Luminus
Home of Healthwatch Surrey

Giving Carers a Voice
Quarterly Insight Report

What we're hearing

April - June 2025

Shining a light on what matters to people.

Giving Carers a Voice

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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.

Our CIC was originally established in 2013 to deliver the Healthwatch Surrey service and ensure the voices of all users of NHS and social care services are heard. We have since built on our expertise and experience and Luminus has grown to 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 April - June 2025

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:

- Surrey and Borders Partnership (SABP) mental health carers forum with Action for Carers, Merstham
- Autism bus with Action for Carers, Guildford
- Carers event, East Horsley
- Sunflower café, Godalming
- Parent carer group, National Autistic Society, online
- Additional needs showcase, Egham
- Rosemary and Sage café, Cranleigh
- East Surrey College, Redhill
- Carers tea party, Phyllis Tuckwell hospice, Guildford
- SABP mental health carers forum with Action for Carers, Cranleigh
- Additional needs showcase, Ripley
- Mums2Mums group, Chertsey
- Godalming College.

Main themes we have heard from April - June 2025

The word cloud below highlights the main themes we have been hearing about this quarter. The most prominent words are Parent Carer, Mental Health, Respite Care, and Dementia.

Where we have shared our insight

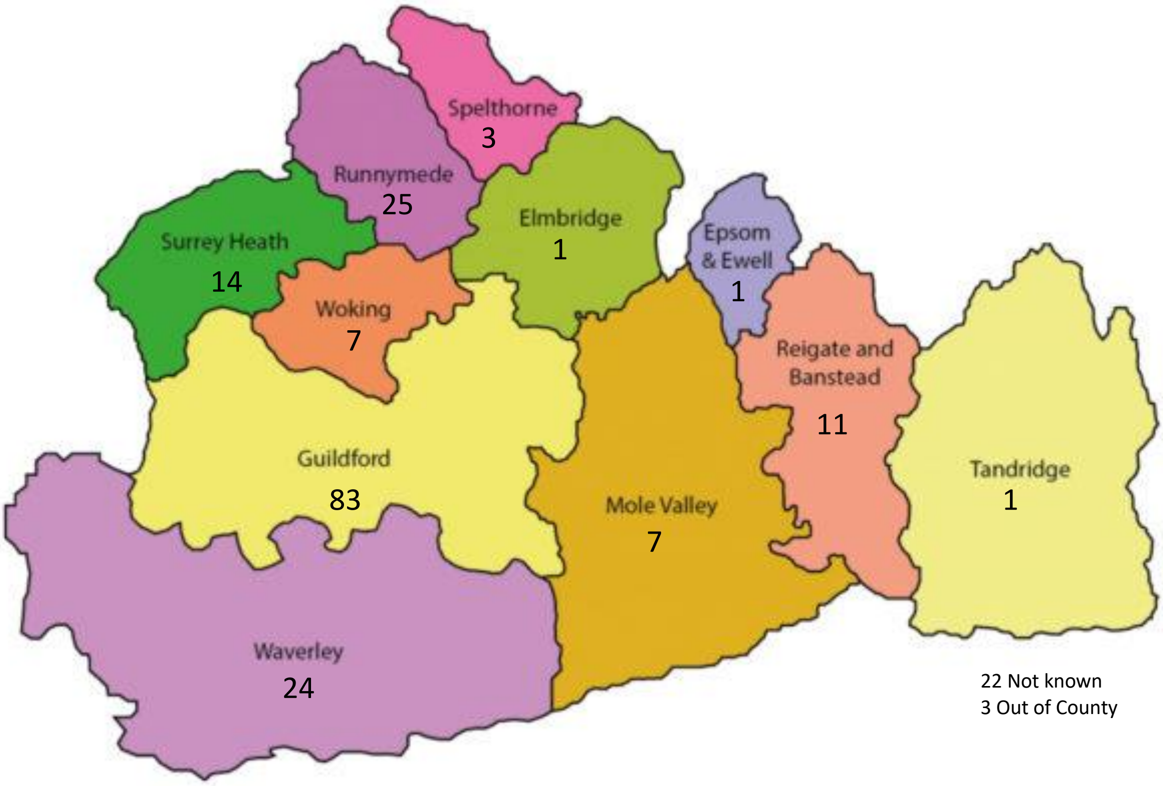
During this quarter we have shared carer insight (key themes and carer experiences) in the following meetings as part of our ‘what we’ve heard’ regular insight sharing meetings.

- South Tandridge health and wellbeing neighbourhood meeting – April 2025, June 2025
- Mental health forum – April 2025
- Carers action group – May 2025
- Health and wellbeing meeting – May 2025
- Epsom/St Helier Carers steering group – June 2025
- Charity leaders forum – June 2025.

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 Guildford (83) and Runnymede (25).



Key themes we have heard from carers from April to June 2025

- Not identifying as a carer
- Isolation and loneliness
- Caring for someone with mental health issues
- Respite care and support
- Carers neglecting their own needs
- Importance of regular support groups
- Not taking into account that someone is a carer
- Juggling employment, education and caring
- Lack of communication with the carer
- Family strength and dynamics.

Not identifying as a carer

We are continuing to speak to people who do not realise that they are carers. We spoke to 202 carers this quarter and many still do not recognise themselves as carers.

> "I care for both my son with autism and my dad who has Parkinson's. I don't really think of myself as a carer. I'm almost expected to take care of him. It's a natural progression isn't it? He looked after me and now I look after him."
> **231327, April 2025**

"I've never thought of myself as a parent carer. I just felt that I was a failure as a parent as many of my friends had children who were getting on at school and thriving but my son wasn't."
233636, June 2025

Isolation and loneliness

"[Carer for son] We get no support. I have some friends in my daughter's year at school but none of them get it. I feel very alone and very isolated. I am fed up and exhausted. This is endless."
234117, June 2025

"I'm a carer for my husband who had a stroke… my husband can't talk now so life is very isolated and quiet for us. He's lost interest in everything, he just doesn't care anymore and that's what I find the hardest thing."
232604, May 2025

"I'm a carer for my wife who has dementia… My whole life is spent looking after her… I'm a chatterbox and love a chat. I miss conversation badly."
233668, June 2025

"Nowadays I have to do everything. I do his jobs around the home, I do my jobs around the home and at the same time I have to look after him… I am always aware and always on duty and always having to be responsible for everything. It takes its toll when you have to do everything."
232601, May 2025

"I live with my parents. Mum has dementia and I think that dad might have too. I have had suicidal thoughts in the past as caring for them both is very lonely and isolating."
233405, June 2025

Caring for someone with mental health issues

"Caring for someone with severe mental health issues is like a roller coaster. I've been caring for him for the past 18 years. I never know how he's going to be each day. Having this carer hub here and the support of the local crisis team has been great for me. Whatever I have needed they have been there for me."
231316, April 2025

"Being a carer for a child with mental health problems is incredibly isolating and difficult. It's endless. I've lost loads of friends over the years as I'm not able to go out and leave my child. She finds it very hard to be left alone, so we can't leave

her. There are no support groups out there for people like me. I wouldn't go to a carer support group, they are all for people who care for people with dementia or for parents of children with autism. Mental health is completely different. It's a real stigma still. People don't understand. From other parents you just hear about how wonderful their kids are and how well their kids are doing and that's why it's easier not to socialise anymore as it just does your head in."
233019, May 2025

"I think that the thing with being a carer of someone with mental health problems, the problems just don't go away. They go up and down and sometimes things are ok for a while and then once you get comfortable with that then things start to spiral again. It's exhausting and never ending. Is there any help out there? Not really. Counselling is very hit and miss. Some counsellors just don't get it and think kids just need to toughen up and learn to be more resilient… As a parent, I feel just dragged down by it all. Looking after someone with depression, is very depressing. Every day is a drag, my child has zero excitement and enthusiasm for anything. So every day I wake up and think here we go again. Exhausting, endless. She's tried to take her own life a number of times and I can't see a positive ending to my situation… I don't attend any groups as none are appropriate for carers of people with mental health problems."
233020, May 2025

Respite care and support

Carers have told us what a difference it makes to them to get some extra help and support in their caring role.

"[Carer for nan who has dementia] I now have extra care for my nan (who lives with me) and it's made all the difference. She had started to wake during the night and then wander, which then woke me up and it was then hard to get her settled again. I work full time and the lack of sleep was making it difficult… Adult Social Care reviewed her care package and put in extra carers. We had a meeting with the care agency, myself and nan, and they went through what she needed and made sure that everyone was happy with the new arrangement. As well as the extra carers coming in, they also call every week to ensure everything is ok. This has made a tremendous difference to me as her carer. I was facing burn out. It means that at the weekends, I get time to spend with my husband and we know that nan is cared for. The same for during the week."
233404, June 2025

"We just can't leave dad. We did have Crossroads Care for 20 weeks and it was brilliant. Mum was able to go out once a week without worrying. Since Crossroads ended, mum is a lot lonelier and feels trapped."
234104, June 2025

We have also heard from carers who are struggling with no support.

> "What support do I get? There is no support. We get no help from friends or family. No one can manage my son except me, my husband and my daughter. We get a break when he is at Challengers once a month."
> **234117, June 2025**

> "I've got two boys. They are both non verbal and aggressive... I've got nothing, I've got no support."
> **234096, June 2025**

Carers neglecting their own needs

We continue to hear from carers who tell us that they are too busy caring to look after their own needs.

> "I'm a carer for one of my children. My other child had their first session last night at Surrey Young Carers. It was good. I'm not registered myself though with Action for Carers. I don't do anything for myself. I'm too busy looking after my children."
> **234099, June 2025**

> "I've had to step down from my hobbies and clubs and my responsibilities now are at home. I'm devoted to caring for my wife. I'm not a carer, I'm a husband and she'd do exactly the same for me if she were in the same situation."
> **232611, May 2025**

We have heard what a difference it makes to carers when they are able to prioritise their own needs sometimes.

> "He's going to a care home for a week in June. He doesn't want to but I need the break. It's costing £2000 a week. I will do it again as I need this time even though it's expensive. [Working in] the charity shop is my break, my respite. It's a good support for me. I do neglect my own health a bit. I can't walk as much as I'd like to and I can't go out and exercise as I used to or want to."
> **232604, May 2025**

> "I have given so much of my life to caring for my husband and looking after his needs. I have forgotten myself and who I am. I have started up some hobbies and started to attend some carers groups which I have found very useful and supportive. I have found caring quite isolating, especially because of what my husband had. We have had to be very careful about going out and mixing with people in case he gets something. I attended the carers group at the hospice and talking there, I realised that I can have a life too and not feel guilty. If I don't keep myself well, who will do all the things that I do for my husband? Talking to you

today, I realise how much support is actually out there but I didn't know about any of these other services. I think sometimes carers are so heads down and caring, we don't look up and see what we need."
233731, June 2025

Importance of regular support groups

"[Carer for husband] This group is the only place he comes to. It's fantastic and a lifesaver for us and for my sanity... This place (Rosemary and Sage café) is heaven. I don't know what I'd do if this place closed down."
232604, May 2025

"As long as I'm in sight, she's happy. This is the only group we come to...This group (Egham dementia carers) is my me time. It's great. I love it. I enjoy playing games here, it's a real break."
233668, June 2025

"[Parent carer] I attend this support group (Mums2Mums) as it's good to get together with other people who understand what you're going through and get you. We also have a laugh, which is important too. We also hear things about services and groups that might help each other. It's a supportive place."
234068, June 2025

"I attend a Parkinsons support group once a month with my dad. We both get lots of support there and it's been so helpful, especially for me as his carer. It's actually been a lifeline, as it's a minefield out there knowing things like what benefits to claim. They helped me to apply and get a blue badge."
231327, April 2025

Not taking into account that someone is a carer

"It doesn't seem to make a difference that I'm a carer, they still don't give me an operation time. I don't think authorities realise how hard it is to make an appointment and how much a carer has to plan in order to get there. It will take both my daughter and daughter in law to help out when I have to go into the hospital. One will be with my wife and the other will take me. They don't give you a specific time... It would be so helpful if there was more thought when someone was a carer and if they could give you a better idea of time. My daughter and daughter in law both work so it means them both having time off work to help me and my wife manage my surgery. What would help? Specific appointment times and people acknowledging I'm a carer and making allowances for that."
233668, June 2025

Juggling employment, education and caring

“My daughter is autistic and also suffers with anxiety. She’s been out of school all year… Getting her to school is emotionally disastrous… I ended up giving up work last year as I had to as she was out of school. And I haven’t been able to go back as she’s been on a part time timetable. We also have 3 out of 4 parents who need help and more care… I can’t work. I miss it a lot. My husband is the main breadwinner now and it’s stressful as we could do with my salary too… I never considered I was a carer so I’m not registered with the doctor or Action for Carers.”
234101, June 2025

“I work full time and I’m a full time carer, it’s tough. But I’ve never known any different so I wouldn’t know what it would be like if I wasn’t caring. Back when I was studying, they really didn’t understand when it came to coursework and assessments. I used to explain I’m a full time carer too but they didn’t get it. It was really hard juggling things and made things super stressful… When you’re a carer and working full time, you just can’t switch off. Always at the back of my mind, I’m thinking about home… My work now have been really understanding with my caring responsibilities.”
232983, May 2025

“I’m a carer for my son and my parents… I don’t cope. I can’t cope… I can’t work, I don’t have time.”
234133, June 2025

Lack of communication with the carer

“My son has no formal diagnosis yet but he’s been under the paediatrician since he was 6 months old. He has mild to moderate developmental delay… The main issue we struggle with is communication. I just wish they would tell me what is going on rather than making me chase and chase. We, as carers, just want to know time scales and then we understand. We don’t want to be kept in the dark. Without knowing how long you have to wait for, you just can’t make an informed choice about what to do. Should we go private? We don’t know as they can’t tell us how long we will be waiting for appointments etc. Also finding out information can be very difficult as a carer. I’m busy and have my hands full so don’t have time to search around for information. It would be better to just have somewhere to go for information or a point of contact to speak to. But as a carer it’s all very confusing. I feel kept in the dark with everything.”
232055, April 2025

“I just wish they would give you a list of what you need to do when you’re a carer. There is no check list or to do list and it would be so useful if someone said to you that you needed to do x y z and helped you with benefits etc.”
232611, May 2025

Family strength and dynamics

> "We nearly lost mum last year when she was in hospital… Even though dad and I are carers for her, we were completely lost without her. She's our stability at home. We need her as much as she needs us. We really struggled."
> **232983, May 2025**

Signposting

On engagement, our team always signpost to appropriate support and care services. Sometimes, people do not want information given to them. Support services are provided where relevant. We also support individuals who require assistance with other issues, such as locating a support group in their local area.

We check in with the group leader if someone has said something we are unsure of or concerned about to ensure that the person is being supported and not alone. We also ensure that support services are aware of appropriate treatment pathways and local support available.

Influence and Impact

- Following on from carers raising questions about the Continuing Healthcare process and what the criteria are, Healthwatch Surrey along with carers have produced detailed information in order to help people navigate and better understand the process and what it entails. Information is available on their Information and signposting website page: Continuing Healthcare - Healthwatch Surrey.
- With input from Giving Carers a Voice and Giving Young Carers a Voice, Surrey County Council have produced a leaflet to help early years practitioners to identify young carers within families. This is available to early years settings on the Early Education Learning Portal. Early Years advisors can send it to settings if they identify children in a setting or if a setting request information about young carers. Surrey Early Years & Childcare Services | Surrey Education Services
- Giving Carers a Voice and Giving Young Carers a Voice are assisting GP support workers in engaging with carers to produce a GP carers toolkit.

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 July to September 2025. 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!

Our Giving Young Carers a Voice reports can also be found on our website page Giving Carers a Voice: Reports - LUMINUS .

Where we are going July to September 2025

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

Place	**Date**
Additional needs showcase, Ewell	02/07/2025
Carers event, Horsley	04/07/2025
Family Voice parent/carer group, Oxted	07/07/2025
Parent/carer group, Lingfield	28/07/2025
SABP Recovery Fest, Guildford	06/08/2025
St Saviours Trekkers Festival, Guildford	12/08/2025
Phyllis Tuckwell hospice carers drop in	14/08/2025
White Lodge family fun day	18/08/2025
MyTime Reigate carers group	21/08/2025
Little diamonds parent/carer group, Stanwell	26/08/2025
Springfield surgery carers event, Elstead	17/09/2025
Godalming College, Godalming	19/09/2025
HomeStart SEN stay, plan and learn	30/09/2025

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:

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