Carers

Insight into what we've heard

November 2019

Contents

Did you know?

Adult Carers are one of Surrey's priority population groups[1]. Health and social care services are focussed on making sure that carers are well supported. Decision makers want opportunities to be created to help carers be part of their local community and they want them to feel less isolated.

The JSNA (Joint Strategic Needs Assessment) estimates that in Surrey[2]:

1. There are 115,216 carers (and 14,000 young carers)
2. 6 in 10 juggle work with caring
3. 1 in 4 are caring for more than 20 hours a week
4. 18,817 carers are from an ethnic minority
5. Only 1 in 4 adult carers have as much social contact as they would like

The Valuing Carers Report (2015) suggests that carers in Surrey could be saving the county £1.8 billion per year[3].

Other Carers UK research[4] suggests that:

- 1 in 8 carers (12%) report that they or those they support received less care or support services during the previous year due to a reduction in the amount of support from social services
- Almost two thirds of carers (64%) say that they have focussed on the care needs of the person they care for, and not on their own needs
- Over two thirds of carers (68%) regularly use their own income or savings to pay for care or support services, equipment or products for the person they care for
- Action for Carers research in 2018 showed that carers are looking for training to help them in their caring role

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[1] Health and Wellbeing Board Strategy

[2] Estimated in 2016, based on 2011 Census data and population projections.

[3] Carers UK and Leeds University Research: Valuing Carers 2015. The national figure is estimated at £132 billion.

[4] Source: State of Caring 2019 - Carers UK (points 7 to 10).

Executive summary

Senior leaders in local NHS and care services recognise the important role that carers play and have committed to ensuring that carers are identified and supported[5].

With this in mind, Healthwatch Surrey wanted to explore what it's like to be a carer, the advantages and disadvantages of registering as a carer and the benefits of being part of a carers' community.

We spoke to 47 carers in a variety of settings in spring/summer 2019. Most had been carers for over 2 years; many had been carers for over 10 years. We analysed what they told us and what other carers had shared with us in the last year.

We heard from a small number of people who have caring responsibilities who have not self-identified as carers (known as hidden carers) and therefore are not able to access the services that are available.

We heard that **being a carer can be isolating and stressful** and that **trying to get help can be frustrating**. Some people told us about difficulties caused by their caring role.

"It's very isolating being a carer, life is so different."

We heard that **being a carer can have a negative impact on working life**; some people have had to reduce their working hours or give up work altogether because of their caring responsibilities. We heard about people not realising that they could take unpaid leave to attend their children's appointments.

"It was only when I resigned (to look after my kids) I found out that I could take unpaid leave for my children's appointments."

We also heard about the financial cost of being a carer.

"I spent £7,000 - all my savings. The equipment is bespoke and personal to that person so I can't even sell it on."

However, we heard that **support groups can be really valuable** for sharing experiences with people who are in the same position who can empathise and listen.

"[if I didn't attend this group]… I'd be lost and miserable."

There were some carers, particularly newly registered in the last two years, who **found it easy to register and received help relatively quickly**.

"I just filled in a form and handed it to the surgery receptionist."

Carers also highlighted a number of areas where they'd like to see improvements in carers support services.

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[5] Health and Wellbeing Board Strategy

"Hospitals/CAMHS could inform parents after diagnosis instead of giving diagnosis and sending them away with nothing."

What we did

During our routine evidence gathering activity[6], over the course of the last two years, there were only 26 instances of people sharing experiences about being a carer (other carers will have spoken to us, but not about their caring role).

We decided to undertake some targeted qualitative engagement with this community in spring 2019, whilst raising awareness of Healthwatch Surrey's services. This was not a quantitative research exercise, but rather an opportunity to hear from carers in an in-depth way, and to bring their experiences to life.

We heard from 47 carers in a variety of ways and in different settings:

- A discussion group with Action for Carers
- A discussion group with Spelthorne ADHD[7] support group
- Engagement events at Action for Carers meetings where we distributed self-completion questionnaires
- Engagement event and online survey with the LGBTQ+ community, using self-completion questionnaires (which covered various topics including being a Carer)

We held two discussion groups with carers in March 2019, involving 10 people at a one-off Action for Carers' Health & Wellbeing event in Farnham and 6 people at an ADHD[8] carers' support meeting in Spelthorne, which was a fairly recently established group.

We also attended some support meetings which were regularly held by Action for Carers where we handed out self-completion questionnaires in Woking and Spelthorne in March, Ash in May and West Horsley in September. In total we received 25 completed questionnaires.

The face to face engagement with the LGBTQ+ community was held in July and an online survey was completed in September, we heard from 6 carers in total.

These activities will be referred to as targeted engagement throughout this report.

This report is based on experiences gathered during our routine day to day evidence gathering activities as well as the specific activities listed above.

Names have been changed and details redacted to protect the anonymity of the individuals that took part.

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[6] Engagement events outside services and on high streets, partnerships with Local Citizens Advice, our information & advice Helpdesk, our Independent Health Complaints Advocacy services and through Citizens Ambassadors (www.healthwatchsurrey.co.uk)

[7] Attention deficit hyperactivity disorder

What we've heard

Caring responsibilities of those we spoke to

During the targeted engagement we mainly spoke to people who were registered carers, many of whom had been carers for a long time. Of the 47 people we heard from:

- Nine had become carers within the last 2 years
- Many had been carers for over 10 years
- Most told us that they were full time carers
- Most were caring for a spouse or partner
- Some were caring for parents, children and grandchildren
- Four were hidden carers[9]
- Of the six carers we heard from within the LGBTQ+ population, only two were known to their GPs as carers, only one was registered with Action for Carers.

Most people confirmed that their GP knew them to be a carer. One person was waiting for a diagnosis for their child and was not aware that they could register as a carer until a friend advised that this was possible.

There are around 115,000 carers in Surrey

Being a Carer

Isolation

We heard that being a carer is a different mindset for some, it can be hard for others to understand the life of a carer, and that being a carer can be very isolating.

"It's very isolating being a carer, life is so different, this [support group] is so positive." Source: Targeted Engagement.

"I do all the cooking but I'm tired too and it would be nice to get out and play boules." We asked the gentleman if he considered he was her carer and he responded; ***"I'm her husband not her carer."*** Source: Hospital Engagement Event.

"It's hard for others to understand, there's an assumption that I am pandering to my children's needs when I say I can't come out for a coffee. I feel validated now that I can say I am a full-time carer. Mentally, it's good to be recognized." Source: Targeted Engagement.

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[9] Carers who are not registered with their GP

Only 1 in 4 carers are getting as much social contact as they'd like

Impact on work

We heard from some carers who have had to reduce their paid work or stop working altogether because of their caring responsibilities.

"I didn't see myself as a carer, but when I gave up my career and then did temping work, I re-labelled myself as a carer." Source: Targeted Engagement.

"I have reduced my working hours from 4 days a week to 1 day a week to prioritise care (for my mother)." Source: Targeted Engagement.

"[Gentleman] is self-employed - he has recently scaled back his hours because he is worried about leaving his wife for too long." Source: Local Citizens Advice.

6 in 10 carers in Surrey juggle work with caring

Financial costs of caring

We heard about the expense of being a carer.

"I have a disabled husband at home and I often access St Peters and Ashford for appointments, every month. We visit the consultant and use public transport to get there or take a taxi, but a taxi is expensive. Bus takes 2 hours.
I also go for blood tests. It's expensive getting there. I've travelled there before and found out once there that the appointment has been cancelled but I wasn't told. It's frustrating when you don't feel well and are caring for someone else." Source: Engagement Event.

"I'm my Mum's carer. She's been in hospital for 3 months…. They have been round to do the checks in my house... I'm just really frustrated as prior to her infection I had kitted the house out to suit her needs. I added in a chair lift, adapted her bedroom etc. She was mobile. I spent £7,000 - all my savings. The equipment is bespoke and personal to that person so I can't even sell it on. After being in here now for 3 months, Mum is now immobile. The nursing staff have told me she is now bedbound. This is because she hasn't been up and active and getting any exercise. I don't believe it - I'm glad to be having her home …. but I'm really disappointed." Source: Hospital Engagement Event.

Over two thirds of Carers regularly use their income/savings to pay for care/support services, equipment/products for the person they care for

Other considerations

We heard that even when the person being cared for is in a care home, the caring never stops. We heard about the distress of putting a loved one into a care home.

"I looked after my husband at home for 8 years, with early dementia. I couldn't cope, he has now been in a care home 13 months, caring never stops, it's not been easy for me." Source: Targeted Engagement.

"People are very critical of you when you put your loved one into a care home and I just couldn't cope anymore." Source Targeted Engagement.

We heard about the impact that caring can have on the whole family.

"[a mother's] son is very dependent on his parents and elder sister and has no independent skills. This makes him very vulnerable as he is unable to make judgements and effectively has no social life outside of school and home. Ideally, he would be assigned a 'buddy' to take him out on occasions and ensure he is kept safe. This would give [mother], her husband and their daughter some time. [Surrey County Council] did give her daughter a young carers' grant which has paid for driving lessons." Source: Helpdesk.

We heard about the strain of being a carer.

"I am a carer who is also the wife of a cancer patient. Never has anyone (not GP, Cancer Specialists or books) told me about the intolerable situation that can develop when caring for a loved one with cancer. So many marriages breakdown during this awful cancer journey, affected by so many couples. No one warns, advises of the possibility & what to do should it become intolerable for one or both." Source: Citizen Ambassadors.

Getting Support

We heard about the challenges and frustrations of trying to get help as a carer.

"[gentleman] would like to know where he can go for help with his wife."
Source: Local Citizens Advice.

"[gentleman] requested a carers assessment which was never actioned, he requested a copy of his wife's care plan and has not been provided with a copy." Source: Independent Health Complaints Advocacy.

"It took 4.5 hours to get an ambulance to my house recently - been one of 3 occasions My husband fell in the night and he is disabled and I couldn't pick him up, he's 15 stone, I can't lift him and he's literally a dead weight. I know it sounds ridiculous but what do I do, I have no one to call on in middle of the night." Source: High Street Engagement Event.

1 in 8 carers reported that they / those they support received less care or support services during the previous year due

Respite

We heard about the need for respite care.

"There also needs to be more support for carers, respite is needed. But you know you find these things out by trial and error. A minimum of 2 weeks [advanced notice] is needed to be booked for respite when I wanted a week. I've been his carer for 12 years." Source: High Street Engagement Event.

"I am the sole carer for my partner and only receive 3.5 hours per week of respite support which often does not show up, resulting in the cancellation of any appointments and other plans I might have made." Source: Helpdesk.

General Practice

We heard about difficulties caused by confidentiality rules in allowing carers to speak for the cared-for.

"[gentleman] has spoken to his own and his wife's GP. They are registered with different surgeries. His GP is unable to help because she is not his patient and did not have anything to suggest. Wife's GP unable to help because of client confidentiality; also, nothing to suggest." Source: Local Citizens Advice.

"Could there be a way for the doctor to have a form to say that the cared-for gives consent for the carer to have their letters/results etc." Source: Targeted Engagement.

Carers' own health

We heard concerns, from the people being cared-for, about what happens when their carer becomes ill.

"[Lady's] husband has been in hospital since November… she has been informed that her husband will not be able to come home… [he will] need to be moved to a nursing home. [The lady] is registered blind… [her husband] was her carer… she has been muddling along since he was hospitalised. She is very concerned about where husband may go and whether she will be able to get to the home easily." Source: Local Citizens Advice.

We heard from carers themselves who have neglected their own self-care due to their caring responsibilities.

"I was becoming very agitated… I ended up in hospital… my blood pressure was 252/137. I was sent straight to [a local Hospital]. I was kept in for 2 days… at the time when my blood pressure was first diagnosed as being so high, my wife and I were looking after my mother who had dementia. This was an incredibly stressful time. I was the carer." Source: Citizen Ambassador.

"My wife died three years ago but before that she had Huntington's disease and I cared for her for 10 years, as her carer. I was advised by the nurses to look after myself. It was because of the nurse that I found I had high blood pressure at 65 years old or so. I had not really had my blood pressure taken regularly or at all before this." Source: Citizen Ambassador.

Almost two thirds of carers (64%) say that they have focussed on the care needs of the person they care for, and not on their own needs

Registering as a carer

We specifically explored the process of registering as a carer, as we had heard that registration had declined recently. Among newly registered carers (less than 2 years), most found it easy to register as a carer. Most registered with their GP. Two people had recently relocated to the area and their new GP told them they were Carers, although they'd had caring responsibilities for much longer.

"I just filled in a form and handed it to surgery receptionist." Source: Targeted Engagement.

"I registered as a carer 2 months ago, via my GP. I then had a phone call and support from Action for Carers." Source: Targeted Engagement.

"I only registered 6 months ago when I moved house and registered with a new GP (having been a carer for 3 children on autistic spectrum)." Source: Targeted Engagement.

"…[team member] from Action for Carers found me and told me I was a Carer." Source: Targeted Engagement.

We heard that registering as a carer can be a really positive experience.
"I only recently found out that you can register as a carer, I did this via the GP 2 months ago, and have had support from Action for Carers - they have been brilliant." Source: Targeted Engagement.

"I had a telephone conversation, they were friendly, helpful, and had useful information. I had an invitation to come to the support group. The staff are amazing." Source: Targeted Engagement.

- People told us that being a registered carer can bring some benefits, such as:
- carers breaks help with getting an EHCP[10] for a child
- improved self esteem
- other practical support such as Crossroads

"I got a carers' break about 3 years ago, used it for a holiday." Source: Targeted Engagement.

"I feel validated now that I can say I am a full-time carer." Source: Targeted Engagement.

"I use Crossroads, they come to me for free and I get 3 hours off per week. They take [the person I care for] to [hospital] for chiropody appointments - they like to take [the person I care for] out for something rather than just sitting at home." Source: Targeted Engagement.

However, we also heard mixed views about registering, some people don't think that registering has made much difference.

"The GP doesn't necessarily check that I'm ok." Source: Targeted Engagement.

"We have heard of the carers' break but don't know what you can use it for or how to access it." Source: Targeted Engagement.

"[When using Carers' Breaks] … you can't go on holiday and leave them, so what can you spend it on? The GP says there's a waiting list for Carers' Breaks." Source: Targeted Engagement.

Some people who had registered a long time ago had no support when they first registered. Some people told us how they had been in their caring role for a long time before they became aware of the support that is available.

"We never heard any more after registering 7 years ago." Source: Targeted Engagement.

"I was caring for my spouse and no one approached me." Source: Targeted Engagement.

"I have been caring for my husband for 8 years, but no one ever told me I was a carer until he went into a care home." Source: Targeted Engagement.

"Going back to the start (1992) I had no information or help; I went 10 years on my own." Source: Targeted Engagement.

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[10] Education Healthcare Plan.

Being part of a carer community

Being part of a support group can be very useful in terms of sharing experiences and having support.

"There was a monthly carers' group (at The Samson Centre), it has stopped for the moment. My wife and I come [to this support group] two days per week. Coming here is about keeping things moving, the other days in the week are for living and enjoying our life." Source: Engagement Event.

We heard that Action for Carers staff are very helpful. We heard that the newly re-introduced Dementia Navigators are excellent.

We heard that people attend the groups to talk to people who are in the same position.

"The other carers and some of the support staff have become my friends." Source: Targeted Engagement.

"It's very friendly." Source: Targeted Engagement.
"[if I didn't attend this group] … I'd be lost and miserable." Source: Targeted Engagement.

"[AFC employee] is a very good person to go to for support, without Action for Carers I don't know where I'd be now." Source: Targeted Engagement.

"You meet friends who are in similar situations. You get some helpful advice." Source: Targeted Engagement.

"This is my first session, but people seem friendly and supportive." Source: Targeted Engagement.

We heard that since Action for Carers took over running the services, there have been some positive and some negative changes.

"The help received is wonderful." Source: Targeted Engagement.

However, some people feel there's a less personal service, with staff spread over a wider area, and fewer outings.

"It's not as personal as it was. They were local. They are now based in Guildford. There's no 1 to 1." Source: Targeted Engagement.

"I didn't always want to go to a big group, I used to get a phone call and an offer of a 1 to 1 meeting if I couldn't face the big group". Source: Targeted Engagement.

"Carers would like to go OUT, Trips! Not just workshops!" Source: Targeted Engagement.

Carers highlighted a number of areas where they'd like to see improvements in carers support services.

"Wider spread [of] information of the service to those who don't know about it." Source: Targeted Engagement.

"Hospitals/ CAMHS could inform parents after diagnosis instead of giving diagnosis and sending them away with nothing." Source: Targeted Engagement.

"More literature on benefits." Source: Targeted Engagement.

Recommendations

1. Carers support groups are vitally important to carers. Therefore, they should be continued to be supported and expanded where possible.
2. Hospital departments should consider signposting carers to carers support services once diagnoses have been made.
3. GP surgeries are important in terms of raising awareness that a person is a carer and signposting them to relevant services. GP surgeries should ensure they have systems in place whereby patients' caring responsibilities are flagged on the system. GP surgeries should also ensure that carers are aware of what healthcare information they will and won't be able to access on behalf of the person they are caring for.
4. This report should be made available to frontline practitioners who will come into contact with carers, but who are not necessarily staff who have specialist knowledge about carers.

Next Steps

This report will be shared with those that took part (and made available in more accessible formats) and with relevant service providers, commissioning organisations, Surrey County Council and authors of the Joint Strategic Needs Assessment.

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