

Giving Carers a Voice Quarterly Insight Report

What we're hearing

July - September 2025



Giving Carers a Voice

Quarterly Insight Report – July to September 2025

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.

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

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.

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. 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 July – September 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:

- Additional needs showcase, Ewell
- Carers event, Horsley
- Family Voice parent/carers group, Oxted
- Surrey and Borders Partnership (SABP) Recovery Fest, Guildford

- St Saviours Church Trekkers Festival, Guildford
- Phyllis Tuckwell Hospice carers drop in, Guildford
- My Time Reigate carers group
- SABP carers coffee morning
- Little diamonds parent/carer group, Stanwell
- Sheerwater community day
- Medwyn Surgery carers event, Dorking
- Springfield Surgery carers event, Elstead
- Godalming College, Godalming
- Home-Start SEN stay, play and learn, Woking
- Parent/carer group, Lingfield
- Austen Road surgery carers event, Guildford.

Main themes we have heard from July – September 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 and Respite Care.



Where we have shared our insight

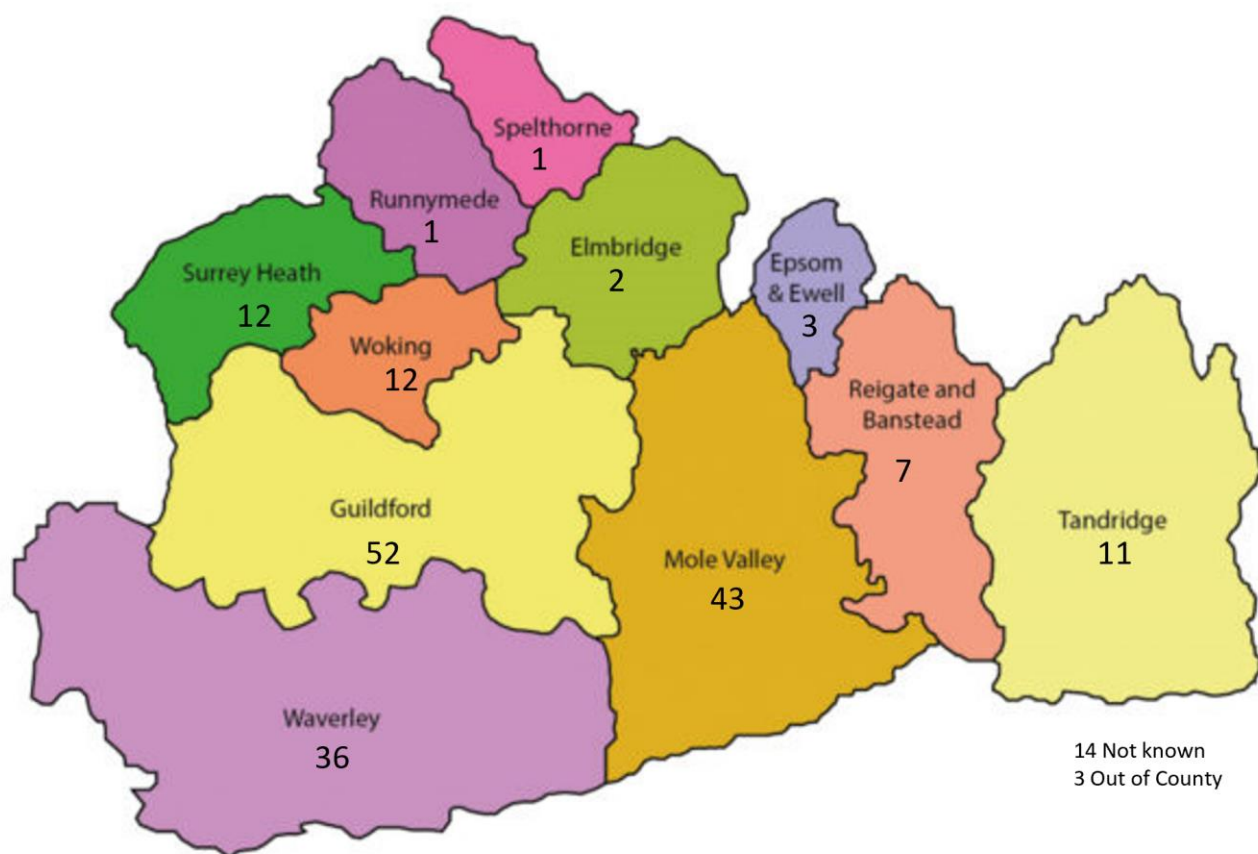
During this quarter we have shared carer insight (key themes and carer experiences) in the following meetings as part of our 'what we've heard' regular insight sharing meetings.

- Northwest Surrey carers action group – July 2025, September 2025
- AACC patient and engagement forum – July 2025
- Carers project group (Woking Borough Council) – July 2025
- Surrey County Council inclusion team – July 2025
- Southwest carers network meeting – July 2025

- Adult Social Care carers practice advisers team meeting – July 2025
- Surrey Heath dementia community meeting – July 2025
- South Tandridge health and wellbeing neighbourhood meeting - July 2025
- Independent Mental Health Network meeting – July 2025, September 2025
- Patients with disabilities and carers meeting – September 2025
- Carers action group – September 2025
- Epsom and St Helier Hospital carers action group – September 2025
- North Tandridge health and wellbeing neighbourhood meeting – September 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 Guildford (52) and Mole Valley (43).



Key themes we have heard from carers from July to September 2025

- Not identifying as a carer
- Carers with their own health needs
- Unable to get a break from caring
- Struggles for parent carers
- Juggling employment and caring

- Worrying about future care
- Stress and isolation.

Not identifying as a carer

We are continuing to speak to carers who do not realise that they are carers. We spoke to **197 carers** this quarter and many still do not recognise themselves as carers.

"I look after my father who is in his 90s but lives independently... I also look after my [adult] son... I then also look after my sister-in-law who is in her 70s... but lives independently. I don't think that I'm a carer. Am I? Could they all manage without me. Absolutely not."

235550, August 2025

"I don't really class myself as a carer. To be honest I've never really thought about it. It's been like this forever and when I was working, my wife took care of everything - the paperwork and the day to day stuff. I didn't realise just how much she was actually doing, until I retired."

300021, August 2025

We have spoken to parent carers who hadn't considered that their children could also be carers.

"I've got 3 kids. My 2 boys have got additional needs. I'd never thought of my middle child as a young carer. I guess we've always just got on with things."

300070, September 2025

"My son has special educational needs (SEN) and is non-verbal... I have two other young children... My son is awake most of the night, and my other children are often very tired in the morning, so they fall asleep as soon as they get home [from school]. I hadn't considered that my 2 other children would also be carers... I'll speak to the nursery and school to check if there's additional support there for them."

300089, September 2025

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](#).

Carers with their own health needs

"I've cared for my husband for several years... I'm finding it hard now to keep going, as I'm waiting for an operation, and I'm in a lot of pain."

300050, September 2025

"My mother has been going downhill fast since my father died last year... She lives on her own and I'm finding it difficult to get over there due to my own health



needs, but I make sure I go there at least once a week. My mobility isn't great either... I didn't realise my GP was able to help, and actually, the practice here has gone above and beyond to help me... I'm looking for a cleaner for when she gets home in a couple of weeks, because I can no longer do it for her as I struggle with my own cleaning."

300049, September 2025

Unable to get a break from caring

Carers have told us about the challenges of taking holidays.

[Carer for son with additional needs] "We were going on holiday but we decided not to go. It was just going to be more stressful than being at home. We can't have him trashing a holiday home and being disruptive in places. It's easier to just stay at home."

300007, August 2025

"There is no one who can look after my mum if I'm not here. Yes carers can pop in sure but they can't do her shopping and all the emotional support she needs 24/7... So I would just love a holiday where I didn't get mum phoning me 20 times a day. Never going to happen. It's endless and exhausting . And no one understands at all unless they've done it themselves."

300081, September 2025

"[Parent carer] We didn't go on holiday this year. It's more stress than it's worth to go away. Far easier to stay at home."

300070, September 2025

Once again, we have heard about the difficulties that carers experience when trying to get respite from their caring responsibilities.

"My husband has early onset Alzheimer's... I would like more respite. I get a break if my son is able to help for a few hours... It is absolutely exhausting and draining not only for me but also our son who lives with us who is quite forgotten in his role of supporting me."

300085, September 2025

"My son is autistic... I don't get any breaks. The family don't understand the struggle we have with our son. They see him as being naughty all the time."

234374, July 2025

"I'm a carer for my [adult] son with additional needs. If I take my eyes off him for just a second when we're out, he wanders off and I become stressed... I don't get any time for myself and sometimes struggle with the intensity of his needs... Going to [carer] groups would be difficult because I can't leave him alone."

234373, July 2025



"The difficulty is that he won't admit that he needs any help and it's hard for me to leave him alone as he falls so often. I'm not sure that he'd have someone that he doesn't know in the house and so I'm stuck aren't I?... He doesn't sleep at night, wakes me up and then wanders around... The lack of sleep every night is really affecting me. I still have to keep going the next day as he needs looking after."

300054, September 2025

"I do not get any respite. I am the primary carer for my son. My family do not have capacity to help and live an hour and half away. My husband works long hours and we rely on his income. I look after all educational and medical needs, I fill in all forms, attend all meetings. I have adapted my work around school... It is very isolating, I don't feel I have people I can ask for help."

300078, September 2025

Struggles for parent carers

Importance of young carer groups

"I have just registered my [child] with Surrey Young Carers as she is a young carer. I don't think there is a young carer group at her primary school. She'd definitely like to meet other young carers and be with other children who understand."

300007, August 2025

"My son really enjoys Surrey Young Carers. He loves being with other kids who get it and get what he deals with every day. He loves all of it... His school don't seem to do anything for young carers. I told the school that he is a young carer and explained that some days he is just going to be exhausted because of his family situation. He has a lot to deal with as a young carer."

300005, August 2025

"My daughter is going to secondary school in September. She wants to go to a school with a young carer group. Unfortunately the school she is going to doesn't have one. It's not that she wants to go to their events or get together. It is more that she wants to be recognised as a carer. She wants to be acknowledged as a carer at the school."

300002, August 2025

Transition from children to adult services

"My daughter is autistic. I'm just really worried about things now she's nearly 18. I am her carer and I need to be involved and included in her care but I worry how to do that. She wants me involved and I need to be. I am not sure how to stay in the loop with things."



Value of specific groups for children with special educational needs (SEN)

"My son has special educational needs and is non-verbal. I have 2 other children... I find juggling it all very stressful and coming here [to this SEN play group] is my way of getting out of the house for the morning with him where he can play with no judgement."

300089, September 2025

"He doesn't sit still. It's hard work. My husband doesn't like to take him to playgroups and inside activities as he can be loud and kick off and my husband then feels embarrassed and anxious. This [SEN] group is good as I don't worry what anyone thinks here."

300069, September 2025

Juggling employment and caring

We continue to hear from carers who have had to give up their paid work due to their caring responsibilities.

"I have had to give up my job to care for [my daughter] and this has had a tremendous financial impact on us as a family. My husband now has to support us all and we can't afford any 'extras' and my older daughter can get quite resentful that she can't have things that her friends have or go out and do things that they can. We just can't afford it. I did try working from home... but it wasn't possible if my daughter was home. You can't work while she is having a meltdown in the background. I'm currently waiting for a decision on PIP and carers allowance. It could take months and we could do with the money now."

300067, September 2025

"I can't work now. I did work full time before my youngest was born and then I tried to carry on with full time work but I just mentally crashed and burned. It was all too much once I became a carer so now I can't work anymore... All the emails and the fighting for him, it is like a full-time job in itself."

300005, August 2025

"I feel completely lost at the moment. I nearly lost my job because of my son's behaviour and his being excluded from school and having to take so much time off to look after him. I have had to give up work now as his needs have got worse and I need to look after him. I'm juggling everything and have zero energy."

300077, September 2025



"I have had to give up my full-time job to care for both my parents and my son with autism spectrum disorder (ASD). There are just so many forms to fill out and then trying to juggle all their needs. I couldn't do everything."

234615, July 2025

"I have 2 other children and they have been affected by their sister's severe mental health issues. Not only because of how her extreme behaviour impacts them but also because I have had to give up my job and so this has impacted us financially... I have no savings and will only have a state pension. Will that be enough to live on? I've had to give up my job and I'm on benefits."

300076, September 2025

"My husband had cancer last year. He's in remission... and has recently returned to work. We struggled financially when he was off work. Neither of us could work and didn't qualify for benefits. I had to care for him 24/7, clean his feeding tube and help him with washing, dressing and going to the toilet. It wasn't easy, but we're over the worst now."

234372, July 2025

A recent report, [The hidden cost of unpaid care: The economic price of locking carers out of work](#), reflects on the hidden cost of unpaid care and the economic price of locking carers out of work.

Worrying about future care

"I care for my dad who has Alzheimer's... I'm just really worried about what is going to happen as he gets worse and we potentially can't cope with the level of care he needs as he gets nearer the end. I don't know what to do. I haven't a clue where to start or who to turn to."

300003, August 2025

"My [adult] daughter has complex needs and now my wife has Parkinson's too... What I do worry about is what will happen to her if my wife and I die before her. I do have another daughter and she says that she will take care of her but that's a huge responsibility for her. I know we need to start making plans."

300021, August 2025

"I am happy now that mum is safe in a care home. The next hurdle is considering what we need to do when her finances run out."

300027, August 2025



Stress and isolation

"I lost lots of friends once he was born as people just don't understand what it's like having a child with additional needs. I have met some parents at Challengers now and also my friend is going through similar issues with her kids so we support each other and do things together. I've been excluded from so much as has my son. People make you feel as though your child is wrong and you're wrong. I've had to develop a much thicker skin now."

300005, August 2025

"Only carers understand what it's like and what you're going through or have been through. We all swapped numbers too and have a WhatsApp group. We text daily and it's a great support especially on those days when things are really bad. It's great just to get a text from another carer who knows what you're going through."

300016, August 2025

"The biggest thing is being home alone and being isolated. Technology can help."

300008, August 2025

"Being a carer is all consuming. I'm with him all the time."

300053, September 2025

"I have been caring for my mum for a very long time... When her caring needs increased, I gave up work. Which means I now support her 24/7, 365 days a year... and my caring responsibilities have doubled [since her recent fall]... I feel constantly exhausted. Most of the time I feel really anxious, depressed, tired and lonely... [I have] very little time for myself and I feel completely drained all the time."

300055, September 2025

"Caring is more mental than anything else. I'm feeling stressed and overwhelmed at the moment. I came here today as I knew that there would be other carers that I knew... We formed a WhatsApp group and now use this to arrange meet ups or just send messages of support to each other. I find this so supportive to have someone checking in on me as we don't have children or close family around."

300013, August 2025

One carer told us about what happened when their caring role ended.

"Once my husband died, the house felt empty and was deadly quiet. The house had been full of carers, doctors, nurses and then suddenly everyone left. And it was empty and then after the funeral we had no visitors coming and going. It was very strange to go from a full busy house to just quiet and emptiness."

300016, August 2025

Valued support for carers

"Phyllis Tuckwell have been excellent. They have been so helpful. They are always at the end of the phone when I need them and they are always there for me."

300015, August 2025

"I have felt really valued by the SABP Community Mental Health team for Older People. I am so lucky to have so much support. Being heard makes all the difference and just knowing that no matter what you're going through, you're not alone."

300009, August 2025

Carers have told us how much they value carer support groups.

"When I can go to any carer activities, it makes a huge difference to my mental health and helps me to carry on more positively. Even going to a carers hub for a coffee is very calming and helpful... [Caring] is exhausting at times, mentally it is a 24 hour concern and worry. And you also worry constantly about the future for your loved one. But when I come home from a carer's activity, I do feel so much more refreshed and positive to carry on."

300033, August 2025

Influence and Impact

- We have been listening to unpaid carers at various events and venues throughout Surrey who have provided vital insight into the challenges that they face. This ensures that services are shaped by real experiences.
- The networking that we do with other professionals and organisations allows ideas and experiences to be shared which broadens perspectives and improves practice.
- Connecting with other professionals allows us to learn from their experiences, share insights and explore new approaches together. These relationships help us to find better ways forward, strengthen our practice and create solutions that meet carers needs. This can be shown by the variety of groups and meetings that we engage with and attend.
- We also work closely with seldom heard communities to amplify their voices and use those experiences to shape ideas and bring about real, meaningful change.
- In collaboration with Healthwatch Surrey colleagues we will continue to seek clarity regarding the dissolution of the Carers Partnership and advocate for robust plans to ensure that carers' voices remain heard, valued and represented at all strategic levels.

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 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!

Where we are going October - December 2025

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

Place	Date
Egham Orbit International Older Persons day, Egham	01/10/2025
Woking Hub	02/10/2025
Community health fair, Tadworth	08/10/2025
Memory Lane dementia carers, Cranleigh	20/10/2025
Age UK Planning for your future, East Molesey	23/10/2025
Additional needs showcase, Ash	27/10/2025
Revive coffee shop, Chertsey	29/10/2025
Care experiences fair, Reigate	30/10/2025
Action for Carer hub, Woking	03/11/2025
Additional needs showcase, Redhill	11/11/2025
Working Together for Woking, Woking	13/11/2025
Bisley community café, Bisley	17/11/2025
Carers rights event with Action for Carers, Epsom Hospital	20/11/2025
Action for Carers hub, Dorking	03/12/2025
Age UK Planning for your future, Fetcham	09/12/2025
Age UK Planning for your future, Esher	11/12/2025

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:

-  Web: luminus-cic.uk
-  Telephone: 01483 301448
-  Text: 07592 787 533 (SMS only)
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