



healthwatch
Surrey C.I.C

Giving Carers a Voice

Quarterly Insight Report – January 2023

Giving Carers a Voice

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What we're hearing

If you would like a paper copy of this document or require it in an alternative format, please get in touch with us.

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About Healthwatch Surrey

Healthwatch Surrey is an independent health and care organisation, empowering the residents of Surrey to have their voices heard. We seek out people's experiences of health and care services and share these with service providers and decision-makers, to support services to improve and tackle health inequalities. We believe that health and social care providers can improve services by listening to people's experiences.

We also provide advice and signposting to help the people of Surrey find the care that best suits their needs. Any urgent or concerning experiences within this report have been escalated to the appropriate teams. All appropriate information and advice and signposting to complaints processes has already been given.

Engagement October – December 2022

This quarter we have visited.....

- Guildford Nursery School
- Young carers 18+youth group
- Surrey University volunteer recruitment fair
- Wellbeing café, The Hive
- Linklight mental health forum
- Home Start, Godalming
- Action for Carers hub, Addlestone
- Spelthorne parent carer group
- Action for Carers hub, Knaphill
- Launch of End Stigma Surrey
- Patient engagement event, Camberley theatre
- St Davids GP surgery, Stanwell
- Home Start, Guildford
- Wellbeing centre, Royal Surrey Hospital
- Action for Carers hub, Shepperton
- Veterans, Surrey carers group
- Action for Carers hub, Cranleigh
- Action for Carers hub, Horley
- Veterans and families listening project, Camberley

- East Surrey Hospital
- Independent Mental Health Network meetings
- Nepalese elders meetings, Camberley
- Alzheimers café, Camberley
- Action for Carers carers rights fair, Camberley
- Action for Carers carers rights fair, Addlestone
- Learning Disabilities parent carer group, Chertsey
- Home Start, Walton on Thames
- Samson Centre for MS, Guildford
- Action for Carers hub, Shepperton
- Frimley Park Hospital
- 8th Annual Commitment to Carers Conference, London
- Eikon LGBTQ+ group, Guildford
- Action for Carers hub, Leatherhead



Main themes we have heard from October – December 2022

The word cloud below highlights the main themes we have been hearing about this quarter.



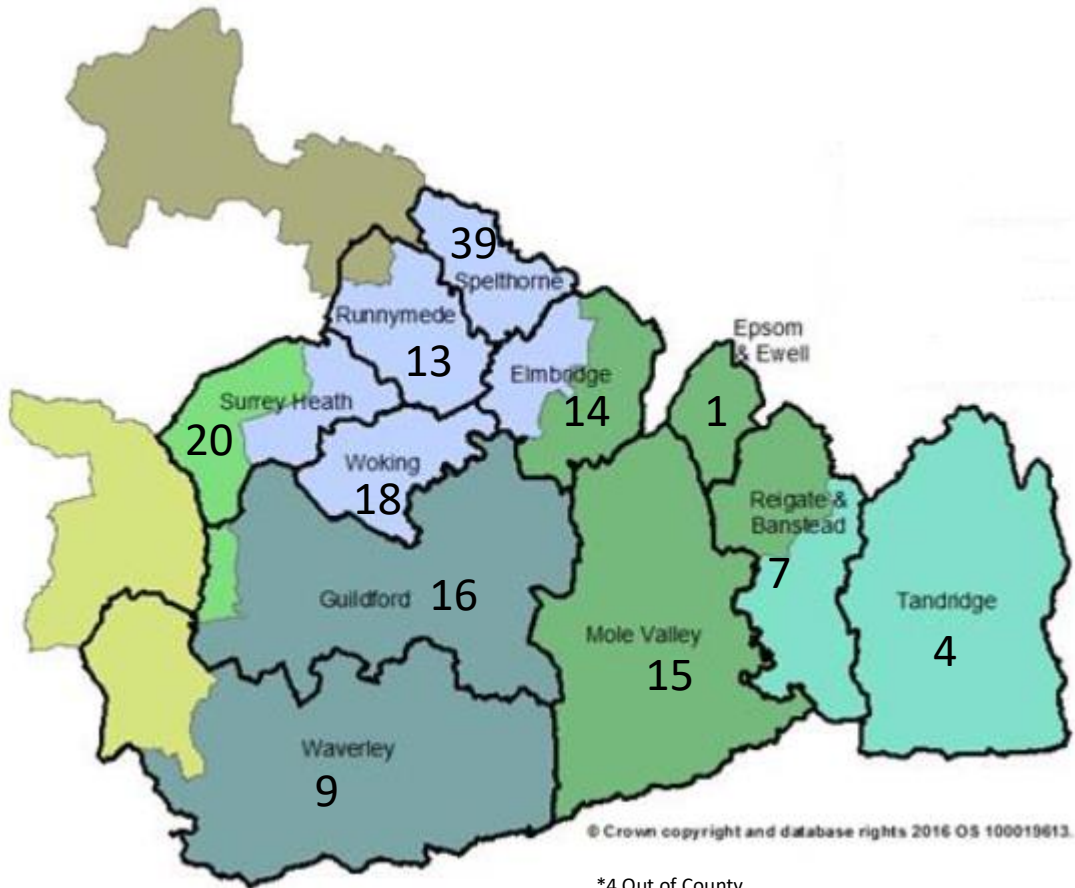
Where we have shared our insight

During Q3 we have shared carer insight (key themes and carer experiences) in the following meetings as part of our 'what we've heard' regular insight sharing meetings.

- Surrey Carers Partnership Board – 6th December
- Surrey and Borders Partnership – 8th November
- Guildford and Waverley Place – 8th December
- Primary Care – 3rd November
- SEC Amb 2nd December

Where we have heard from carers

The map of Surrey below shows the number of carers we have heard from in each area of Surrey between October – December 2022.



*4 Out of County
*9 Not known

Not identifying as a carer

We are continuing to speak to carers who do not realise that they are carers. We spoke to 169 carers in Q3, of which 7% did not identify as carers. The reason this number is lower than previous quarters is due to the targeted carer events in Q3.

“My son has ADHD but I wouldn't call myself his carer. Maybe my wife as she does more but not me. I'm sure if I asked her she wouldn't call herself a carer either. We're his parents. We do these things for him. He needs reminding to take his medication, eat properly and get dressed... We have a daughter too, she is affected a bit by her brothers behaviour but I wouldn't consider her a young carer. I guess I should ask her how she feels about her brother's behaviour. I think that she has her own needs too.”

181198, October 2022

Communication concerns

Communication continues to be a key issue we hear about.

“I am registered as a carer with the surgery but this means nothing. They offer no flexibility with the appointments and keep asking to speak to my son. He has learning difficulties. He has absolutely no understanding of what they are saying or asking him. I keep having to explain this time and time again. Why isn't this recorded on his notes. It's not only the GP though, it's all professionals.” **183598,**

November 2022

“I'm at the end of my tether. My husband had 8 falls in 7 days... My husband refuses to have carers in as he says that I can cope. I can't. He tells them that we don't need anything but I'm not coping ... [My husband] has multiple health issues and is deaf and blind. He can't remember things either. When they speak to him [in hospital] when I'm not there, they won't take their masks off and he is deaf and lip reads. He also can't see well. So he nods at things that he has no understanding of... Nobody has spoken to me about discharge and what will happen. If they were to ask him, he'd just

nod along and agree with what they were saying as he wouldn't be able to hear or understand." **180833, October 2022**

"[Carer for brother in his 40s with learning disabilities] One of the GPs had rung my brother and he had told them that he didn't want to take his tablets any more. It was agreed that I, as his carer, would always be consulted about his medication as he doesn't have the capacity. This should have been recorded on his record at the GPs. It wasn't. I now have to go through the process all over again. It's so frustrating trying to battle with everything. Sometimes the Dr will talk to me and sometimes they hide behind the confidentiality - where is their common sense? ... I have explained that when they call, they need to do this when I am there. He can't talk to them about his health issues as he doesn't understand what's going on. I see him every day and I think he has health issues that need looking into. Not speaking to me is restricting his access to preventative care..." **183040, November 2022**

"I care for my mother who is 86 and has dementia. [Mum had a fall and was taken to hospital]... She came into the hospital Friday evening and there was no communication or information whatsoever. She has dementia and would have been confused as to where she was. I couldn't talk to her as they said there was no phone... I did complain to the charge nurse on the ward about this lack of communication and not being able to talk to my mum to reassure her and explain things to her. She was in a room on her own with no TV or access to a phone. She has dementia and no one seemed to take this into account and try to make things easier for me to talk to her. I found out that she had had tests and scans and I hadn't been consulted or informed about them until afterwards. I have POA and would have liked to have been informed before to see if all these things were necessary. But if they were, I could have explained things to her. They didn't do a competency test on her all the time that she was in the ward, so how did they know what she understood and what was happening to her? They should have discussed things with me. She gets confused. On her exit notes, there is no reference to say they tested her for mental capacity... After 8 days I rang the ward and was told that she had been moved

but no one knew where she was. I thought that she had died. It was so upsetting and distressing ... My complaint is about the zero communication and limited contact that I had with my mother.”

181195, October, 2022

“[Carer for husband with mental health issues] There was a discharge meeting but as his carer, I wasn't invited. I was phoned up with the result. I wanted to be invited and I should have been involved. The voice of the carer isn't heard properly. They are just not listening. We don't have a voice. We are treated like we don't matter, dictated to and just ignored. The mental health system should be hearing the voice of the carer across the board. I naively thought that services and support for me as the carer would just kick in. I didn't realise that I would have to be proactive and be constantly ringing people. I never thought of myself as his carer. It was my GP that recognised that I was...The last 3 months have just been like a Tsunami for me.” **183316, November 2022**

Seeing things from the carers point of view.

“My husband [80] has renal failure and has been in Frimley Park for the last 5 weeks. The care he has received has been exemplary but they don't talk to me as his carer. When they do they talk, they say stuff in medical jargon which I don't understand [carer is 78] I then forget what they have said. I need them to tell me what my husband needs when he comes home as I want the best for him but I don't feel that I have all the information to do this at the moment... I feel like I have no control over what is going to happen. Who do I ask? No one seems to see things from the carers point of view.” **183256, November 2022**

“I wanted to apply for the council tax reduction as I am entitled as a carer. They required 8 different documents. The instructions were unclear. All originals. Really obscure ones such as passports, proof of income, pensions information. We're in our 80's and I'm the carer for my husband who has Alzheimer's. Eventually I decided that I wouldn't bother. When you're in the business of caring, this is all too much... My husband had to have a new hearing aid. The NHS ones

were no good and so we have paid for a very expensive one privately with Bayfields. The staff assumed that he could use an app on his phone to use the hearing aid. He has Alzheimer's and he can't. We managed to get the app on my phone but that was no good as it gave his details. Nobody asked me as his carer if he was able to use the app. The staff need training. They told us so many things and gave us so many instructions, I couldn't take it all in. I had to try to listen, remember it all and look after my husband at the same time. It's all too much. The staff should know that I'm a carer and that being the age we are, we need more time and clear instructions. Things written down. Maybe a call to see how we're getting on. It's all very confusing."

183258, November 2022

We have heard how things work really well when the carer is involved.

"They know that I am a carer and they give me flexible working so that I can attend all the appointments with him [Royal Surrey... When he was discharged [from hospital], everything was discussed with me. If I could tell any carer a top tip, it would be to tell all professionals that you are a carer from the very beginning." **183252, November 2022**

Difficulties accessing respite care

People have told us about the importance of respite care.

"[Carer for husband with dementia] Once a week for two years, we had the same lady from Crossroads care come for three hours. It was an absolute godsend. She became like part of the family. She was fantastic. My husband liked her and I trusted her completely and was able to leave my husband for three hours and go out. Three hours on a Friday afternoon isn't long and sometimes we made it to the shops in Kingston and back but then you hit Friday late afternoon traffic. But you can't choose which sessions you get at Crossroads, but I was just grateful that we had the help. I don't know how I would have coped without Crossroads care." **182295, November 2022**

Carers are finding that they can't find respite care that is suitable for them and their needs.

"My problem for respite care is that it's difficult to find sitters in the evening and that's mainly when activities are on. Crossroads care will tell you when they have a slot for you, so you don't get a choice. I was given Friday afternoons but only for 10 weeks. The sitter was wonderful though." **182322, November 2022**

"You also get no choice as to what days are offered to you. I was offered Mon or Weds afternoons. You do get to say a preference on the form but it's all down to staffing. I can't drive so I have to rely on friends who are free on a Monday afternoon. What's there to do on a winters afternoon? That's the problem too. If the respite had come through in the summer, at least I could go for walks or catch the bus somewhere. But I don't like to do that in the winter when it gets dark so early." **182830, November 2022**

Some carers however report that they are still struggling to access any respite care.

"We've just been told [2 carers], by Crossroads Care that they don't provide respite care for parent carers as they don't have the paid, trained staff to be able to do this." **183320, November 2022**

"We have no family or friends for help or for me to talk to. I don't know how I'm going to get through the weekend. I have no respite at all... We were on the waiting list for Crossroads Care but they really need to be more flexible... I feel so resentful that my life has come to a stop." **182323, November 2022**

Financial impact of being a carer

Carers have told us how caring is impacting them financially.

“My son has learning disabilities. I've just been sent a bill for £700 for home/school transport. This has come completely out of the blue. How can I afford to pay this in the current economic situation? I was told that as he no longer attends an educational establishment [attends Post 19 in Farnham] and so transport has to be paid for. You have to ensure that your child's transport needs are included in their EHCP and even then, it's not legally covered.”

183824, December 2022

“[Carer for husband in his 80s with dementia] I am worried about the cost of living crisis. He can't walk so I have to drive everywhere. Also he likes to turn the lights on, it's one of his things.” **180590, October 2022**

“[Works full time] I'm a single mum and a carer for my mum. I get nothing, no support. I put so much in and get no help financially.” **176564, October 2022**

“I can't survive on carers allowance. I'm running two homes, food shopping, and running my car. I can't afford it. It's like having two homes and four children. I do all their shopping, their laundry. I have no savings left. I had to give up my job in December 2021 to care full time for my mum. I am heading towards burnout. I cannot do this anymore. I need to save myself and my kids from poverty. I need to step back. I'm a 15 minute drive away from my parents and it's just costing me a fortune. I can't afford it. I'm on universal credit but it's not enough. I'm not trained to care for someone with dementia and I don't want to do it. It's ruining my mental health.” **182301, November 2022**

Stress and wellbeing

Once again this quarter people have been sharing their experiences about the impact on their wellbeing from being a carer.

“Being a carer has been very stressful. My stress levels got so bad that I ended up in Royal Surrey Hospital as a blood vessel burst due

to the stress. I burst the macular and now I have lost sight completely in one eye. I am a carer for my husband who has Parkinson's. I was in a terrible state until I got referred to Action for Carers. I was at rock bottom until I came to Action for Carers and since then things are improving as I am getting more support. Everyone is so helpful and supportive and it's invaluable." **182357, November 2022**

"As a carer you just plod on. I am very lonely and feel very isolated without her. We were together 6 years before she went into the home and I miss the companionship. Looking after her at least gave me a purpose, now I feel lost without her. I still visit her twice a week. I come to Action for Carers regularly for company also." **182432, November 2022**

Valued support for carers

"Without Action for Carers, mum would have been completely abandoned with caring for dad. We had no other support from the GP or other services. He couldn't get out of the house, so nor could she. COVID ultimately became our saviour with the switching of the gatherings [Action for Carer meetings] to zoom. They made such a difference to mum to hear the stories of others, getting the emotional and practical support she really needed. In turn I am sure she was able to offer support to others by sharing her experiences. But honestly without it, we got nothing." **180674, October 2022**

"I get one of my sons to come up on a Friday so I can come to the Action for Carer hub, it's so good to talk to other people in the same boat as me." **184237, December 2022**

"We have had a Home Start volunteer helper coming in for an hour [once a week] which has been brilliant and now we are coming to the [Home Start] group." **176748, October 2022**

Thank you

A big thank you to everyone we have met and who has taken the time to share their experiences of being a carer with us. Below is a list of where we are visiting from January to March 2023. If you have a group you would like us to come along to and visit then please email us at carers@healthwatchesurrey.co.uk. We are very keen to hear from as many carers as possible from all over Surrey so we'd love to hear from you!

Where we are going January - March 2023

The following table shows in the first column the places and dates for our upcoming visits.

Place	Date
Churches for Horley foodbank, Horley	04/01/23
Action for Carers hub, Guildford	09/01/23
Home Start, Farnham	12/01/23
Action for Carers hub, Epsom	17/01/23
Wellbeing café, Guildford	18/01/23
Surrey and Borders Partnership Carers Action Group	18/01/23
Eikon LGBTQ+ group, Guildford	02/02/23
Ukrainian hub, Woking	07/02/23
Action for Carers hub, Hersham	09/02/23
ATLAS young peoples group, online	01/03/23
Action for Carers hub, Caterham	23/03/23
Action for Carers hub, Haslemere	27/03/23
SEN parent carer group, Farnham	29/03/23

Please note these dates are subject to change and additional visits may be added.

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