

Giving Carers a Voice Quarterly Insight Report

What we're hearing

January to March 2026



Giving Carers a Voice

Do you support the people who care for you?

"I just and then But"

Please for

Luminus
Giving Young Carers a Voice

Luminus
Giving Carers a Voice
Quarterly Insight Report
April - June 2025

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Giving Young Carers a Voice

- Are you under 18 years old?
- Do you look after someone - parent, brother, sister or someone else in your family - who couldn't manage without your help?

You don't need to be a registered carer. To contact us:

For further information and advice:

- 0303 303 0023
- 07592 787583 (text only)
- info@luminus-vc.uk
- <https://www.luminus-vc.uk/giving-carers-a-voice>

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We support all families with children and young people up to 25 years old and the professionals who work with them

- Search for quality childcare
- Support your child's education and development
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date with local information services for families in Surrey

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Giving Carers a Voice

Your Voice matters
Please scan the online carer questionnaire.

Thank you!

Giving Carers a Voice

Quarterly Insight Report – January to March 2026

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.

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 January – March 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:

- Action for Carers hub, Shepperton
- Merstham Community hub, Merstham
- Memory Lane café, Cranleigh
- Parent/carer group, Redhill
- Age UK, Planning for your future, Walton-on-Thames
- Runnymede foodbank, Runnymede
- Carers event, Bookham
- Wellbeing fair, Godalming College
- Age UK, Planning for your future, Ewell
- Dementia memory café, Leatherhead
- Dementia memory café, Banstead
- Chertsey foodbank, Chertsey
- MyTime carers group, Reigate
- LGBT history month, Staines
- Age UK, Planning for your future, Dorking
- Age UK, Planning for your future, Bramley
- Age UK, Planning for your future, Weybridge
- Age UK, Planning for your future, Cranleigh
- Research café, Woking.

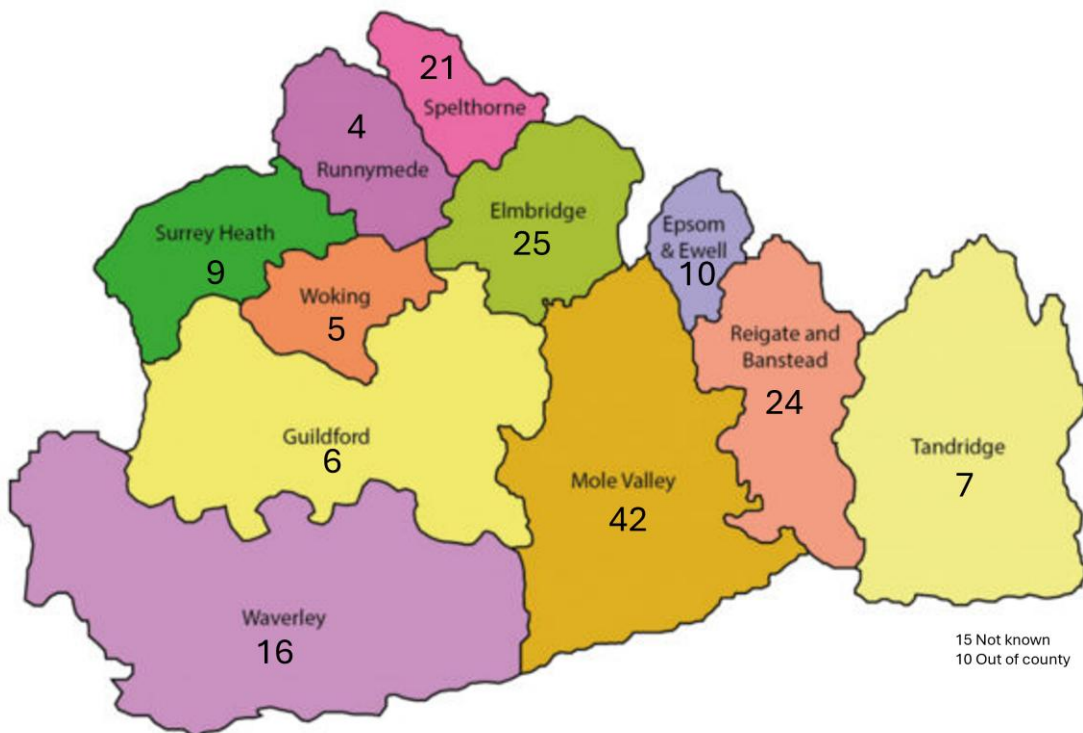
Main themes we have heard from January – March 2026

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



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 Mole Valley (42) and Elmbridge (25).



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:

- Merstham neighbourhood meeting – January 2026
- Northwest Surrey carers action group – January 2026
- Preston partnership meeting – January 2026
- Runnymede health and wellbeing partnership meeting – January 2026
- Horley neighbourhood meeting – February 2026
- South Tandridge wellbeing and neighbourhood meeting – February 2026
- Epsom and St Helier carers steering group – March 2026
- Northwest Surrey carers action group – March 2026
- North Tandridge wellbeing and neighbourhood meeting – March 2026.

Key themes we have heard from carers from January to March 2026

- Not identifying as a carer
- Stress and wellbeing
- Challenges of caring for someone with dementia
- Difficulties facing parent carers
- Struggles of caring for someone over 18
- Juggling employment and daily life with caring responsibilities
- Not sure where to turn for help and advice
- The value of support groups for carers.

Not identifying as a carer

We spoke to 208 carers this quarter and many still do not recognise themselves as carers.

“No, I'm not a carer. Definitely not. I cook meals once a week for my elderly parents and take them over for them to put in the freezer. I'm trying to keep them as independent as possible for as long as possible. They are quite stubborn and keen to not have any help or carers.”

300321, March 2026

“I'm not quite a carer yet. My husband is at the early stages of dementia. And we're ok at the moment, we don't need any help and we are fine.”

300319, March 2026

“I don't think I'm his carer yet. I don't like that word. We look after them because we love them, it's what you do if you care.”

300246, February 2026

"I don't really think of myself as a carer. He has dementia but can do most things for himself and he still drives."

300213, January 2026

"I'm not really a carer. She wouldn't like me saying that or thinking that I am. Could she manage without me? Not really. She had a stroke and has lost the use of one arm and uses a stick to walk. She can do some things but relies on me a lot. I don't think that she'd like me applying for benefits. We're ok."

300210, January 2026

Stress and wellbeing

Carers have told us about the impact that caring has on their own wellbeing and mental health.

"When people ask me am I alright, I always say 'If she's ok, then I'm ok'."

300243, February 2026

"My wife was diagnosed with dementia 5 years ago. I think as a carer that you internalise your stress as you're so busy trying to destress them."

300256, February 2026

"One morning, he went back to bed in the morning as he said he was so tired. He slept for over 24 hours. I was so worried, I kept going in and checking that he was still breathing. It's things that like that you just don't understand until you're in the situation. I couldn't sleep, I couldn't relax, I was so worried."

300246, February 2026

"The caring has taken its toll on me. I can't work anymore as I have lots of health conditions going on now. I am so stressed and scared... People always ask if I look after myself, but how can I? I can't sleep. As soon as I go to bed, my mind just thinks and thinks and worries. I can't stop thinking about it all. It's going round and round. I've got a lot of stress and health problems now because of all the caring."

300293, February 2026

"Everyone tells us as carers to take time for ourselves, but all my time is taken up caring. I'm either ferrying my daughter to her activities and appointments or taking my husband. Where is this free time I'm meant to have? Caring is all consuming. It just takes over your whole life... It's a combination of a lack of motivation and a lack of energy to go anywhere else or do other things. I'm always worrying about someone or something. I do want to do other things, but I'm just so tired dealing with everything. There is always something to do and some



appointment or other to take them to. I really can't do this anymore... My husband is having an operation in a couple of weeks and I'm not sleeping with worrying about this. What if it goes wrong? It will all be back on me... All our time as carers is spent looking after our cared for. It would be lovely to have some time to ourselves, but that simply isn't the reality."

300202, January 2026

"I'm a carer for my [adult] daughter... I work full time and I'm a single mother. I feel like I get no support. It's relentless... I never get a break. It's just the two of us at home as I'm a single mother. I just wish I could get her out more. Every day is a struggle and is endless."

300219, January 2026

"I'm a carer for my husband... This last year, he has just got weaker and weaker. He's just so debilitated. It means we've lost all access to our social outings. The loss of social contact is very difficult. If we do go out, this has its own anxieties anyway... Things are very hard. I'm really struggling. I do have a wheelchair but it takes a long time to do anything, to get him up, dressed and out the house takes me about an hour."

300237, February 2026

"Being a carer is very tiring and never ending but I do think it's an honour and I'm so honoured that I am able to care for my husband."

300236, February 2026

"Now that she is living away from me [in a care home], I realise how tiring caring for her was."

300255, February 2026

Challenges of caring for someone with dementia

We have heard about many of the challenges that carers face when caring for someone with dementia.

"After diagnosis, I was hit with so much information that it was overwhelming to the point of madness. I didn't know where to start."

300249, February 2026

"My wife has Alzheimer's. She was diagnosed about 5 years ago. She does nothing now, that's half the problem... I just don't get any break. The other day my son took her out and then I get the emergency call saying he'd lost her. She goes walking about and escapes all the time. She was lost for about an hour and he was very upset about it. So even when I have a break, I still get the calls and I still have the worry. There is no life now. Life just dies.... The real struggle is her going out



for walks and the police bringing her back. It's happened multiple times now... She is incontinent now too... She's always running away so I have to keep an eye on her constantly. Luckily, she does sleep well, so I can sleep and not worry about her running away at night."

300235, February 2026

"My husband has been diagnosed with dementia... He suffers from terrible anxiety so it's rather like having a toddler in the house."

300248, February 2026

"Mum was diagnosed with dementia in 2021... But even though she now had a diagnosis, there was nothing offered to me to help support her as her carer. It was like 'bad luck, that's a shame' and I was just left to get on with it."

300255, February 2026

"He's gone downhill since Christmas. I think a lot of people with dementia do in the winter. So, it's been more challenging for me. I can see that he's deteriorating. I have made an appointment to see the GP this afternoon. He will say that everything is ok and then I'll tell the GP the truth."

300211, January 2026

"Mum has just been diagnosed with dementia... My brothers and I go for a week every month to help out with stuff, but the other 3 weeks she's on her own. And she can't cope. She doesn't accept yet that she's no longer able to cope on her own. It's a long way to drive and I'm not getting any younger, so it takes its toll on me now. The drive and the week busily helping mum is really exhausting. I am of an age now where I have my own health concerns too and I'm not a spring chicken anymore. It's frustrating as a while back I suggested she move nearer to me or one of my brothers but she didn't want to. I wish she had now. It would make things so much easier for us. Mum's always been an outgoing person, but now she has withdrawn. She's withdrawn from life and society and won't go out. I guess that's the dementia."

300299, March 2026

Difficulties facing parent carers

Issues around diagnoses

Carers have told us how they feel abandoned once their child is diagnosed.

"I think what's missing for parent carers is help when your child is first diagnosed. I was just given a leaflet and left to get on with it. I have had to find groups and help through Facebook groups and talking to other families."

300221, January 2026

"My children got their diagnoses and that was that. You're given a report and told to get on with it."

300217, January 2026

Parent carers have spoken about the value of getting an early diagnosis for their child.

"My sons' nursery picked up that they thought there was something wrong with him. I couldn't really see it as I have ADHD myself. It was so important that he was picked up and diagnosed early. All nursery staff should be Special Educational Needs (SEN) trained as this early diagnosis and getting the Education, Health and Care Plan (EHCP) has really helped him. He is in a mainstream school and thriving."

300220, January 2026

Lack of understanding

Parent carers have told us how they feel that other parents without children with additional needs don't understand what they go through.

"My normal friends just don't get it so I lost a lot of friends. I now am only friends with mums with kids with SEN."

300217, January 2026

Stress of the school day

"It's a real struggle to get both my girls to school. I don't get a break at all. When the kids are at school, I'm preparing myself for the fallout of the day and waiting for the phone to ring with what the youngest one has done today. Then, as soon as they get home from school, we have the fallout from the day... The girls thrive in the summer holidays as there is no added pressure of having to conform to something."

300217, January 2026

"He has not been coping well at school and he was homeschooled for a few years. He's settled into school now. He doesn't necessarily like it, but he's going. He doesn't want to go but he goes. The school holidays are so much better as it's much less stressful for him and therefore me."

300218, January 2026

Helpful support for parent carers

One carer told us about an occupational therapy (OT) support line that they accessed while waiting for their son's autism assessment, which had been very useful.



"My son is currently waiting for an autism assessment. I called the service to double check their waiting time, as his nursery and me are wanting to implement strategies and are considering applying for an EHCP. While discussing waiting times, the staff member I was speaking to asked if there was anything specific we needed support with in the meantime. I mentioned that we are struggling with his sensory seeking behaviours and keeping him safe at nursery and home. She told me about the OT support line, which parents can call and speak to an occupational therapist. I called the service and had to leave a message, but they called me back when I asked and gave me lots of suggestions and followed up with an email. The OT also made sure I was aware of the speech and language support that is also available. Really good service and useful to have as we develop strategies to help my son. As a parent, it is also really reassuring I can get advice and guidance whenever we need it."

231466, March 2026

Struggles of caring for someone over 18

Carers have spoken to us about the challenges they face once the person they care for is over the age of 18.

"It's also so frustrating that, as she is an adult, I'm not told anything about her care or medication. Unless she chooses to tell me. She can consent to this, but she has to consent every time she attends an appointment and when she is ill, she just shuts me out, but I'm still expected to pick up the pieces as a carer."

300202, January 2026

"I have 3 boys, my middle son is autistic... I come here otherwise I am with my son 24/7. He hasn't been in school since he was 13... My son has had workers who have come round and taken him out. But it doesn't last. They get him to a certain place, for example, where he can get on a bus by himself, but then he regresses back to square one. All the support has stopped now that he's turned 18. There is nothing available now. He can't deal with too many people, he won't go to a group."

230999, January 2026

"I've been trying to get the nappy allowance increased by the continence service. He never ran out of them while he was with children's services, but now he is with adults, they reduced his allocation from 6 a day to 4. How do they make that decision? He is getting bigger, everything is increasing in size and volume, he is doubly incontinent, but they reduced the number of nappies. I have to pay to buy more and this is expensive."

300265, February 2026



"It's very different and difficult once they are over 18. It was a terrible transition from children's to adult services. I tried so hard to get her into college every single day but in the end I had to pull her out... I just don't know what to do. What do we do for young people like her? She can't work, she never goes out, she spends all day in her room. I don't want that for her... There are so few provisions for young people if they can't go to college or work... I never get a break. It's just the two of us at home as I'm a single mother. I just wish I could get her out more."

300219, January 2026

The role of a carer can change over time. We heard from one parent carer how things have changed positively for her as her son is now in his 20s.

"My son is back home, which is the best thing for him. I can make sure he eats well, manage his medication and organise things like his dental appointments. He now orders his own medication from the NHS app but I need to remind him. We also have regular reviews with the ADHD team. They have adjusted his meds and we have a brilliant ADHD nurse. It's reassuring to know that every couple of months someone is checking in on us. His mental health has improved... I feel a bit surplus to requirements now. It's funny when you spend years being a carer and suddenly you're not really needed any more. It's been a sort of job for me for such a long time. It's almost like I don't know what to do with myself... I guess it will now be nice to be able to do some things for myself."

300282, March 2026

Juggling employment and daily life with caring responsibilities

"My daughter has ASD... It's been really hard during the school holidays as she can't be left by herself and I work full time. I'm juggling all the time, trying to look after her and still work. Luckily, I am self-employed and have some level of flexibility and my husband helps too. But there are no clubs/groups for her to go to. So I tend to work late and then I'm tired in the morning."

300204, January 2026

"Until fairly recently, I was running my own business, but I'm going to have to give that up as I just can't cope with caring for my daughter and my mother. Self-employment is stressful but it's the only way that I can juggle my caring roles and earn a bit of money. I'm using a foodbank now and I can't run my business at the moment due to caring. I just don't have the time or energy to look after myself."

300203, January 2026

"He was diagnosed with cancer about two years ago after he had had a stroke. I'm a full time carer for him now. I can't work as he needs caring for full time. Every



day is so busy doing his medication, washing him, taking him to his many, many appointments. These past two years have been so busy just caring, I haven't been able to think about arranging anything else. It's just been about caring and surviving."

300234, February 2026

My mum and dad live independently, but my mum was diagnosed with dementia a year ago... I'm struggling at the moment. I work part time, am an only child and have a family of my own. I can't see them every day and they refuse to accept outside help... It's just all overwhelming. I haven't got the time to see them every day and have my own life too... How do I force them to have more help in their home when they don't want to?"

300260, February 2026

"I was working full time, but I couldn't now. I don't think that I could even work part time now, as my son needs me. I am on tenterhooks while he is at school, in case they call me."

300220, January 2026

"I'm a single parent and my son has ASD. I work full time so it's difficult to get out to daytime hubs and groups."

300263, February 2026

Not sure where to turn to for help and advice

We have spoken to many carers who do not know where to turn to for help and advice.

"I'm a carer for my mum. I haven't a clue what to do, or where to start, or what we are entitled to as carers. I just don't know where to start."

300229, February 2026

"My wife was diagnosed with dementia a year ago. I am feeling completely overwhelmed. I haven't been signposted to any services."

300225, January 2026

We spoke to a couple of carers at a carers event organised by their local practice, who told us how useful the carer event had been to help them navigate where to go for help and support.

"I have lived abroad for years and so I don't know what benefits we would be entitled to or what is out there in terms of support for her... The GP sent me the invite to this carer event and it is for carers, so I must be her carer. I have found it so useful. I had no idea about Action for Carers and that they are there to support me. I will now go and register. It's also useful to know that they can also support



my grandchildren as young carers... It might help them to talk to other young people who have mums who have mental health issues, like my daughter does.”
300242, February 2026

“At the moment I'm fine, but it's good to know what else is out there for carers if I need more help and support in the future.”
300240, February 2026

Worrying about how to plan for the future

A major worry for carers is how to plan for the future for a time when they may no longer be able to care for the person they are currently caring for.

“My main worry is what happens if something happens to me, either short term or in the long run. Our family lives over 600 miles away and so it would take them a while to travel down here.”
300243, February 2026

“We are carers for our disabled daughter [in her 50s]. We are very happy looking after her. I am just concerned now, at our age, that we need to start putting things in place for when we are no longer here or able to care for her. I am looking to put a plan in place for the future, but I just don't know where to start.”
300231, February 2026

“I'm just so worried about the future. I don't know what to do. I'm in my 80s, so I know I do need to think about this. I have an adult son with learning disabilities, so I need to set up a trust for him for when we are not around.”
300245, February 2026

“My wife has early stage Alzheimer's. I have a heart condition and MS myself so my physical disabilities make it much more difficult to provide for my wife's mental difficulties. It's always on my mind about what would happen if something happened to me.”
300238, February 2026

“I'm a carer for my husband, who is ten years older than me. He was diagnosed with Alzheimer's in 2022. I'm very worried about the future and what would happen if something happened to me. I know how important it is that I look after myself. I'm worried if something did happen to me that my husband would then need more care and would then run out of money. I know I need to think about this and get more things put in place and in order to put my mind at ease. This Age UK, Planning for your future event has been excellent, it's been so useful.”
300280, March 2026



The value of support groups for carers

"I was at my wits end with no support. I then came to this group (Banstead Manor memory café) and actually just burst into tears as I realised that I wasn't on my own. It has been a lifesaver. I needed to know that I was doing the right thing for my mum. I just didn't know."

300255, February 2026

"Memory Lane café is an oasis in the chaos of life."

300215, January 2026

"I get a lot of benefit from coming to this group (Action for Carers hub) and talking to the other carers. It gets me out and I can have a bit of a rant about him and know it won't go any further. Some are in the same position as me, others have different caring responsibilities, but we all care and share the frustrations and anger sometimes."

300208, January 2026

Some carers have mentioned that they would like to see more men attending local support groups.

"I'd like to meet other mums who have neurodiverse children, and one of the mums here today, and I have swapped numbers to keep in touch. I think it would help if there were more groups that parents could come to, not just mums but dads too."

300274, February 2026

"There are more ladies at this group than men. It would be nice to have a few more men to chat to."

300259, February 2026

"There are no groups for dads, but it's been good to come here today and meet some mums who have been so welcoming and have given me loads of information and advice on getting my daughter to sleep at night."

300273, February 2026

Influence and impact

- Draft recommendations for the Joint Strategic Needs Assessment (JSNA) informed by carers have been developed and will be shared with carers for feedback.
- The evaluation of the carers breaks scheme is close to completion.
- Luminus continues to engage with communities to identify and support unpaid carers while strengthening partnerships and networks to enhance collaborative support.



- Following the Giving Carers a Voice team attending a dementia café in February 2026, one carer told us afterwards:

“I found this session very useful. I got to hear and appreciate other carers experiences in a much more condensed manner than would normally occur. Thank you for your interest and providing this opportunity.”

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 April to June 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 April - June 2026

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

Place	Date
Action for Carer hub, Cranleigh	20/04/2026
Mental health carers group, Spelthorne	20/04/2026
Parent carer group, Redhill	21/04/2026
Age UK, Planning for your future, West Clandon	28/04/2026
Age UK, Planning for your future, Leatherhead	30/04/2026
Trekkers parent carer group, Guildford	14/05/2026
Carers event, Royal Holloway, University of London	04/06/2026
Elmbridge Mencap family session, Walton on Thames	20/06/2026

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

Our address is:

Luminus, GF21 Astolat, Coniers Way, Burpham, Guildford, Surrey, GU4 7HL



[#EndPovertySurrey](https://www.instagram.com/EndPovertySurrey)

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