

Giving Carers a Voice Quarterly Insight Report

What we're hearing

October - December 2024



Giving Carers a Voice

Quarterly Insight Report – October to December 2024

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

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 October - December 2024

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, Woking
- Sight for Surrey Meet up and Catch Up, New Haw
- Additional Needs Showcase, Cranleigh
- Face 2 Face dads parent carer group, Chertsey
- Action for Carers hub, Farnham
- Dementia group, St Johns Church, Caterham
- The Meeting Room, Ashted
- Carers catch up, Richmond Fellowship online
- Action for Carers hub, Merstham
- Action for Carers hub, Hersham
- Carers Rights fair with Action for Carers, Camberley
- Carers Rights fair with Action for Carers, Farnham
- Action for Carers hub, Godalming
- Action for Carers hub, Epsom
- Dementia carers group, Age Concern, Banstead.

Main themes we have heard from October - December 2024

The word cloud below highlights the main themes we have been hearing about this quarter. The most prominent words are mental health, parent carer 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 community meeting – October 2024
- NE Hants/Farnham/Surrey Heath mental health forum – October 2024
- Surrey Downs carers action group – October 2024
- Carers action group – November 2024
- Older peoples network meeting – December 2024
- North Tandridge community meeting – December 2024
- Carers Partnership Board – December 2024.

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.

Report on identifying, involving and supporting unpaid carers who have a relative or friend in a care home

We have shared this insight with commissioners, providers and carers who participated with the report.

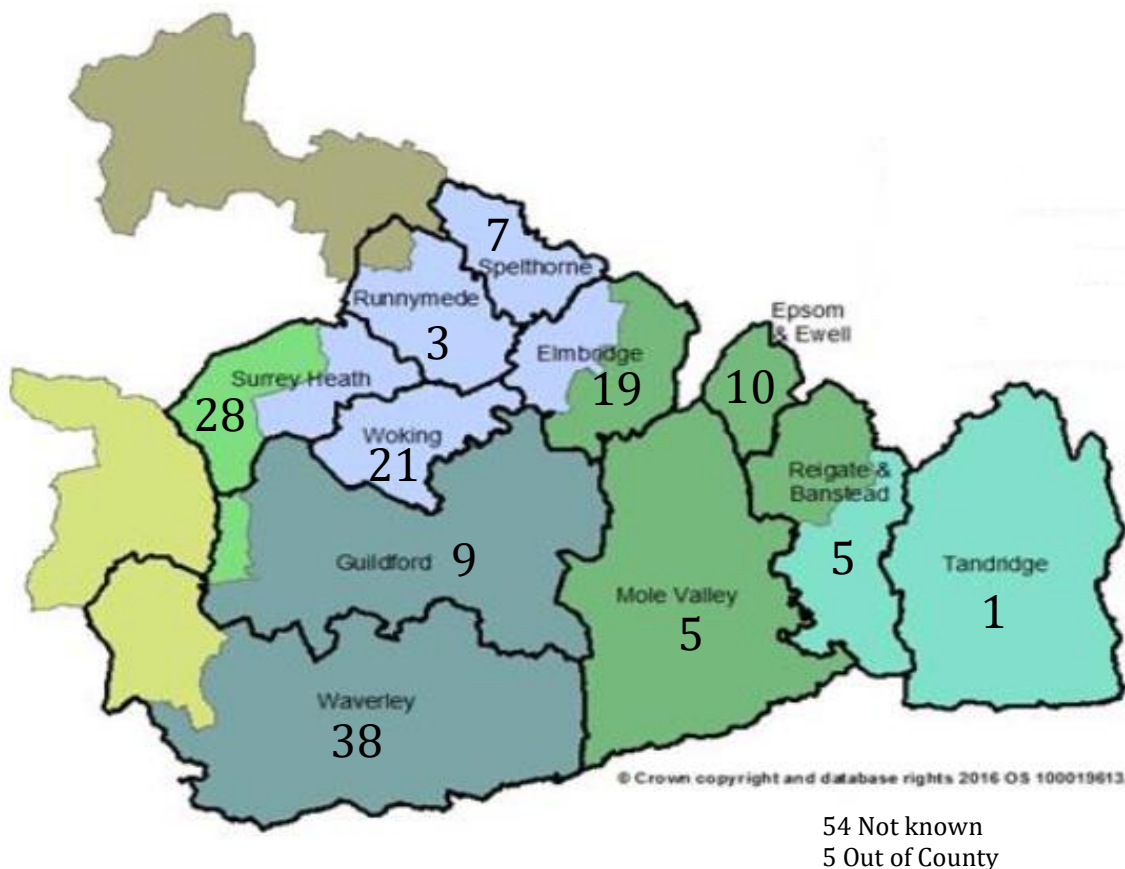
The key findings we reported were:

- The importance of regular communication
- Carers feeling part of the caring team
- Carers having access to care home management when issues arise
- Carers being involved in care planning
- Involvement of carers in activities and outings
- Meeting personal preferences.

A copy of this report can be found at [Care-homes-Identifying-involving-and-supporting-unpaid-carers-November-2024.pdf](#) .

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 Waverley (38) and Surrey Heath (28).



Not identifying as a carer

We are continuing to speak to people who do not realise that they are carers. We spoke to 205 carers this quarter and many still do not recognise themselves as carers.

“My mother-in-law who is [in her 80s] and has Parkinsons still lives independently but with support from all the family. I don’t think any of us think of ourselves as

her carer. We just do all these things as we love her. Could she manage without all our help and support? Definitely not, so I guess we all are her carers. I really hadn't thought or recognised myself as such."

225228, November 2024

"It's just your wifely duties isn't it? I never thought that I was a carer, I just got on with it. It's what a wife does."

222792, October 2024

"I wouldn't class myself as a carer as we're both still working. She is still independent and we don't live together... I think of a carer as someone who is caring for someone older who has more physical needs. I drive her around as she can't and do all the online things as she can't do this either. As she gets older and might need more help, then I might view myself more as her carer. It sounds odd to refer to myself in that way when we're both quite young. She couldn't manage without me. I'm her partner not her carer. It sounds odd to say that."

223156, October 2024

Stress and wellbeing

Once again, mental health is the main issue we have been hearing about from carers and the impact that caring is having on them.

"I'm struggling a lot... I come last and I don't even think about me. How can I? I do wonder sometimes how can all this happen to me. What have I done to deserve this? ... I've now realised that I was a young carer too. I've been a carer all my life."

225158, November 2024

"I can't get my head around the fact that he can't remember things, leaves lights on etc... These things are such a shock. I feel quite overwhelmed by it... It's having to take on all the things he used to do as well as the things I need to do.

Sometimes things just make me so angry. I now have to be part of everything. I am his security blanket."

226066, December 2024

"I am a carer for my husband, son and mother and running on an empty tank so a better night's sleep would make a huge difference."

226515, December 2024

"I am utterly exhausted. I did go and see my GP and told them how tired and exhausted I was because of my caring responsibilities and they offered me Prozac. I don't want to go on anti-depressants. There must be some form of counselling for me as a carer. I do try to have some time for myself, even if it's just going for a walk with a friend... But you don't like to burden other carers with your worries do



you? I have been a carer for years but no one has ever told me about support for myself. I've just carried on. Now I feel that I'm burning out and need something for me."

225542, November 2024

"I'm just exhausted and it's all getting too much for me. What I would really like is someone I can talk to about all this who is just here for me. The same person who knows all about my situation, so I don't have to keep explaining it."

225247, November 2024

Carers with their own health needs

"As his carer, I find it incredibly isolating. I can't work as my whole life is just about my son and trying to do the best for him. I worry constantly. I ignored my menopause symptoms as I didn't have the time to get any help for myself as I was too busy trying to get help for my son. I now have osteoarthritis. I don't know how long I can continue to carry on caring."

225034, November 2024

"I'm worried as I need to go to hospital probably in January or February for surgery. What if I have to stay in? How can I? I care for my wife."

226071, December 2024

Challenges caring for someone with mental health problems

"As a carer of someone with severe mental health problems when you are in dire straits you don't have the capacity to reach out and phone people... I just don't understand why nobody talks to each other. Services just are not joined up. People don't reach out to you."

226067, December 2024

"I'm a carer for my husband who has anxiety and depression. He's been like this for two and a half years... I can't work anymore. I had to give up my job to look after him. I have nothing now. Life is a struggle. He saw someone from the Community Mental Health Recovery Service (CHMRS) and had 6 appointments over a 6 week period. But this is a long term problem and 6 weeks just isn't enough... I can't think about what I'm doing today let alone tomorrow or future plans. It's all too much to take. I wake up in the night panicking and stressing. I am struggling. I can't carry on like this for much longer. My mental health is suffering hugely and I can't cope. I can't carry on."

225163, November 2024

"It's a constant battle, I am not receiving any carers support. I don't work anymore because I was constantly on the phone trying to sort out stuff for the kids. I have been trying to do courses on how to support children with mental health, you really feel the pressure of trying to get it right."

223369, October 2024

"When you have an adult child with severe mental health problems everything that hits you just keeps changing and you can't predict it so it's very hard to develop strategies and coping mechanisms."

226068, December 2024

Struggles for parent carers

We have heard that many parent carers are unable to work due to their caring responsibilities.

"My wife is the full time carer for our son who has ASD... One of us had to give up our job in order to fill out all the forms and fight for what help and support we needed for our son... Don't get me wrong. We do miss her income but we had to make sacrifices to battle the system. It takes so long to get anything done and one of us had to concentrate on all the admin and doing this."

223539, October 2024

Parent carers have told us that sometimes others don't understand their situation which can add to additional stress and pressure for the carer.

"It's all very stressful and frustrating. We're carers for our son who has autism and ADHD. Every day when I go to school, the teachers are waiting for me to complain about this or that and to tell me he's been naughty. Every day when I collect him I feel so judged."

223452, October 2024

"Our own family don't understand about our children's conditions. We have avoided going to family events when they were younger as their behaviour would have been too much and this did cause issues. But now they are older, we did go to an event recently and the family saw what they were like and are now much more understanding."

223541, October 2024

Not enough support for young carers

Parent carers are concerned about their other children who are young carers not getting adequate support.



"My youngest has additional needs and my eldest is a young carer. I don't feel there is enough help for young carers. Everything is about the parents. She is registered with Surrey Young Carers but can never get onto any of their activities. A weekly group would help her more because she gets very anxious and if she got to know people she would feel better."

223461, October 2024

Transitioning from children to adult services

"There shouldn't be a hard stop at 18. There should be a transition for people identified as vulnerable. I think it should be a gradual transition. That would benefit both carers and the cared for... Now my child is over 18, I'm blocked out. I don't know what is going on. It's really, really hard for me. Having done everything for him for ten years, I'm now blocked out. I don't think they realise how much of the hidden support that goes on to keep them [the cared for] fine."

226250, December 2024

"We look after our grandson he's [in his mid teens]. He is autistic and has learning disabilities... It's actually harder now from our perspective as he gets older. When he turns 16 he will get his own money via his own bank account and very soon he will be considered an adult and transition to adult services, when he is in fact not able to make those adult decisions."

225891, December 2024

"I have a daughter with Down's syndrome... We are going to have an issue soon with our daughter. The youth club that she attends is only for people up to the age of 25. So she will have to leave and there isn't anything else for her. So, she'll be all excited for her birthday and then we'll have to tell her that she can't go to the youth club anymore. She's been going for 7 years and has made lots of friends. She will be very upset."

223936, November 2024

Lack of respite care

"I'm a carer for my son [in his 40s] with severe mental health issues... There is a huge gap for people like us wanting respite. We want a break but we can't find anybody who our son will trust and who he knows. Trust is the biggest issue and so many carers just don't stick around so how can we ever get respite care. We can't. And as we age, our friends who used to help us out sometimes are getting older too and it's just not possible."

226067, December 2024

"Respite care is also a challenge. [They] have a long waiting list... It's so important for parents to have time to themselves and time to go out with the other children



in the family. Everyone gets affected by the one who has the special needs. It's really difficult."

223542, October 2024

"Challengers is great but there needs to be more services for parents to have a break. Many, like us, have no family close who could help... [My daughter] has to be watched constantly. So, even if we are on a break, we don't get a break as she is with us."

223544, October 2024

Difficulties for carers looking after people with dementia

"My husband won't have anyone else in the house, so it's really difficult to be able to come out by myself. He can be left for short periods, but otherwise I have to take him everywhere with me. Everything then takes more time and I don't get any time alone. It's so difficult. We have had Crossroads Care for respite in the past. Now it's just me doing everything on my own."

225033, November 2024

"I used to go 100mph and now it's 5mph as it takes so long to get someone dressed, get someone to understand, get someone to agree to do something. It took me a long, long time but I've now learnt to go at my mum's pace not mine. Your whole mindset has to switch."

226069, December 2024

"It's like dealing with a child but much harder as they are meant to be your equal."

226335, December 2024

"You always have to be two steps ahead and thinking ahead. It's very wearing. You just keep plodding on. It's not easy. It's exhausting. He asks me whether he should flush the toilet now. It's all day these silly things. It's draining. I don't get any respite at all."

226337, December 2024

"It's sad as he's not anyone I recognise anymore. It's like living with a stranger."

224500, November 2024

"At the moment I am able to come out as the cleaner is there to keep an eye on her. It's her short-term memory that's bad. I use a whiteboard to write and communicate, so she can read it when she keeps asking where I am... She is already saying that she wants me with her and she'll come out with me but I really do need this time alone."



Worrying about the future

"My son [in his 30s] has ASD and lives with me and I also have guardianship for my granddaughter... My main concern is what will happen to my son and granddaughter when we're not there. We don't have power of attorney over my son as he doesn't have mental capacity."

225164, November 2024

"My wife and I are each other's carers. I care for her as she has Alzheimer's and she cares for me as I have Parkinson's... I'm really worried about future care costs as going into a home is so expensive. I don't know what to do. I'm very worried. At the moment we don't have any help or support, it's just us two."

225157, November 2024

"I live with and care for a relative that is in their 90s and has vascular dementia. I'm finding his behaviour very tiring and stressful. I just feel left. I feel like I've been thrown in at the deep end and nobody seems to care... I'm worried that if he has to go into a home, the house will need to be sold to pay for his care and I will be made homeless."

222796, October 2024

Gap in support for kinship carers

"I care for both my grandson and my husband who has cancer. There is definitely a gap in services for support for carers like myself. We're called kinship carers. There are groups for people who foster and for those who adopt but not for people like me. There are things online but I like to get out and meet face to face... I can't plan things as I can't go and attend groups/hubs if he is with me. I take him to and from school and so this limits my time as well. I know that they can't plan the groups and hubs to suit everyone but I think there will be many carers like me, who would appreciate more flexibility – maybe offer afternoon and evening groups occasionally. Most seem to be in the morning, which I definitely can't make due to the school run... So, because of the lack of suitable groups for kinship carers, I don't get any support for myself as a carer."

225232, November 2024

Valued support

"Space2BYou have been fantastic... After these 3 sessions with Space2BYou, she is smiling, she is more motivated and she has actually left the house twice."

226072, December 2024

“Because of the KITE Therapeutic Learning Service team he is doing much better. They saved our family. Over this past year they have been working on getting him out of the house without us. They are amazing. They literally have given us our boy back.”

223465, October 2024

Influence and Impact

- Following feedback from Giving Carers a Voice, there has been a review of continence services in Surrey. A leaflet is currently being produced for GPs to give to carers with information about what is available and what they can do while waiting for a referral.
- After the Giving Carers a Voice report about unpaid carers with their cared for in care homes ([Care-homes-Identifying-involving-and-supporting-unpaid-carers-November-2024.pdf](#)), Surrey County Council are now developing a toolkit for good practice in care homes to support carers and their families.
- As a direct result of Luminus hearing feedback from carers, 2 GP support workers are now in post in Surrey.
- The Giving Carers a Voice and Giving Young Carers a Voice teams are currently working on feeding into the Joint Strategic Needs Assessment (JSNA) for Surrey to help identify where there are gaps in services for unpaid carers.

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 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 January to March 2025

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

Place	Date
Rare dementia support group, Banstead	07/01/2025
East Surrey autism, ADHD and neurodiversity support group, Reigate	17/01/2025
Surrey and Borders Partnership (SABP) mental health carers forum with Action for Carers, Cranleigh	20/01/2025
Mytchett memory group, Camberley	21/01/2025
Action for Carers hub, Leatherhead	24/01/2025
Surrey and Borders Partnership (SABP) mental health carers forum with Action for Carers, Leatherhead	24/01/2025
Surrey and Borders Partnership (SABP) mental health carers forum with Action for Carers, Guildford	27/01/2025
Action for Carers hub, Banstead	28/01/2025
Action for Carers hub, Cranleigh	03/02/2025
Bisley community café	17/03/2025
Mental health carers support group, online	17/03/2025
ASD/ADHD support group, Epsom Downs	28/03/2025

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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