



Carers said...

Finding information,
advice and support
for the caring role

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Essex



The Department of Health is currently working on a new strategy for carers that will set out how more can be done to support them. They have set up a ‘Call for Evidence’ so that they can hear from carers, those who have someone who care for them, businesses, social workers, NHS staff and other professionals that support carers.

They want this strategy to take into account the lived experiences of carers, including their health and financial concerns, so that they can access the support they need to live well while caring for a family member or friend.

Currently there is a gap between what national initiatives set out to achieve and the experiences that carers have themselves as individuals.



Carers said...

“I think it’s important for them to hear the stories and what we go through and what we have to face because every day is a challenge. It’s a 24 hour job... you’ve got to think about them all the time, make sure they’re safe and that you’re doing the best for them.”

Janet - Carer

collectively with carers, to invest wisely and to act decisively to address the challenges facing carers.

“Hearing is the key. So if you’re asking people what they think, even if it’s boring and they’re going on, if you’ve asked you must listen!”

Ann - Carer

Through this submission, Healthwatch Essex hopes that:

- this report will bring the lived experience of carers in Essex to the heart of where national policy and strategy are developed, so that the local voice of carers can influence how support and services for carers are developed and organised.
- the insights that carers have provided will be used to strengthen local initiatives for statutory and voluntary agencies to work

Acknowledgements

Healthwatch Essex would like to say a huge thank you to all the carers who took time out of their busy caring schedules to share their experiences with us and to help us to better understand their lived experiences.

Thank you to Essex County Council and also to the community support groups who allowed us to meet with their members and beneficiaries and reach a wide range of carers from a variety of backgrounds.

Executive summary

This report outlines what Healthwatch Essex has learnt by listening to carers using a variety of methods. Our work provides an insight into the lived experience of carers, and shows that carers have hugely diverse needs and experiences. Whilst this can make it difficult to generalise about the experience of carers as a single category, we have, in this report, tried to identify common themes relevant to the consultation.

Above all, we have learnt that carers often don't put themselves first. In fact, carers have sometimes told us that they don't really want services for themselves - they want services that will make the lives of the people that they care for better. This is because where services don't meet people's needs, this can put additional pressure on carers.

Yet whilst carers may not put themselves first, they play a crucial role as the 'glue between services' for the person they are caring for. Carers often play a role in bringing different parts of a complex health and care system together, in mediating and personalising this care, and acting as a single point of contact or conduit for information.

“We just carry on as carers day to day - it becomes a normal role, just part of your life. We don't often think that we have got help out there when we should get it...”

Frank - Carer

Our work - such as the research study, *Exploring the Lived Experience of Carers in South Essex*¹ - provides an insight into what the everyday experience of being a carer is like, and what it feels like knowing that tomorrow is likely to be filled with many of the same challenges as today. In particular:

- Carers will often only recognise and use services to support themselves in their caring role if they have identified themselves as a 'Carer.' Often this only occurs once the carer is in crisis, hence understanding what would enable earlier identification would help services to be more pro-active in their support.
- Carers often find it difficult to navigate through a maze of information and services. They want more joined up, personalised services for the people that they care for and want to be recognised and respected as being an important 'cog' in that persons care.
- Carers often have different support and advice needs during their time in the caring role, such as at the point of diagnosis when they are more likely to seek information about the condition of the person they care, rather than find out about support for themselves.

The more intense the carers' role becomes the more you are silenced.

Christopher - Carer

¹ <http://www.healthwatchesessex.org.uk/wp-content/uploads/2015/04/Healthwatch-Essex-Carers-Report-Full.pdf>

Background

There is no shortage of existing research and guidance in relation to carers, yet all too often the voice of carers is 'seldom heard'. As Healthwatch Essex, we are an independent charity that listens to and represents the voice of users of health and social care in Essex, including carers. There are estimated to be around 146,000 unpaid carers in Essex who look after another person every day who may be ill, frail or disabled.

The work underlying this submission reflects the lived experiences of many hundreds of carers who live in Essex.

In an attempt to gather the stories and experiences of a diverse section of carers caring for people with a wide variety of need, we spoke to people on a one-to-one basis using interviews, as part of small focus groups and as part of larger meetings and community events. This included established Carer Support Groups and meetings of condition specific voluntary and community organisations, user and carer meetings, employee carer groups linked to statutory sector organisations as well as running our own events. We also invited individuals to write about their experiences for a series of Blogs which we published on our website.

In what follows, we have tried to capture and summarise the experiences of these carers in such a way as to be relevant to the Department of Health consultation.

The right information... at the right time

“Behind closed doors, many families are caring for family members, partners or friends. You don't even stop to think “I am a carer now;” you look after someone because you love them, because it's for better and for worse, because it's your responsibility and they would do it for you if the situation was reversed, because you are the one who can.”

Anon - Carer

There is no one sort of person who is a carer – they're just someone who sees that another needs a bit of help and steps in. Sometimes it becomes more complicated than perhaps both had anticipated. Often people don't set out to become carers but slowly the tasks grow and they become immersed in a caring role alongside all the other responsibilities of day-to-day life.

“To anyone else who is caring for someone, I am thinking of you, you are doing a great job in tough circumstances, even if you don't think you are. If you are feeling low or exhausted please do get help from every agency or service out there, they are there to help you – don't wait till you reach crisis point; there is help, advice, respite and support.”

Anon - Carer

When someone begins their caring role the systems are confusing. There are services out there who provide excellent support for carers, but those carers who haven't previously self-identified or sought help before, need signposting to it from whichever service they turn up at whether it is their GP, the mental health trust or local community carers group. This can help to empower people to meet their own needs, and in some cases, may help to prevent a situation reaching crisis point.

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

Anon - Carer

Carers in the community

Many carers told us about how they had found out about support and services available to them from other carers in their community. A number of them described how they had encouraged others to identify themselves as carers and to access support for themselves and made recommendations about services that they themselves had found useful.

“My next door neighbour... I said to him there is help out there through carers [support group] and I also gave him the number of the lady that I had at Citizens Advice Bureau.”

Carolyn - Carer

We found that older carers, working age carers and parent carers had very different help-seeking behaviours and support channels. Older and parent carers were more likely to access 'peer support' through school or carer support groups. Working carers and carers of working age presented as particularly isolated in their caring role.

Parent carers of younger children were more likely to depend on peer support provided either informally at their children's school or through 'coffee mornings' and informal drop-ins. Difficulties with the completion of forms and the complexity of the benefits system were talked about more often within this group of carers.

Carers talked about getting together to offer informal peer support. It has not been possible to capture the extent of the existence of carer 'peer support groups' across Essex, as these often run very informally - such as a group of carers getting together over lunch once a month - yet for some carers they are considered a lifeline.

In terms of advice, information and support, working carers and carers of working age showed more reliance on internet and social media for information and support.

“If I need to find out anything I ask my Cystic Fibrosis Mums Facebook group.”
Anon - Carer

National research undertaken in 2015,² in partnership with carers organisations, found that carers value the internet for accessing support through online communities, for researching health conditions and for finding information to help with their caring responsibilities.

“If you've got access to the internet, that's where you'll find most information these days.”
Kristian - Carer

Access to the internet and social media were seen by some to be an important tool to help carers save time, bring information together in one place and offer flexible and tailored support when carers need it - night and day.

“A lot of it I have to find out myself, which is just by having a practical mind and being told 'We can't get you that' and thinking - well it must exist!”
Chris - Carer

Some carers, particularly older carers, reported that they did not have access to, or use of, the internet and therefore may be missing out on the benefits the internet can bring making them further disadvantaged as more and more information and support is delivered using technology.

2 Tinder Foundation (2015), *The Health & Wellbeing of Unpaid Carers; where can digital skills and community support add value?*

Finding the right information, advice and support

“Help is out there if you can make the right contacts.”

Frank - Carer

There is a wide range of information and services available which aim to match the needs of a diverse range of carers and their individual caring situations. The key question is whether carers want to depend on a single point of contact which is easier to market, or whether carers want to be able to ‘pick and mix’ from the services which work for them.

Overall, carers want reassurance that when things begin to get too much, they can rely on the reciprocal support of services that they have implicitly supported through their caring role.

“It is vitally important that we look after carers, because we’ve got nothing without them; the country would just fall down on its knees without carers and most of its done for free.”

Carol - Carer

A key issue for carers appears to be the point at which a carer is identified as such, and takes on this label. At the point of diagnosis of their cared-for person, carers will often not immediately identify themselves as a ‘carer.’ This is likely happen at a later date, but should ideally happen at a point before they find themselves in crisis.

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

Anon - Carer

Identifying carers and encouraging them to self-identify can be one of the main challenges in supporting carers. But for those carers who identify themselves (or who are pro-actively identified) as a carer, advice and information can be accessed and is greatly appreciated.

Yet, what we heard from carers is that they need support a lot earlier. They need services to be much more proactive about identifying them, the role they’re playing and the impact that might have on them. That way they can get information advice and access to support earlier in their caring role.

“Carers often don’t really accept that they are carers - they think that they can do it all themselves and in the end they end up being as ill as their loved ones.”

Kay - Carer

Carers cannot continue to provide care without financial security and protection from financial hardship, both in the short and long-term. Nearly half of carers providing the greatest levels of support have told Carers UK that they are struggling to make ends meet.³ The financial impact of caring is often long-lasting and continues even after their caring role has ended.

“With the minimum wage increasing, if you’ve had a personal budget for many years it gets increasingly more difficult to hold onto good personal assistants.”

Anon - Carer

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

Anon - Carer

Many carers reported the difficulties of managing their way through complex benefits systems; particularly those who were caring for more than one person or who had disabilities themselves.

In line with national research,⁴ carers in Essex told us that many of them had given up work, or had reduced their working responsibilities because of their caring responsibilities. Given the stresses and strains that can result from balancing multiple responsibilities inside and outside the workplace, it is unsurprising that one in six carers give up work or reduce their hours to care.

“The more employers can do to limit the levels of depression and stress, the more it will bring down the costs of employee sick leave and other hours of business lost.”

Anon - Carer

Nationally, it is estimated that one in nine people in the workforce are juggling care with paid work.⁴ Staff survey results for Essex County Council and South Essex NHS Partnership Trust place this figure at more like between 23 to 25 per cent of their workforce.

Information and support from voluntary and community organisations

Many carers talked about two key issues: first, finding the information needed in a timely fashion, and then secondly the difficulty of managing their way through the vast amounts of information that was available.

“Central point of contact - that’s all I ask for. As a full time carer I don’t have time to see all these different groups.”

Frank - Carer

“Just said ‘we will send you a pack to read.’ No follow up, no useful advice.”

Jim - Carer

Trusted, local support from community organisations are often considered to be vital to the health and wellbeing of carers, but are also key to delivering support and learning in friendly and safe environments which carers are more likely to stay engaged with and benefit from.

Yet carers report very mixed experiences of community and voluntary organisations. For some the support that they had received from carers support organisations was describe as a ‘lifeline.’

“A personal visit and a person who cared about my concerns and how best they could be met and by whom.”

Anon - Carer

“Action for Family Carers - that is the one place who helped me when I really needed it.”

Janet - Carer

For others, the support provided through ‘condition specific’ organisations was found to be the most useful.

“You don’t want to speak to just anyone do you? You know, a ‘jack of all trades’... you want someone who knows about your loved ones condition and how it affects them.”

Anon - Carer

Carers reported that they tended to use condition specific organisations for information, such as the MS Society, Age UK, and Parkinson’s UK. This was reported to be particularly the case at the outset of caring, and perhaps at a point at which they had yet to self-identify as a carer. A number of carers talked about ‘growing out’ of these condition-specific organisations after a while - when they were comfortable with their knowledge levels. Many then continued to use ‘all-purpose’ carer support groups or turned to peers for support.

⁴ Carers UK (2016), *State of Caring 2016*.

Most spoke about using different bits of information from different organisation to get a blend of support that helped to meet their needs, as well as the needs of those they cared for.

What came across consistently was that voluntary and community organisation were highly regarded for providing what was described by one carer as – **“information in a human form.”** **Bob - Carer**

“I would certainly recommend Alzheimer’s [Society], they were definitely a great help to me both in doing a practical course as well as giving advice... and general carers [support group] here. The two together have been almost my entire form of advice.”
Peter - Carer

In addition to access to information and advice, carers appreciated the support that they got through accessing respite care for their cared-for.

“Sometimes you want just a break to think, to do something other than the practical 24 hours a day... help with things like helping someone to wash, dress, go to the loo, help them as they walk, give them their medicine and lifting them.”
Anon - Carer

“I was offered support and respite. Made a big difference to our lives.”
Anon - Carer

However, respite care in itself was not seen as a ‘fix all’ solution, and sometimes was reported as coming with its own pressures.

“Even when you do get a break it’s hard to shift out of being the carer and you start worrying about what’s going on at home or upstairs while you’re not there.”
Anon - Carer

Information and support from health and social care services

“PALS has made a big, big difference because it meant there was somebody... they have contacts. It might be the wrong thing to say that they fight our corner but that is exactly what they are doing.”
Mary - Carer

Carers told us that they can often struggle to navigate the complicated pathway between the NHS and social care and access financial support in a very complex social security system.

“Statutory organisations need to work together... joined up working for all the statutory organisations will be brilliant if it happens.”
Liz - Carer

We often heard frustration from carers about how when services don’t work together, carers keep having to repeat their story multiple times to multiple agencies. They expressed a desire for systems to work better to support the people they care for, so that this, as a by-product, would support them in their caring role.

“Why do we as carers need to keep repeating information to every professional that engages with our daughter who has a learning disability? Surely there must be a way of collating information previously provided or recorded centrally, so that all teams can have access to the information, and read and study the information in advance rather than just having to start afresh each time?”
Dave - Carer

The Care Act 2014, which came into effect in April 2015, strengthened the rights and recognition of carers. It gave local authorities a legal duty to assess any carer who requests an assessment or who appears to need support.

Carer Assessments are one way in which carers can be identified by local authorities in order to access the support that they need. However when surveyed by Healthwatch Essex, many carers were not aware of how to access an assessment and some reported having to reach breaking point, or argue their case, before being able to access a Carers Assessment.

“It was only when things reached crisis point that I was offered a Carers Assessment. I had visited GPs, Hospital Consultant Appointments, day centres but no one offered me any support to care for my wife. They all knew I was struggling, but not till I was on my knees did they mention this.”

Anon - Carer

In the Healthwatch Essex report, *‘Carer Assessments in Essex - What do Carers say?’*⁵ two thirds of carers reported that they did not think, or were not sure, whether having had a Carer Assessment it had helped them in their role as a carer.

The Carers UK ‘State of Caring’ 2016⁶ research found that those supporting someone with a mental health condition were less likely than other carers to access a Carers Assessment within six months.

“When is it going to become standard practice that any close friend or relative of someone with alcohol or drug problems, who comes into contact with police or any of the treatment or mental health services, is automatically encouraged to have a Carers’ Assessment, looking at the situation which they are in and their support needs in their own right?”

Rose - Carer

Some carers of people with mental ill health reported positive experiences of working with their local mental health trust. However this was not universal.

“I would go to my local mental health team, we have a good resource centre in our area.”

Sue - Carer

Building services for carers using carer’s lived experiences would assist in the development of good and fit-for-purpose support. At Healthwatch Essex, we know that often NHS and social care arrangements for patient and customer feedback are often fragmented between departments and organisations.

This fragmentation hinders planning and militates against providing a good experience for patients and service users.

“How can we improve the relationship between carers and Health professionals to better use carers’ knowledge of the person they care for?”

Les - Carer

5 <http://www.healthwatchessex.org.uk/wp-content/uploads/2016/01/Carers-Assessments-in-Essex-FINALv2.pdf>.

6 Carers UK (2016), *State of Caring 2016*.

Carers told us that they want services that wrap around the individual and the family, rather than having to deal with systems that simply don't flex to meet the needs of people. A particular area of frustration were the difficulties that carers experience in negotiating information sharing with professionals.

“One of the big issues is around information sharing protocols, I think that's the key issue in my view because at the moment it's a massive barrier to supporting carers if workers feel that they can't talk to the carer because they don't have permission to do that.”

Rose - Carer

Technological support

“I think what people who need care, and their carers, really need is a support network and any technology is not a replacement, but an aid.”

Anon - Carer

Technology-based solutions need to be considered given the challenges associated with delivering interventions in the currently changing economic, social and environmental situation within which we live. This is a rapidly developing area as new technologies develop.

“My experience of trying to look after people with technology is that it is very difficult and often doesn't work...”

Anon - Carer

Technology can make support available to those who might not be able or willing to access traditional support for families involved in caregiving, such as those living in rural areas or those who have other family or work calls on their time.

However in our engagement with carers we have found that carers were often unconvinced of the benefits of technology and were suspicious of it being used as a backdoor way to reduce support services.

“... if they are seeing technology as a cost-cutting exercise and a replacement for people it will not work. If they can see it as part of a whole package of investment, including well trained and valued staff who are given time to care for people and support families, then it will be much more successful and may well keep people out of institutions.”

Anon - Carer

Summary

Unfortunately for many carers, support often isn't mentioned until things are getting difficult to cope or manage. This stands in contrast to the ideal scenario of carers being pro-actively identified and supported to know about what support is available to them.

So, the challenge is to find and appreciate these people for all that they do for others. Our collective aim should be for support for carers to exist in the background so that carers know that, when things get tough, they already know where to go to. Just knowing that information and support is there if required can be enough.

Changing demographics and an ageing population mean that three in five people will end up caring for someone at some point in their lives. The number of carers in the UK is set to grow from six million to nine million in the next 30 years. This is an issue none of us can afford to ignore.

It's not something that can just be left and left... you just think some of this is not rocket science - let's just make it happen."

Rose - Carer

Recommendations

- 1. Greater personalisation in the assessment and tailored provision of information and services for individuals will be the one thing that will most support carers.**
- 2. More awareness raising and suitable messaging to carers at a local level to ensure they can benefit from the online and offline support already available. This could build on both generalist and specialist providers of information and support such as local Healthwatch organisations or dedicated carer support organisations.**
- 3. Continued roll out of Social Prescribing, which has the potential to provide a menu of support for carers will be key to specifically engaging with GPs going forward and will use the unique reach of community organisations to help carers understand the support that is available to them in their own communities.**
- 4. Better promotion of Carers Assessments; what they are and how to access them with information provided to carers about what they can expect to happen as a result of having one.**
- 5. Clear information sharing between organisations so that carers can stop having to tell their stories numerous times and assist the pro-active identification of carers, and the development of guidelines for practitioners about information sharing with carers.**
- 6. Adoption of Carer Friendly HR policies in line with recent legislative developments which give carers the same rights as their cared-for and gives employers the opportunity to show their employees they too care.**

I find as a carer you are not a person, you're not a human being - you're nothing. It's important that we get the respect for the job that we do.

Janet - Carer

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