

Giving Carers a Voice

Quarterly Insight Report

What we're hearing

April to June 2026



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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. We achieve this through bespoke projects, co-design, contracts, mentoring, research, and training. Our vision is to create a society where everyone's voice is heard so we all receive the support we need for our wellbeing.

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.

Luminus carer project

Luminus recently completed a project for the HomeFirst service. HomeFirst is a Surrey Downs Health and Care service that cares for people within their homes and communities and supports them when being discharged from hospital to help them regain as much independence as possible and reduce the risk of hospital readmission. They also support people with acute level care at home in the community to avoid them having to go into hospital. The project scope was to better understand the experiences of unpaid carers supporting patients using the service. Following on from our research and analysis, we were able to make recommendations to HomeFirst to help develop their services going forwards to ensure carers get the best possible outcomes. Our key findings were related to improving communication, support for carers and training and equipment. More information can be



found on our website at <https://luminus-cic.uk/wp-content/uploads/2026/06/HomeFirst-Patient-and-carer-research-1-pager-May-2026.pdf>

Engagement April – June 2026

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:

- Mental health carers group, Spelthorne
- Parent carer group, Redhill
- Age UK, Planning for your future, West Clandon
- Age UK, Planning for your future, Leatherhead
- Action for Carer hub, Epsom
- Action for Carer hub, Guildford
- Trekkers parent carer group, Guildford
- Dementia event, Guildford
- Carers event, Royal Holloway, University of London
- Memory café, Oxted
- Additional needs showcase, Woking
- Little Stars, Chertsey.

Main themes we have heard from April – June 2026

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



Where we have shared our insight

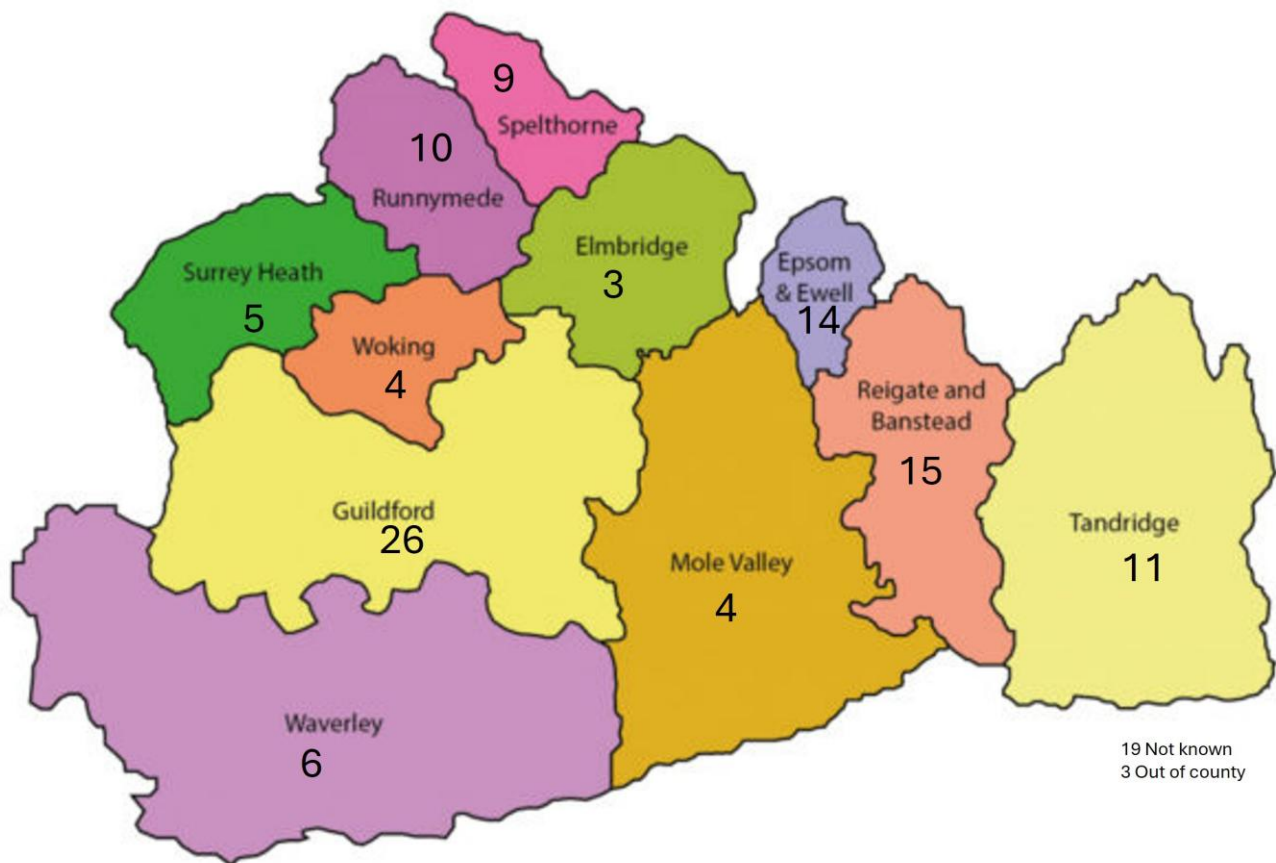
During this quarter, we have shared carer insight (key themes and carer experiences) in the following meetings as part of our 'what we've heard' regular insight sharing meetings.

- Runnymede community meeting – April 2026
- Preston partnership meeting – April 2026

- Reigate and Banstead Borough Council carers group – April 2026
- South Tandridge health and wellbeing meeting – May 2026
- Horley partnership meeting – June 2026
- Southwest carers network meeting – June 2026
- Epsom and St Helier steering group meeting – June 2026.

Where we have heard from carers

This quarter, we have engaged with 129 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 (26) and Reigate and Banstead (15).



Key themes we have heard from carers from April to June 2026

- Difficulties getting a break from caring
- Not knowing where to go for help and information
- Not involving the carer in the discharge process
- Stress and wellbeing
- Juggling many roles as a carer
- Struggles with balancing work alongside caring responsibilities

- Concerns for parent carers.

Difficulties getting a break from caring

Carers have told us how hard it can be to get time off from their caring responsibilities.

"I mean having a break is wonderful but how can you do that when there is no one to look after your loved one? Where can I find someone to look after my wife? I don't care about the money but I can't buy people. I can't buy another me."

300365, April 2026

"I like to play bowls but I'm trying to get someone to look after her [my wife] while I do this as I can't keep relying on neighbours to help out. It's expensive. They charge £36 an hour which is extortionate if you want to play bowls for a few hours. It's just not affordable. I've tried explaining to these agencies that she just needs company not medical care. It's impossible."

300446, June 2026

"I wanted respite. I contacted loads of care homes but none could give me dates when they would definitely have availability in the next three months. I understand they want permanent residents and not just temporary ones but how am I supposed to get a break if I can't find him anywhere to go. I need the certainty of a date so I can make plans for myself if I want to go away. I need to plan and make sure my partner is cared for and safe. What can I do?"

300368, April 2026

"To look after myself? I try to get a cup of tea without it going cold, that's a good day."

300352, April 2026

"I don't get a day off from him. It's constant. If he's not physically with me, he's texting all the time."

300391, May 2026

"It would be lovely to do something for myself as it's hard caring for her when I have my own health needs and I get tired easily. But I have to keep going and looking after her as if I don't, nobody else will."

300386, May 2026

Not knowing where to go for help and information

We continue to speak to carers who are struggling to find the relevant help and information that they need.



"I'm a carer for my wife who has dementia. She got the diagnosis and then we were just left. I had no idea where to turn to for help and no one helped us... As a carer, you are too busy caring all day to spend your day doing research on places to help."

300365, April 2026

"I feel quite lost. I don't know where to go for information. It is just so confusing. I don't know who to ask or where to go or what to ask. You don't know what to do. And as a carer, you don't have time to do it."

300455, June 2026

"I'm just exhausted and don't know where to go for help or if I can carry on with this but what choice do I have."

300385, May 2026

"It would be useful if you, as a carer, were told what the processes are when you apply for things, such as Council Tax reduction. You have to get Attendance Allowance first, then you can apply. This isn't made clear. So, I have to apply for Attendance Allowance, wait for approval and then ring the council again. It all takes time and my mum is elderly and not getting any younger. To put it bluntly, time is not on her side. The Attendance Allowance is used to help with the cost of carers going in, so my brother and I can carry on working."

300362, April 2026

Not involving the carer in the discharge process

One carer told us how he was not consulted during the discharge process for his wife following a recent hospital overnight stay.

"My wife was in hospital last week. The paramedics took her to hospital and she spent the night there. I spoke to the hospital and arranged to pick her up the next day. When I went to pick her up she was not there and had already been sent home in an ambulance. My wife has Alzheimer's. I drove home from the hospital to find my wife and two ambulance men standing on the doorstep as my wife does not have a key to get in. I was not consulted about this change in discharge. It was bad communication. Maybe she agreed to this discharge but she has dementia so the hospital should have questioned it or checked with me."

300446, June 2026

Stress and wellbeing

Once again, carers have been telling us about how their caring role affects them.



"We're all getting older. You just muddle through. I don't know who you'd shout to, to say we're struggling."

300352, April 2026

"I care for mum. I'm just really worried about her falling over and stuff. I worry all the time about my mum as I love her very much."

300366, April 2026

"At times I need to get away and just scream."

300392, May 2026

"Emotionally I am finding it exhausting. I have found for the last 2-3 weeks that I am grieving the person that my sister was before Alzheimer's was diagnosed... I really didn't want to be my sister's carer... I feel guilty for saying that I don't want to be her carer."

300390, May 2026

Juggling many roles as a carer

We have heard from carers about the many different tasks they do in their caring roles.

"I do so many things for my mum that I don't have the time to think about doing things for myself. The biggest stress that I have is worrying about my mum. I also have to organise and attend all her appointments."

300363, April 2026

"She was diagnosed [with dementia] two years ago. I literally do everything now. I have to tell her what to do all the time or she won't know or do anything. It's exhausting."

300448, June 2026

"Gran was always fiercely independent and hates to ask for help. Both gran and grandpa found it incredibly difficult to accept the changes when gran got ill with dementia. Changes such as grandpa having to cook and take control of all the things that gran always was in charge of. They both found that very hard."

300447, June 2026

"My wife has Alzheimer's. It's hard work... It's getting worse. I'm the chauffeur, cook, cleaner, carer and memory bank for her."

300446, June 2026

"Everything to do with caring is just so complicated... It's a minefield. Take completing the Attendance Allowance forms. My mum wouldn't have been able to complete these. As for the Continuing Healthcare (CHC) for my dad, she wouldn't have had a clue. There are so many barriers and everything is so complicated. She



is elderly and if it wasn't for me, I don't know what she would have done. Even I found the forms complicated and they took a long time to fill out."

300361, April 2026

Some carers have also told us how they are relied upon to deal with online access for their cared for.

"My mum can't do anything digitally, not on a computer or a phone. She doesn't like using it and won't use it. So, it's all left to me. She's lost confidence in even trying. So with her banking, she worries that she'll press the wrong button and do it wrong."

300363, April 2026

"Gran's husband was her main carer but we lost him this year... He didn't have Facebook and he wasn't able to do things online or digitally... A lot of people his age have caring responsibilities and my grandpa used to get very worried and stressed as he couldn't do things online. Services need to remember the older generation and make things accessible for all. A lot of elderly carers must be in a similar position."

300447, June 2026

Struggles with balancing work alongside caring responsibilities

For many carers, it can be challenging to manage their paid employment alongside their caring role.

"I care for my dad who has dementia. I don't live with him and he does have carers coming in. But I'm really struggling at the moment. Even though he has carers, he constantly rings me. It's so wearing. He forgets that he has rung, so he rings again. I feel that I have to answer in case he is ill or has a fall. This is day and night, so I never get a break. I work full time and it's just exhausting... I feel so guilty if I don't answer the phone and am not at his beck and call but it's exhausting and I don't know how long I can carry on like this."

300385, May 2026

"It's impossible for me to work. I'm like my daughters' personal assistant (PA). Constantly fighting for them and ensuring that their needs are met. Even when things are settled, you're waiting for the next crisis to occur... As a parent/carers you're in constant fight or flight mode which is exhausting."

300357, April 2026



"I was self-employed and had my own business but I had to give it up to home school my son and do all the admin to get him into a specialist school. My husband is also self-employed and money is tight now."

300356, April 2026

"I have changed my working pattern to now work from home, so that I can keep an eye on her. I used to go to London and that was a bit of a break, but I don't like to leave her... It does mean that I don't get a break."

300392, May 2026

We have heard what a difference it can make to carers when they feel supported as a carer at work.

"I went from working full time to part time. I didn't have the physical or mental capacity to carry on working full time to the standard and capacity that I was happy with. I wasn't working here when the caring started and I wasn't supported which is why I had to reduce my working hours. Working here is different. I have a supportive manager, and the environment supports working carers... Being a carer and working here is great. They allow staff the flexibility to attend appointments so you're not using up your annual leave. I also have to travel an hour to get to where mum lives. All this impacts you financially as a carer."

300363, April 2026

"Financially, I have to work as I'm a single parent but I'm lucky that I can work from home and my employers are understanding. I can attend this [carer support] group, which is important to me and my wellbeing as long as I make up the time."

300360, April 2026

"I have multiple caring roles at the moment. But I'm ok juggling it all. Work is very supportive... This staff group started when a survey was sent round to try to identify staff members who might be carers... I appreciate knowing that this [staff carer] group is here and that there are people that I can talk to who are in the same/similar situations. Knowing that the organisation is carer friendly is a positive too. I want to work but I also need to care as well."

300364, April 2026

Concerns for parent carers

Worrying about the transition to adult services at 18

"Our daughter is very vulnerable. She doesn't understand the outside world and doesn't see that it isn't safe for her. She's [age] but her mental age is much younger. How can she now be treated as an adult and taken out of children's services when her mental age is around 8 years old. It's very worrying."



Importance of groups for young carers

"I'd like her to know other young carers so she could talk about things. I do talk to her about the situation but it's not the same as I'm her mum. I can't understand how she feels about being a young carer and what it's like for her to be a carer for her sibling. It's a real emotional drain on her as she gets leant on a lot by her sister. I do feel for her. She says there isn't a young carer group at school. I wish there was as she really could do with it."

300382, May 2026

"The young carers enjoy the group at school because they have formed friendships, can talk openly in it, and everyone is supportive and caring."

300444, June 2026

Lack of groups for adults with additional needs

"There is a real gap for adults with additional needs. There are no groups out there for them. Where are they expected to socialise? It's as though once their health needs are being met, that's all they need. But they do need to have their social needs met too. This is forgotten... These young adults with needs need to have somewhere that they can go and hang out. There is nothing out there for these young adults. Once they are in their 20s, there is nothing and they are just dropped and left."

300395, May 2026

Valued support for carers

The Giving Carers a Voice team visit many groups across the whole of Surrey, and we continue to hear praise and support for the many groups we go to.

"This group [Little Stars, Chertsey] is fantastic... You make real bonds with the people here as we all understand what each other is going through. It's a great support."

300456, June 2026

Influence and impact

"Thank you so much for your time and talking to me during the break... You were so helpful and made me feel a whole lot better and less guilty about my thoughts relating to dad. The links you sent through are great as I didn't realise there was so much information out there, I could access, such as the Royal British Legion. I really struggled with dad's diagnosis initially, as the consultant told him he had



dementia and then discharged him, with no further information or signposting, so having people and organisations like yourself is great and fills a gap."

Carer, 300405, May 2026

"I just wanted to say thank you again for all the really helpful information you provided to me. I followed up on the carers payment and it was paid last week, so thanks for having told me about it as I would never have known otherwise."

Carer, 300452, June 2026

"Amazing morning. You are both very skilled and experienced in your roles. Completely felt so comfortable with your support and guidance in the session last week."

Group leader, Carer support group, May 2026

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 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 July - September 2026

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

Place	Date
Age UK, Planning for your future, Dorking	29/07/2026
Parkinsons group, Milford	03/08/2026
Stroke group, Ashtead	05/08/2026
Mytchett memory lane café, Camberley	11/08/2026
Action for Carers hub, Addlestone	12/08/2026
Trekkers festival, Guildford	18/08/2026
Action for Carers hub, Epsom	02/09/2026
Action for Carers hub, Farnham	04/09/2026
Action for Carers hub, Woking	07/09/2026
Community inclusion event, Woking College	09/09/2026
Action for Carers hub, Hersham	10/09/2026
Action for Carers hub, Redhill	11/09/2026
Action for Carers hub, Oxted	14/09/2026
Freshers fair, Nescot, Epsom	15/09/2026
Action for Carers hub, Cranleigh	17/09/2026
Freshers fair, Godalming College	18/09/2026
Age UK, Planning for your future Awareness Day	22/09/2026

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)
-  Email: info@luminus-cic.uk

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We are proud to have signed up to the End Poverty Pledge – [End Poverty Surrey – Good Company.](#)