

Giving Carers a Voice

Quarterly Insight Report

What we're hearing

October to December 2025



Shining a light on what matters to people.

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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 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

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

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. These experiences form the basis of this report.

The lived experiences quoted in this report are in people's own words and therefore reflect their personal perspective and perception, not the views or opinions of Luminus as an organisation. When we are engaging with people and the individual has incorrect information about a provider or service, we endeavour to provide them with up to date correct information. We also offer signposting for other local support services and organisations where relevant and appropriate.

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. 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.



Engagement October – December 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:

- Egham Orbit International older persons day, Egham
- Woking hub
- Community health fair, Tadworth
- Age UK Planning for your future, East Molesey
- Additional needs showcase, Ash
- Revive coffee shop, Chertsey
- Action for Carer hub, Woking
- Heathcot Medical Practice wellbeing community workshop, Woking
- Additional needs showcase, Redhill
- Angelic coffee morning, Woking
- Working together for Woking, Woking
- Bisley community café, Bisley
- Carers rights event with Action for Carers, Epsom Hospital
- Carers fair, Guildford
- Still Me dementia café, Redhill
- Action for Carers hub, Dorking
- Age UK Planning for your future, Fetcham
- Age UK Planning for your future, Esher.

Main themes we have heard from October - December 2025

The word cloud below highlights the main themes we have been hearing about this quarter. The most prominent words are stress and wellbeing, mental health, parent carer, dementia and isolation.



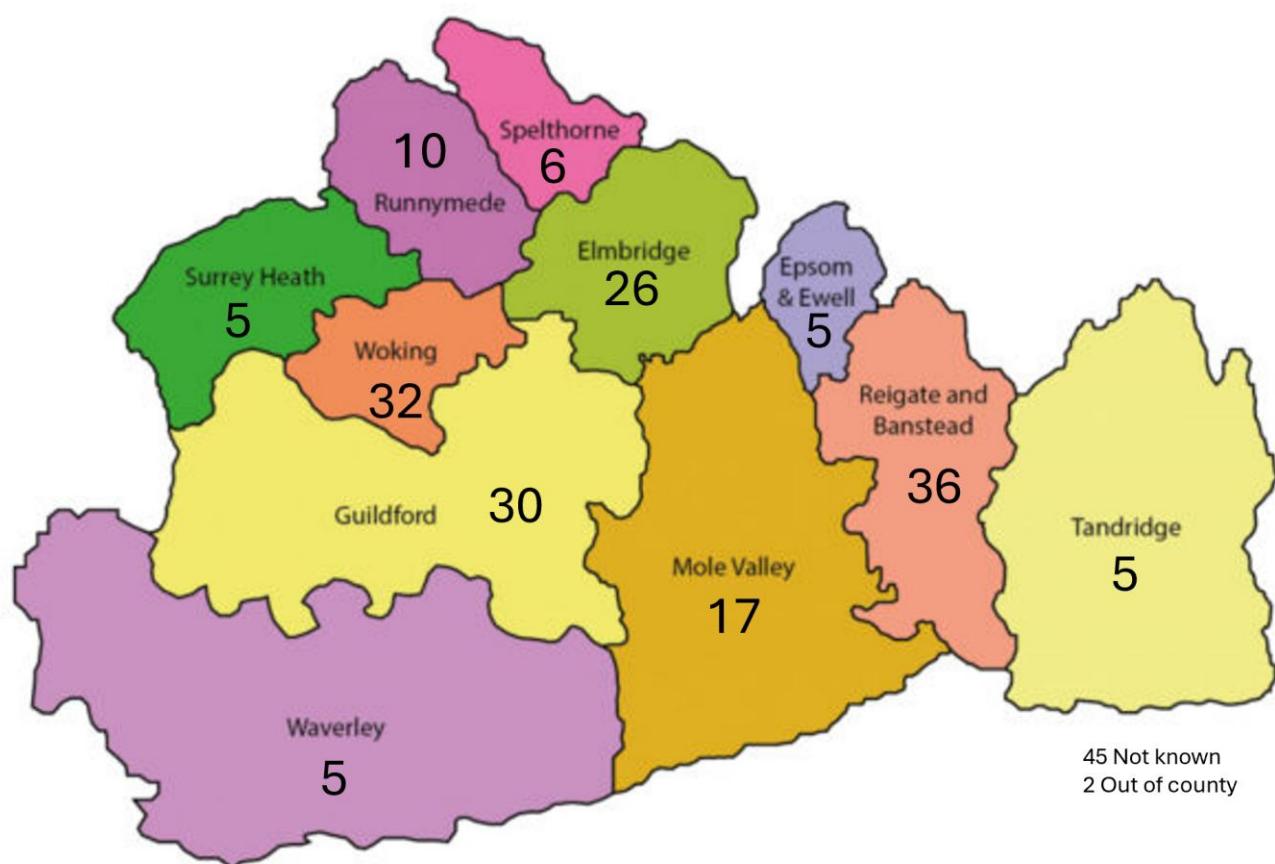
Where we have shared our insight

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 meetings:

- Preston partnership meeting - October 2025
- Older peoples service providers forum - October 2025
- Southwest carers action group - October 2025, November 2025
- Redhill and Reigate health and wellbeing neighbourhood meeting - October 2025
- Woking isolation and loneliness group - November 2025
- Northwest Surrey carers action group - November 2025
- Independent Mental Health Network meeting – November 2025
- North Tandridge health and wellbeing neighbourhood meeting – December 2025
- Carers steering group – December 2025
- Redhill West partner network meeting – December 2025.

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 Reigate and Banstead (36) and Woking (32).



Key themes we have heard from carers from October to December 2025

- Not identifying as a carer
- Lack of support and advice following hospital discharge
- Unable to get a break from caring
- Struggling with work and caring
- Not sure where to turn to for help
- How delays can have a knock on effect on carers
- Worrying about the future
- Things that can make a difference to carers.

Not identifying as a carer

We are continuing to speak to carers who do not realise that they are carers. We spoke to 224 carers this quarter and many still do not recognise themselves as carers.

"I work full time so I can't be a carer, can I? I didn't realise. I have 2 children with SEN (special educational needs)... and no one has mentioned that I'm a parent carer and there is support out there just for me. I didn't know what a parent carer was."

300121, October 2025

"I had no idea that I am a carer until you came and spoke to me... I've been thinking about what you said and I do think that I am one for my younger daughter who has complex physical needs. My husband is a carer too then. I think we both could do with some help and support... I might need some information about what benefits we are entitled to. We both work and so I'm not sure if we would. No one has suggested that we could be carers and yet we have been in touch with various professionals throughout her life. Thank you for letting me know what's out there for us as carers. I wouldn't have known otherwise."

300119, October 2025

"We wouldn't say we are his carers, we are his parents supporting him, just as we do our other children."

300156, November 2025

Lack of support and advice following hospital discharge

"My mother was recently in hospital after she had a fall... She was discharged... and I had no idea how to take care of her and what her needs would be... I got the medication and it included morphine. On the discharge papers it said 2.5ml but when I got the prescription, it said 1.5ml. I asked the doctor what was the correct



dose and they said that I should never have been given this to administer. A nurse or doctor only should do this. They are trained, I'm not. What would have happened if I had given her the wrong dosage?... I feel like I have just been left with my mother to get on with it. No help, support or advice with how to cope with her. No follow up at all... I am also very wary of touching her with her broken bones as I don't want to cause her any more harm. No-one has shown me how to wash her safely. I'm just left to get on with things."

300092, October 2025

"My husband had prostate cancer. He was sent home [from hospital] with all the paraphernalia but no support... We ended up in A and E when his catheter fell out. I didn't feel it was right for us to be there but there was no one else who would help so we had to go there. I am an unpaid carer, in that he couldn't manage without me and I do lots for him but I couldn't do that... He's going in again in December and I am really worried about how we will manage."

231141, November 2025

Unable to get a break from caring

Carers have told us how challenging it is to get a break from their caring responsibilities.
"I don't do anything for myself as it's difficult because of her. If I say I'm going to go out, she wants to know why and where I'm going. It becomes easier to just stay home with her. I suggest various things but she won't go. I feel like I'm walking on eggshells around her all the time. Everything I do or suggest is wrong. It's such a difficult situation."

300134, November 2025

"My husband has had Parkinson's disease for several years. His health is deteriorating as he gets older and needs me to help him more with personal care, eating and drinking and getting around. It's stressful and affects my health as I don't get a break from him now."

300097, October 2025

"My wife has dementia, and I don't get any time to myself except when I come here [swimming] for an hour when the carers come in. If we didn't live close by, I wouldn't be able to do this. I get very stressed and frustrated at times. It's a lonely existence."

300098, October 2025

"I'm a mother to three young boys and care for my mum full time so 'me time' doesn't happen often."

300174, November 2025



"My partner needs 24/7 care and support. My caring role started in 2017 and back then it was minimal support now the caring role is very real and extremely taxing... I would love opportunities to have time out away from my partner... I have my own health issues which I need to take care of. Adjusting to being totally responsible for the management of all things practical as well as caring leaves little or no energy to address my own issues. I get no break."

300127, October 2025

One carer told us about how getting a break from caring made her feel less stressed and able to carry on with her caring role.

"I care for my partner who has a heart condition... Having the carer wellbeing payment has been a lifesaver. I have been able to get someone to sit with my partner while I had a day at the coast with a friend. I have also had a couple of lunches with other friends. I wouldn't have been able to do these things without the payment. It has given me the quick respite I needed in order to come back to my caring responsibilities feeling refreshed and able to cope. Getting some time apart is always helpful when you generally spend lots of time together. He has, I think, appreciated the fact I have been less stressed."

300185, December 2025

Struggling with work and caring

Once again, we have heard from carers about the difficulties trying to balance work alongside their caring responsibilities.

"Both my children... are struggling in mainstream school and my daughter is currently out of school and my son is on a restricted timetable. This is really difficult for my wife and I to manage and we both work. Luckily I am self-employed and I can try to work around when they are home. It's not so easy for my wife as she works shifts but is now trying to do more nights, so she can be home during the day. It's not ideal as she is tired from looking after the children during the day and then has to work. But what can we do? We both need to work to pay the bills and live... We have both always worked and we're not going to stop. It's good for our mental health."

300183, December 2025

"I work full time and I care full time for my partner. She... can't move or walk and she is doubly incontinent. I'm at the end of my tether. I have no time for myself... I don't know what to do. I don't want to go to any support groups and sit around and chat to other people. I don't want to cry with other people."

300163, November 2025

"My husband was diagnosed with Alzheimer's in 2022. I identified myself as a carer as I had to give up my job as I was having to do more and more for him."

300164, November 2025



"I have been a carer [for my daughter] for the past 15 years... I am exhausted as a carer, and I don't know what to do... I had to take a step back because I couldn't do it anymore... When I came back to carry on my caring role, she was a mess... I have had to give up work to look after her. I also take her to and from all her appointments, which is a massive drain on my energy and money. I am not a bad mum, but I have my own health conditions and taking on such an intense caring role is draining."

231143, November 2025

However, we have heard what a difference it makes to carers when employers recognise their caring role.

"I work full time but take time off to attend this group as it's so supportive and helpful for me. My employers are very good about letting me use the carers leave so that I can take my mother-in-law to hospital appointments."

300139, November 2025

Not sure where to turn to for help

The health and wellbeing of those we care for can change over time and carers often do not know what steps to take or where to seek appropriate help or advice.

"My wife has mental health issues but I'm worried that she might have dementia too. I'm not sure how to get her to go to the doctor and discuss this. It's tricky. I can see her changing and I don't think it's her mental illness, it's more than that."

300134, November 2025

"My husband had a stroke in 2023. In 2025 he started treatment for bladder cancer. I have been seeing a decline in his mental ability. I think he has the beginnings of dementia as I can see the deterioration. However, he refuses to accept that there is anything wrong with him. He won't come to the GP. I just don't know what to do next."

300133, November 2025

"As a carer, it's sometimes hard to see when things are going downhill until you reach crisis point. That's why it would be good to still see health professionals when things are ok as they are more likely to notice things. As a carer you just live with it and deal with it."

300176, December 2025

How delays can have a knock on effect on carers

One carer explained how delays in receiving results can have a direct effect on the carer themselves.



"We were waiting 5 weeks for the results of an ECG that she had. This was a difficult time as the waiting made her mental health worse as she thought that there was something seriously wrong with her. As her carer I then have to manage all this."

300134, November 2025

Worrying about the future

Concerns about what lies ahead and how to plan for the future are constant worries that we hear from carers.

"I'm a carer for my husband. He is very deaf and has Parkinson's. My main worry is what if something happens to me. At the moment, we cope, I cope. I have plenty of health problems myself too, you do at my age... I don't really know what there is out there to help us."

300180, December 2025

"We care for each other really. I am registered as my wife's carer. I guess I am more her carer than she is mine. My main worry is the future and what will happen to her if something happens to me and I can't look after her."

300179, December 2025

Things that can make a difference to carers

Carers have told us how sometimes it's the small things that make a big difference to them in their caring role.

"I must say how pleased I am with my pharmacy which is an independent one. They provide a dosette box for his medication, so it's all sorted out for him. Previously, I had to sort the medication for him. This has been a real help for me as his carer and a weight off my mind. Knowing that if I go down, at least his medication is ok... It's sometimes the small things that make a difference to us as carers."

300129, November 2025

"My son comes here [Nurture Through Nature] once a week, which has been a lifeline for both of us. He gets to do things he enjoys and I can join in or have a cuppa."

300154, November 2025

"My son has severe mental health issues and leaves the house very, very rarely... he needed to have a [procedure] at hospital. I really didn't know how I would get him to go, knowing that the general receptions areas are busy and he wouldn't be able to cope. I phoned the cardiology department and explained the situation. I did manage to get him to the hospital and when we were there, we were shown into a private room and then seen immediately. Everyone was so kind and considerate



because of his mental health issues and his needs. Again, what could have been very stressful for both of us wasn't as the cardiology department listened to what my concerns were as his carer and acted appropriately."

300129, November 2025

Influence and impact

- Contributed to the Health and Wellbeing report, providing insight into the impact of poverty and financial hardship on carers.
- Supported the development of the Joint Strategic Needs Assessment (JSNA) through contributions to the bereavement section ensuring carers' experiences and needs were appropriately reflected.
- Worked collaboratively with Adult Social Care to support the development of carer induction training, strengthening staff understanding of carers roles, identification of carers and support pathways.
- Continued to identify and engage individuals who do not recognise themselves as carers. Increasing awareness of caring roles and access to information, advice and support.
- Participated in a joint carer event with Action for Carers Surrey, Adult Social Care and Surrey Welfare Rights Unit contributing to improved professional awareness of carers identification and signposting. Feedback indicated increased confidence among professionals to ask about caring roles and provide appropriate referrals.

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 2026. 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!

This report focusses on carers over the age of 18. Our Giving Young Carers a Voice reports can be found on our website page [Giving Carers a Voice: Reports - LUMINUS](#).



Where we are going January - March 2026

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

Place	Date
Action for Carer hub, Shepperton	07/01/2026
Age UK, Planning for your future, Redhill	13/01/2026
Merstham Community Hub, Merstham	14/01/2026
Horley community centre, Horley	16/01/2026
Memory Lane Café, Cranleigh	19/01/2026
Parent/carer group, Redhill	22/01/2026
Age UK, Planning for your future, Walton-on-Thames	26/01/2026
Carers event, Bookham	04/02/2026
Wellbeing fair, Godalming College	10/02/2026
Age UK, Planning for your future, Ewell	11/02/2026
Dementia memory café, Leatherhead	11/02/2026
Dementia memory café, Banstead	13/02/2026
Age UK, Planning for your future, Dorking	02/03/2026
Age UK, Planning for your future, Bramley	10/03/2026
Age UK, Planning for your future, Weybridge	16/03/2026
Age UK, Planning for your future, Cranleigh	19/03/2026
Age UK, Planning for your future, Redhill	24/03/2026

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
-  Text: 07592 787 533 (SMS only)
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