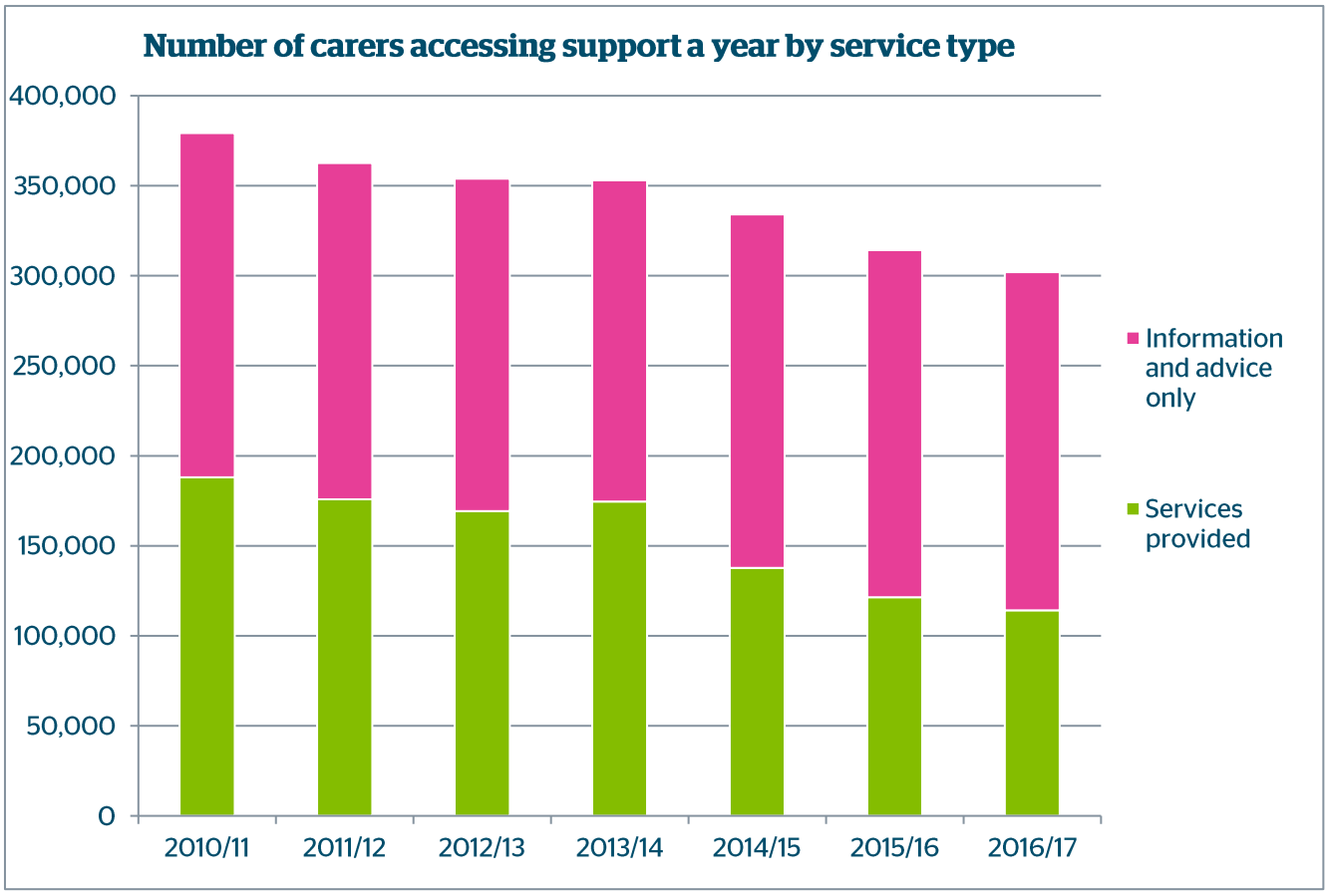
The number of carers receiving support from their council decreased by 35% between 2011 and 2017.[4] Over the same time period the number of carers increased steadily by 6% each year.

Less support is being offered to carers, while demand for support is rising. This has resulted in a situation where more carers are living with unmet support needs and only receiving formal support when they reach a point of crisis.

Information and advice for carers

Under the Care Act, Councils have a duty to provide information and advice about local support services, so people know where to turn when they need support, and to help them plan for their future needs.

A lot of carers, as well as people with care and support needs, have told us that accessing reliable information and advice about local services is challenging. Over recent years the number of carers accessing information and advice services has decreased, though at a comparatively slower rate than the number of carers receiving support services.



[4] *NHS Digital, Adult Social Care Activity and Finance Report* https://digital.nhs.uk/data-and-information/publications/statistical/adult-social-care-activity-and-finance-report/adult-social-care-activity-and-finance-report-england-2016-17

The chart shows that last year 188,000 carers accessed a local authority information and advice service, a decrease of 2% compared to 2010. While the decrease is relatively small, it is surprising. We would have expected the figure to have increased steadily in line with growing levels of need and the duties placed on councils in The Care Act.[5]

We would also have expected that as fewer people received formal support services, the number of people receiving information and advice, or other signposting services, would have increased proportionally.

Waiting times

The Care Act says that all carers are entitled to an assessment for support from their council.

However, many carers have told us that it's often difficult to access assessments for support, while many aren't even aware that they're entitled to one.

We also know that when carers do get an assessment, it can have a positive impact on their health and wellbeing.

> **"Having the wellbeing check was like a release valve going off, somebody finally seeing that I'm still a person and one that can't do it all, all of the time.**
>
> Carer speaking to Healthwatch Torbay, 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

While carers' assessments can effectively identify and address people's support needs, people aren't receiving them at an appropriate time, and aren't aware of what their rights are. This means that carers are often not in a position to plan and arrange support until an urgent need arises.

> **"Mum (sole carer for her two children who are autistic) has told them [social services] she is desperate and at rock bottom. She has only recently started getting disability allowance, but only because NHS staff told her about it. She has asked for respite or some support, but no-one seems to be helping her."**
>
> Carer speaking to Healthwatch Kent, February 2018

[5] In 2014/15 NHS Digital changed their data collection methodology. In our estimation this change has had no substantive impact on the numbers reported.

Coupled with issues around accessing assessments, we also found that carers have to wait a long time for assessments and services, despite often being at a point of critical need.

We submitted a Freedom of Information request to every council in England asking them for:

- the average (arithmetic mean) time carers had to wait for an assessment once requested
- the waiting time between the assessment having been completed and the agreed package of support beginning.

The data we received showed that on average, a carer has to wait 57 days from requesting support from their council, to getting the support they need.[6]

A waiting time of 57 days between requesting an assessment and receiving services is not unreasonable given the pressures councils are under. What is concerning, is the level of need and urgency that people requesting assessments are in. A wait of over two months when a carer's need is urgent is likely to have a severe impact on their wellbeing.

The number of councils who hold this data is very small. Only 25% were able to provide the data we requested.

While a problem has been identified, a lack of clear data will prevent us from properly understanding the true scale of the issue and the resources needed to resolve it.

Identifying carers and their needs

Councils are under significant financial and demand driven pressure, as such many are struggling to plan, commission and provide services to carers, and often they do not have an accurate understanding of the level or scale of need within their local area.

Only a quarter of councils record data on how long carers have to wait to receive assessments or support services. While anecdotally and from qualitative evidence we know many carers experience very long waits for support, without clear, localised data and insight into the scale of the problem it will be harder to resolve. It also makes it harder for councils to make a strong, evidence based case for additional resources to meet the needs of carers.

We asked every council in England what assessment they had made of the number of carers who lived in their area. 48% told us that they didn't know, or had made no assessment.[7]

[6] Values given are a weighted average, derived from council level data on arithmetic mean waiting time and number of assessments requested.
[7] Of 152 councils responding 'do not know' to Freedom of Information request 'According to the council's estimate, how many carers are currently resident in the council area?' submitted in April 2018.

This is a considerable gap in council data. The fact that this data is not always available is a major barrier to properly planning service delivery, and ensuring that the duties councils have under The Care Act are fulfilled.

Conclusion and recommendations

What we've heard from the public, as well as the data we've collected and analysed, highlights the fact that carers provide an invaluable service. It also highlights the little recognition they get, and their struggle to access the support and assistance they're entitled to when they really need it.

Many councils are struggling to provide timely assessments and support to carers, and many carers are simply doing without until their need becomes urgent.

The Care Act provides a clear and strong framework for how councils should support carers, but the evidence we've seen suggests that the intentions of the Act are not being delivered.

We've also seen that many councils lack the data and insight to understand the needs of carers in their area. To address these issues we suggest that:

1. Councils should start routinely collecting service user level data on waiting times for carers assessments and services. This will 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 carers' 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 so that they can consistently identify carers before they reach a point of crisis. Support services should be planned and commissioned around this data, focussing on addressing current gaps in provision and unmet need.

Acknowledgements

We would to say thank you to all of the carers, family members and friends whose views and experiences are crucial in helping us to achieve our aim of improving health and social care services for everybody across the country.

Thank you to all of the local Healthwatch, and those working with them, for sharing the experiences of people who care for somebody else.

We would particularly like to say thank you to the following local Healthwatch whose dedicated work with carers over the last four years has contributed towards developing our understanding of carers living in England today:

Bexley, Blackburn with Darwen, Bolton, Bradford and District, Brent, Bristol, Cheshire West and Chester, County Durham, Croydon, Derbyshire, Essex, Gateshead, Hampshire, Haringey, Lambeth, Leicester, Norfolk, North Somerset, North Tyneside, Reading, Slough, Staffordshire, Torbay, Tower Hamlets, Wakefield, Wandsworth and Wiltshire.

We would also like to thank all of the external organisations who have reviewed and commented on this work as it progressed, including:

ADASS, Age UK, Alzheimer's Society, Carer's Trust, Carer's UK, CQC, LGA, LGSCO, NHS Digital, NHS England, NICE, The Nuffield Trust, the MS Society, SCIE and Sense.

About us

Healthwatch is the independent champion for people who use health and social care services. We exist to ensure that people are at the heart of care.

We listen to what people like about services, and what could be improved, and we share their views with those with the power to make change happen. We also help people find the information they need about services in their area.

We have the power to ensure that people's voices are heard by the government and those running services. As well as seeking the public's views ourselves, we also encourage services to involve people in decisions that affect them. Our sole purpose is to help make care better for people.

Role of local Healthwatch

There is a local Healthwatch in every area of England. They provide information and advice about publicly-funded health and care services.

They also go out and speak to local people about what they think of local care, and share what people like and what could be improved with those running services.

They share feedback with us at Healthwatch England so that we can spot patterns in people's experiences, and ensure that people's voices are heard on a national level.

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