

Luminus

Home of Healthwatch Surrey

Giving Carers a Voice Quarterly Insight Report

What we're hearing

July - September 24



● Shining a light on what matters to people.

Giving Carers a Voice

Quarterly Insight Report – July - September 2024

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 Luminus

Luminus is a Surrey based independent community interest company which exists to empower people to have their voices heard. We are an enterprise driven by social value, that invests in the local community. We help organisations provide equity of access, and the best services possible, through the inclusive involvement of local people. Our vision is to create a society where everyone's voice is heard so we all receive the support we need for our wellbeing.

Initially set up as an independent, trusted partner to communities and local health and care services to deliver the Healthwatch Surrey service - ensuring the voices of all users of NHS and social care services are heard, we have built on our expertise and experience. Luminus has grown to also shine a light on the experiences of carers, young carers, those who are affected by substance use, and people most at risk of health and care inequalities. We achieve this through bespoke projects, co-design, contracts, mentoring, research, and training.

About Giving Carers a Voice

Giving Carers a Voice listen to the experiences of carers (of all ages) to ensure their views are heard in the design and delivery of the services they use.

If people look after anyone who couldn't manage without their help they are a carer.

Engagement July – September 2024

This quarter we have visited the following places to speak to carers and hidden carers to hear their experiences and to signpost to the relevant services where needed/appropriate:

- Autism carers support group, The Lost Sheep, Caterham
- Carers group, Phyllis Tuckwell Hospice, Farnham
- YMCA parent carer group, Reigate
- Loveworks foodbank, Merstham
- Loveworks foodbank, Reigate
- Knights garden centre, Godstone
- Surrey Young Carers family fun day, Painshill
- MHA dementia friendly club, Redhill
- The Meeting Room, Leatherhead
- Horley library
- Parkinson's carers coffee morning, Ewell
- Parent carer group, Camberley.

Main themes we have heard from July - September 2024

The word cloud below highlights the main themes we have been hearing about this quarter. The most prominent words are mental health, parent carer and quality of care.



Where we have shared our Insight

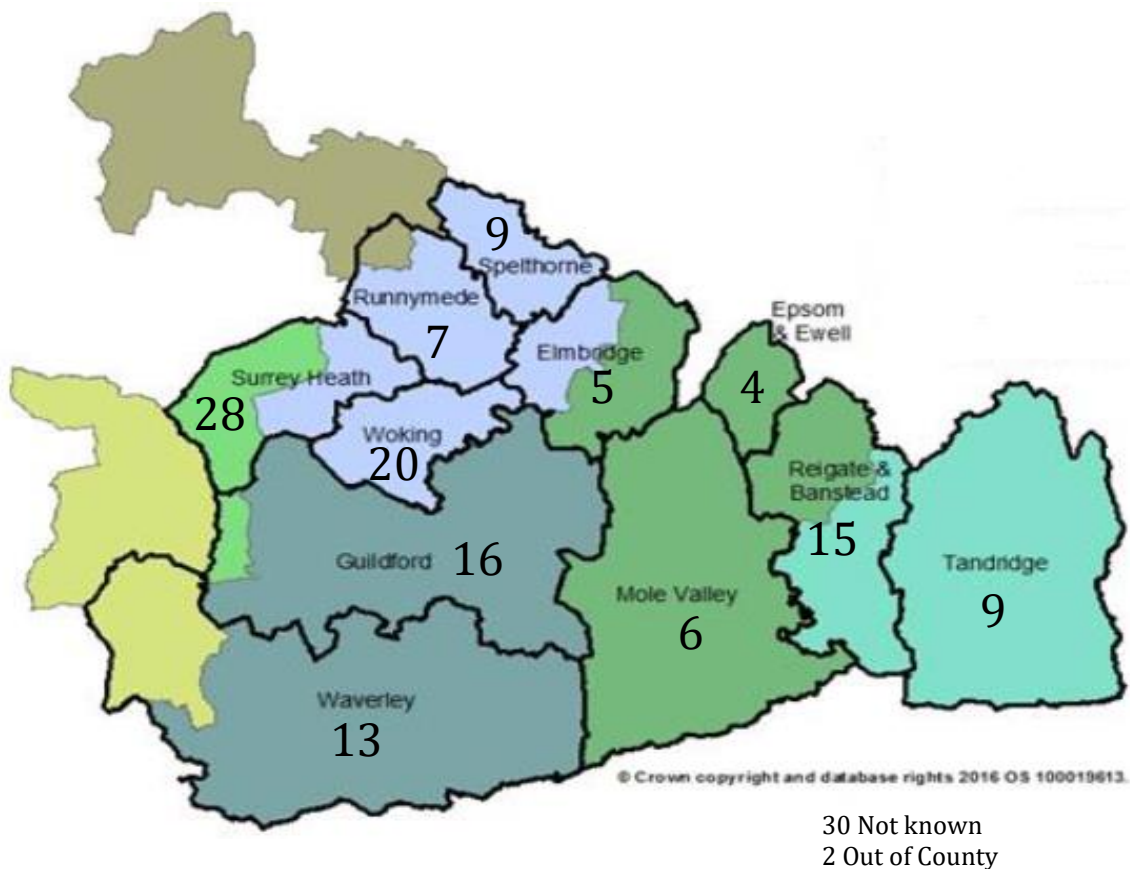
During Q2 we have shared carer insight (key themes and carer experiences) in the following meetings as part of our 'what we've heard' regular insight sharing meetings.

- North Tandridge community meeting – September 2024
- Northwest Surrey carers action group – September 2024
- Older peoples network meeting – September 2024
- Carers Partnership Board – September 2024
- Independent Mental Health Network meeting – September 2024.

If we hear a case of concern regarding a person's safety, we immediately signpost the sharer to the appropriate body and escalate the case with the provider/commissioner.

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. This quarter, we have heard the most from Surrey Heath (29) and Woking (20).



Not identifying as a carer

We are continuing to speak to carers who do not realise that they are carers. We spoke to 164 carers this quarter and many still do not recognise themselves as carers.

“After listening to what you have said today, I think that my wife might be a carer and need someone to talk to. We have 2 daughters [teenagers] and they are both adopted but the younger one has a diagnosis of autism... She doesn't have an Education, Health and Care Plan (EHCP) as she is homeschooled. We have never been referred to any services as parent carers or had any help and support apart from the adoption services. They didn't mention that we were parent carers and neither has our GP. Hearing you talk today I think that my wife might need some help and support. Our youngest daughter is homeschooled and my wife does the majority of that and I think that it's getting to her a bit as it's full on. I have no idea of what is out there in terms of support. I suppose that we are both parent carers but I'm not at home all day tutoring and teaching. I do work from home a lot, so I am around but I'm working. Most things are left to her. We hadn't thought of our older daughter as being a young carer but I think that she could do with talking to other people who are in the same situation.”

221513, September 2024

"I've looked after my close friend for many years. We don't live together, but we have always been close. Since he was diagnosed with Alzheimer's, I have done everything from arranging medical appointments and attending them with him, to his shopping and paying his bills; the list goes on. I hadn't considered that I might be his carer, I just do it because he's my friend, and he doesn't have any family... I assumed an unpaid carer would have to live with the person or be a family member. It's good you came today and spoke about unpaid carers and who they might be... I'll talk with Action for Carers and also my GP."

221968, September 2024

Stress and wellbeing

Once again, mental health is the main issue we have been hearing about from carers and the impact that caring is having on them.

"How does being a carer make me feel? Stressed, overwhelmed, anxious, overworked. It's also the constant multi-tasking and lack of sleep. Most carers just suffer in silence."

222442, September 2024

"There is just so much to juggle and so much to handle. I can't manage it all. I have 3 children. I am struggling."

222451, September 2024

"[Carer for son with autism and ADHD] I am crumbling. I have ADHD myself and I can't cope."

222457, September 2024

"I look after my wellbeing by chatting to friends and eating a lot of chocolate."

221969, September 2024

"I am [in my 70s] and I am struggling with care for my [adult] daughter. She has been sectioned many times. She doesn't live with me but phones me every day... needing help. I feel desperate sometimes and my GP has just offered me medication. I have nobody to turn to professionally. I have previously thought about ending my life just to escape."

220307, August 2024

"2 years ago I gave up my job as I was working full time. It was all too much. I'm a carer for my daughter and my husband. I hit rock bottom and my daughter found me and my suicide note and my pills."

222029, September 2024



"I have found being a carer [for my husband] very overwhelming but I do try to take care of myself with exercise but I do feel guilty about leaving him alone. He is perfectly ok to be left at the moment. My niece lives with us and works from home, so I know that he is not alone. It's also hard for him to think of me as his carer. He says I want you to be my wife not my carer but the reality is that I am his carer. It does change the dynamics of your relationship and he's a proud man."

221744, September 2024

Difficulty accessing information and support

Carers are telling us that they are still struggling to access the information and support they require.

"The dementia services for nan have been phenomenal but there hasn't been a lot of information of what help I can get as her carer."

221952, September 2024

"I find that I'm just overwhelmed with all the information that I'm given... I didn't know about Action for Carers, the focus groups and the Giving Carers a Voice service. Why has nobody told me about them? I think that a map of all the services that are available for carers would be really useful. I now know that there is help out there but if I hadn't come here today, I still would be none the wiser... Being a carer I don't have that much spare time and I'd like to spend time on what is really useful for me."

221956, September 2024

"It is difficult for people from our community who don't have English as their first language. The mention of social services is scary. A carers assessment sounds like you're being assessed and judged. They need these things explained to them, so they know that actually these can be sources of help and support. It's hard to translate these things sometimes and so you don't access the help/support. These are barriers. It's a shame. Why do we have to struggle and shout to get heard. Why can't things be made easier for carers?"

222442, September 2024

"I just don't know where to go for emotional support for her or for me. I just don't know where to go at all or who to turn to."

222451, September 2024

"My son was diagnosed [with autism] last November 2023 and then we were just left. They gave me some leaflets but I couldn't read them all as I have ADHD so just can't process all of that information. I feel abandoned and alone. Just diagnosed and told to get on with it."

222457, September 2024

"My wife is now [late 70s] and was diagnosed with dementia. Although we had the diagnosis nothing really changed for us. I wasn't given any information or advice. I was just left to get on with it... My GP hasn't given me any information or help at all. There should be someone or something that tells you what you're entitled to. Nobody does... I had a lovely dementia navigator who helped me and listened to me but she suddenly phoned and said that her contract was terminated and she didn't know what was happening next. I haven't heard from anyone since then. No letter of explanation. Nothing."

220515, August 2024

However some carers have had a more positive experience.

"I have to say I've been amazed by the support I have had as a carer this time round. There has been proactive reaching out to me. I've had phone calls from people, I've been told how to self refer for stuff. I even had a GP phone me at 9pm one evening. I was referred to Action for Carers. They were amazing and sent me loads of information through. Just them knowing you're there and them reaching out to me made a huge difference. My other son is also now re-registered with them as a young carer. In terms of carer support for me, a completely different experience."

221979, September 2024

Struggles for parent carers

Need for specific parent carer groups

"I would be lost without the White Lodge Centre because otherwise, there is no support for parent carers with neurodivergent (ND) children. I'm registered with Action for Carers, but the groups they run are not ND specific and are general groups... so I don't go to any of their groups anymore."

221138, September 2024

"I have 2 boys with ASD and ADHD. One... struggles socially so finds it difficult being with neurotypical children. We have tried different groups but he says that the other children aren't nice to him. He can be disruptive. The parents at his school have formed a group... So, all the children are neurodiverse and we all understand each other. As parents we also support each other and I find this very useful. He likes these groups and outings... It's all very difficult, tiring and stressful."

219466, August 2024

"I attend these YMCA groups as every time I attend, I come away feeling that I have learnt something... My time as a parent carer is limited, so I don't want to waste what time I have going to groups that don't offer me something. I need things that will actually help me... I am registered with Action for Carers but their

groups tend to be further away for me. It might be my impression but it seems like they are more targeted at older carers and those caring for someone with dementia. That's not what I need. I wouldn't want to go to a group where the issues are mixed. I like that we're all parent carers and our children are roughly all the same age. So we're all going through the same things at the same time."

218472, July 2024

"I like that we're all parent carers too (at this group). I didn't really like the mixed groups where most of the people were older and caring for older people. We're all in the same boat here and that's nice. It's really good for peer support as well. If you are having a problem, someone else has probably been through the same thing too."

218581, July 2024

Challenges in transitioning from children to adult services when children turn 18

"My son is only [age] but I'm already worried about how he will transition to adult services. Nothing has started yet for this. He won't be an adult at 18, there is no way that in just a few years he will be an adult. I think they need to differentiate between children with additional needs and those without as we all know that children with disabilities and neurodiversities develop very differently. It's something that needs sorting out. Those kids need a bit more time and so do us parents. Even if they just pushed it to 21 that would be something. It feels so wrong."

221981, September 2024

"I'm also finding it very difficult as he is now 18 and professionals ask him if he needs help (which he does) and he says no and then it's all left to me. I do still need the help and support."

222440, September 2024

"[Our son] is autistic. We just don't know how to help him at uni. He won't stand up for himself, he says everything is fine if you ask him. He needs someone to advocate for him and help him and support him. We're so out of control now he's at university. We've spoken to the university and they've been really unhelpful. He's a vulnerable boy. We don't know what to do."

222446, September 2024

"Things need to change with regards to the transition from children to adult services. How can they say that our children with special needs are adults at 18? There needs to be some sort of different scenario for children like my son and for parents like me. Or at least some flexibility but there is nothing. We can't attend appointments with them, access records without it all being approved by the child."



When they aren't engaging with services, the parent doesn't know. It's worse for us now he's over 18 but it also costs the system more as I've needed more support as it's been more traumatic. If I had been involved then we would not have hit crisis point and I could have intervened so he stayed engaging with the services he needs."

221979, September 2024

Not being identified earlier as a carer

"I think schools need to think carer when you first start a school and not wait until something happens. If people were better educated on what was out there then maybe they would get the support they needed sooner and with less trauma involved. I remember when my son started school, the teachers just said he was naughty. How is that useful to me as a mum? It's just not. It would have been helpful to get information and advice about being a carer. Parents know when they have a child who is different from other kids. We know and we just need help."

221981, September 2024

"I'm interested in young carers being identified in schools. My daughter is registered as a young carer with Action for Carers and it's so important that they are identified and supported in schools and also taught what a young carer is so they can self-identify. Her sister has ASD/ADHD and is going through puberty. So there is lots of pressure on her, above and beyond what other young people are doing especially at exam time."

222330, September 2024

Not acknowledging and understanding autism

"My son [teenage] is autistic and was diagnosed aged 3. The early diagnosis I think was really helpful... My husband and his family have always struggled with the diagnosis and don't really recognise or acknowledge it. I think it's a cultural thing and they don't necessarily think it's a real thing and say that you can't use it to excuse his behaviour... I think my husband is also on the spectrum which is why he doesn't want to acknowledge it."

217774, July 2024

"My daughter is autistic... I just didn't know where to go or who to turn to. My mum is old school and before my daughter was diagnosed my mum just used to say she was attention seeking. Even now she still doesn't get it... I can't talk to my mum about things at all."

222029, September 2024

"It's a cultural barrier. I feel very alone and as though people in my community just don't believe the diagnosis and don't understand."

222451, September 2024

"Things are very difficult. I don't have any support and I can't tell my family about his autism diagnosis as they don't believe in it. They just see it as naughty and see me as a bad parent... Things are very stressful. I feel very isolated. I don't go out as I feel judged when we go out as my son can hit me when we are out of the house. People look at me and judge me. I am very anxious and I just don't go out anymore... I have no support from my family or community. It's different in my culture and I am judged for the way my child is. In my community they don't recognise ADHD and autism."

222457, September 2024

Difficulties for under 18s who are carers

"My son is [age] and was registered with Surrey Young Carers. He was told that after 2 years, they could no longer help him... He needs support in person, not in a newsletter. There are never enough places for their events... He is affected by his sister's high needs and we don't get to spend enough time with him because we have to concentrate on making sure she's safe all the time. He understandably gets resentful at times. It is unfair to him, and my husband tries to spend as much time with him on the holidays and weekends as possible, which means I'm left with our daughter, which I find difficult to cope with."

221167, September 2024

"My daughter would prefer a more regular young carer group rather than just in the holidays or online. I don't mind driving her to places as long as she is happy. The Surrey Young Carers events get booked up quickly, even the online ones. There isn't anything in Spelthorne. I guess it's because it hasn't always been part of Surrey, and I hope this changes."

220168, August 2024

Coping when your caring role changes

Caring once your cared for is in a care home

"I'm not coping well with the feelings of guilt that I can no longer look after him [husband] at home, and it seems I've abandoned him, which I'm told, with time, I'll adjust to. There is a sense of loss and grief when you need to place your loved one into a residential or nursing home which no one will understand."

218319, July 2024

"It got increasingly difficult for me to cope with her at home. It does make me feel guilty that I couldn't keep her at home with me but I do feel now that I am back to being her daughter again and not her carer... Now that she's in the home, I feel more of a daughter again. I know that she's safe and I've come to terms with the fact that she's not always happy. What else could I have done? She couldn't look after herself and she needed more than I could give her too. I do still regard myself as her carer and the home acknowledges that. It's not as intensive as before but I'm still a carer."

221556, September 2024

"Even though mum is in the care home, I am still doing the admin and finances, so I'm not physically caring any more but I do still do things for her that the care home can't and neither can she."

220265, August 2024

"Someone asked me if I missed him as it has only been recent. I can honestly say no and I know that that sounds hard, but I feel like I've got my life back. It was exhausting caring 24/7."

220505, August 2024

Worrying about how to fund future care

"[Mum is already in a care home.] My only concern is financial. We self fund but it is a worry about what happens when the money runs out. Will she have to move homes? How much will the council pay? There hasn't been that next steps discussion. I think it would be helpful to actually have this discussion at the beginning. Then we would know and not have this constantly at the back of our minds."

221556, September 2024

"I know that her condition will get worse. I don't know when. She could go downhill really quickly or stay like this. That's the trouble with this horrible illness. [Wife has dementia.] It's just unclear and you can't really plan but you did really get me thinking about the future and it's the cost of the care that's really worrying me. Although we own our own home, we don't own all of it... I'm not sure what we'll have to pay or contribute but the thought that we might have to pay over £1600 per week is really frightening. We just don't have that kind of money. I'd really like to talk to someone who can just talk me through it."

221278, September 2024

Healthwatch Surrey have produced a report outlining the information people may require when considering self funding future care. This report can be found on the Healthwatch Surrey website: [Who can help me plan for my future as an older person? - June 2024 - Healthwatch Surrey](#).



What carers need

"There is a gap in services for carers in Ash. There used to be something but that went and now there are no carers groups that are local. Yes, there are ones in Guildford but that's quite a journey for elderly carers and the transport links aren't great. There needs to be more local carers support."

221955, September 2024

Valued support

"White Lodge are amazing with their support and advice but they're stretched and do everything they possibly can for us all."

221139, September 2024

"I come to this group [Action for Carers] as I don't feel judged and it's a safe space to talk freely. Being a carer is so isolating and so frustrating but coming here gives me a real break."

220297, August 2024

"The Beacon Centre has been a lifeline for me and without the help, support, and advice from all the staff, I wouldn't have been able to cope with being a carer, managing the finances, and my wellbeing as well as my husband's."

218319, July 2024

Influence and Impact

- Working with Surrey Safeguarding Board to ensure their carer information section on their website is accurate, current and up to date.
- Working with Surrey County Council to develop a dementia carers training resource.
- Throughout our engagements, we raise awareness of what help and support is available for carers in Surrey. We have been able to help carers we meet by signposting them to vital services to help and support them going forwards.
- Carers told us that the current carer breaks offering was not meeting the needs of some carers. This led to a review of the service and we worked with carers and Surrey County Council on a co-production piece which looked at how the service could better serve carers. Subsequently a new offering has been developed offering more flexibility to carers. This is due to launch later this year and will provide carers with 70 hours of respite to be taken over the period of a year.
- The outcomes framework which Giving Carers a Voice developed for Surrey County Council has now been shared with Surrey Heartlands who will now look to incorporate this into their work going forwards.

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 October to December 2024. If you have a group you would like us to come along to and visit then please email us at info@luminus-cic.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 October to December 2024

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

Place	Date
Action for Carers hub, Woking	07/10/2024
Sight for Surrey Meet Up and Catch Up, New Haw	16/10/2024
Additional Needs Showcase, Cranleigh	22/10/2024
Face 2 Face dads parent carer group, Chertsey	23/10/2024
Action for Carers hub, Farnham	01/11/2024
Dementia group, St Johns Church, Caterham	04/11/2024
The Meeting Room, Ashted	05/11/2024
Carers catch up, Richmond Fellowship online	06/11/2024
Action for Carers hub, Merstham	07/11/2024
Parkinson's carer group, Milford	11/11/2024
Action for Carers hub, Hersham	14/11/2024
Family Voice Surrey annual event 'Empowering parent carers' Egham	15/11/2024
Carers Rights fair with Action for Carers, Camberley	20/11/2024
Carers Rights fair with Action for Carers, Farnham	21/11/2024
Action for Carers hub, Godalming	03/12/2024
Action for Carers hub, Epsom	04/12/2024
Dementia carers group, Age Concern, Banstead	11/12/2024

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

Contact us

Contact us through any of the channels below.

We'd love to hear from you:

-  Web: luminus-cic.uk
-  Telephone: 01483 301448
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