

## Giving Carers a Voice Quarterly Insight Report

What we're hearing

April - June 2024



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# Giving Carers a Voice

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## About Luminus

Luminus Insight CIC (known as Luminus) is an independent, not for profit organisation, which exists to empower people to have their voices heard in the design and delivery of public services, and to help organisations provide equity of access and the best services possible through the inclusive involvement of local people.

We were originally set up in 2013 as Healthwatch Surrey CIC, to deliver the local Healthwatch service in Surrey, covering NHS and social care services. Luminus continues to deliver the [Healthwatch Surrey](#) service and we have also now expanded our scope to provide local people with a voice on other public services and the wider determinants of wellbeing, and changed our name accordingly. Further information about our services is available on our [Luminus website](#).

## 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 April - June 2024

This quarter we have visited the following places to speak to carers and hidden carers to hear their experiences and to signpost to relevant services where needed/appropriate:

- Action for Carers hub, Cranleigh
- Action for Carers hub, Shepperton
- Dementia carer support group, New Haw
- Keep living the life you want event with Age UK, Godalming
- Action for Carers hub, Hersham
- Arty crafty chitty chatty group, Hurst Green
- Sight for Surrey, Oxted
- Dementia carers information afternoon, The Hunter Centre, Haslemere
- Memory lane café, Cranleigh
- Dementia friendly carers café, Leatherhead
- Home Instead Pub and Pastries, Windsor
- East Surrey Hospital with Action for Carers for Carers Week 2024
- Carers stand at Surrey County Council for Carers Week 2024
- Lucan Pavilion café, Laleham
- Dramatize café, Knaphill

## Main themes we have heard from April – June 2024

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



## Where we have shared our insight

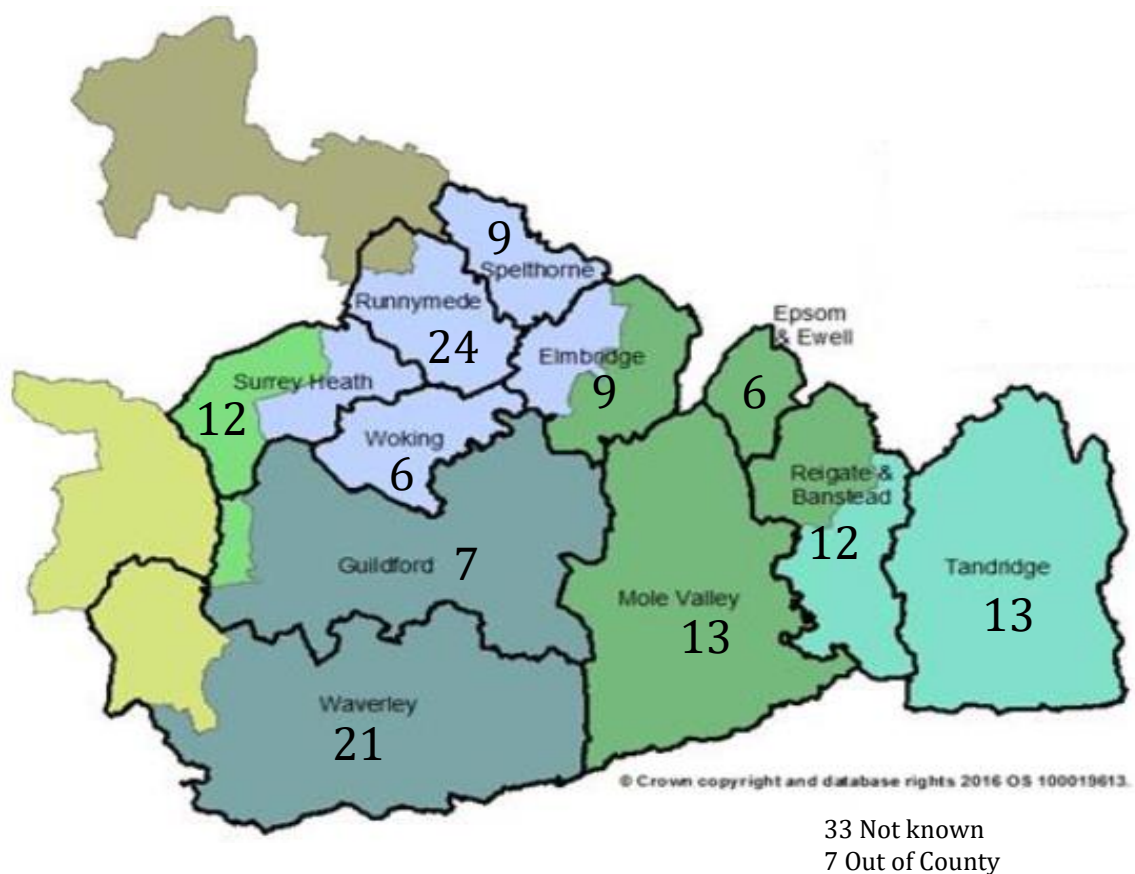
During Q1 we have shared carer insight (key themes and carer experiences) in the following meetings as part of our 'what we've heard' regular insight sharing meetings.

- Adults, Wellbeing and Health Partnerships – April 2024
- Carers Partnership Board – June 2024
- Older people's network meeting – June 2024
- Combat Stress – June 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.

## 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 Runnymede and Waverley.



## Not identifying as a carer

We are continuing to speak to carers who do not realise that they are carers. We spoke to 172 carers in this quarter and many still do not recognise themselves as carers.

"I haven't really thought of myself as a carer even though I know I care for him. It takes its toll... I don't feel like a wife now, I feel like his carer. I'm up and down the stairs all the time, to give him things and get things. I'm [in my late 80s], it's exhausting."

**215143, May 2024**

"Both my parents need caring for (they are deaf). It's taken me 40 years to realise that I'm a carer and have been all my life."

**216727, June 2024**

## Stress and wellbeing

Once again, this quarter people have been sharing their experiences about the impact on their wellbeing from being a carer.

"Being a carer is so lonely. I've lost friends due to a lack of understanding. It's a continual grief, I've lost my wife and lose her every time I leave after visiting her."

**214000, April 2024**

"Mum lives with me and won't have carers. She won't accept any help from anyone except me. She refuses all other help and prefers me to do it all. I need to find more support around our area as it's very full on for me. It's all on me for everything. I do feel a huge burden of responsibility although I know I shouldn't as it's my responsibility as her daughter."

**216668, June 2024**

"My sister took early retirement but now she is just looking after mum and dad. She's there every day for a couple of hours to give the carers their break. She's really stressed out and exhausted with it all. She really needs a break. Mum rings her though when she's not there... It's too much. She's really struggling, I am quite worried about her. My escape is work but she doesn't get a break. I am worried... I'm very stressed now."

**216101, June 2024**

"Caring impacts normal life. It engulfs your life. I just want to be a normal grandma and do normal things. I have two kids and they both have their own kids and I want to spend time with them and just do fun things. I feel constantly burdened by my caring role."

**216722, June 2024**

"We don't have visitors anymore as I can't cope with that. It's all too much. The world has narrowed a lot since his decline... I am ok although I do get lots of aches and pains in my joints but that's old age... It's very difficult, stressful and endless."

**213585, April 2024**

"No-one chooses to be a carer, it's something you fall into and just accept. I do cry a lot, it can help."

**213999, April 2024**



## Lack of dementia support services in some areas of Surrey

"I got in touch with the Admiral nurses service, but it was in Epsom and they didn't cover this area. Why is it that Guildford get this service, but we can't? It's just not fair... I did have a dementia navigator who was brilliant. When they went, I didn't get any communication to say what was happening or what they were being replaced with. They just disappeared and I was back to square one."

**215481, May 2024**

"There doesn't seem to be provision for people like her with early onset dementia. Ideally having something like the Admiral nurse service that Guildford have, would be great. I would really appreciate talking to someone about what to expect, how to deal with his denial, coping mechanisms. Someone who treats me as an individual and doesn't just give me another leaflet."

**215496, May 2024**

"My husband was diagnosed with dementia... Nothing was offered to me as a carer in the way of advice/help and support. I was just left with the diagnosis and literally left hanging."

**215481, May 2024**

"I'm a carer for my husband who has dementia. It's getting worse every day. I'm now struggling to leave the house as I don't like to leave him. I know I need help but I'm just at the beginning with all of this. I don't get any help, I do it all."

**214529, May 2024**

We have heard from those who are able to access dementia support services.

"The Admiral Nurses are great. If they can't answer the phone, they always ring you back... Admiral nurses are always there at the end of the phone for me. They support us as carers and give us all sorts of ideas and suggestions. They always ring you back. They are a real lifeline."

**213297, April 2024**

## Juggling employment with caring

"I gave up my job when I had my son (who is autistic) and I eventually went back to work part time. My work has suffered though due to my caring role and the challenges. I have to now not work in the holidays at all as I just can't."

**213399, April 2024**

"I still work part time but will be retiring soon. I don't want my free time to now be filled with caring for my mum but I feel that that's the way it's heading."

**215147, May 2024**

"My parents won't accept help from anyone other than family and now (the family) are all getting fed up with it and it's all being left with me. I've got my own family to look after and I work, so how do I prioritise everything and everyone? It's getting really tricky and I'm finding it hard."

**216727, June 2024**

"It's all left to me. I've had to give up work because I couldn't cope with it all and my own health issues on top."

**214190, May 2024**

## Challenges for parent carers

### Caring for children with mental health conditions

"We aren't given any training to look after and cope with our very mentally ill children. As carers we are just left to get on with it. I don't have the knowledge about the medication they are on, the side effects, what to expect. Nobody ever explained any of this to me. Even now after caring all these years, training would be helpful. Things like what triggers certain behaviours and how to de-escalate them... Also to explain to partners about the condition, so they don't think it's you who causes the problems! This happened to me with my child's personality disorder. It was always my fault as my child would say I did ABC and this is what upset them, even though I didn't. My partner would believe them."

**213404, April 2024**

### Challenges of caring for children once they are over the age of 18

"It then gets worse when they are 18 and deemed to be adults and with capacity. You then have absolutely no access to any information and you're not told anything. But you're still expected to look after them 24/7 with no help or support or break. You're just adrift and having to deal with them, manage a house, maintain other relationships, fill out endless forms, attend appointments etc."

**213404, April 2024**

"The challenge is that care needs don't stop once someone is over 18. My son is on 6 different types of medication and under the care of lots of different teams. Things are not joined up. He now receives all the emails and all the letters as he is over 18. I am his registered carer but they no longer have to go through me... I just find now that he can decide if I am involved in his care or not it is very difficult. I feel more helpless now than I did when he was a struggling little boy. He is a





young vulnerable teenage adult who has enough of a grasp to think he knows and knows best.”

**216730, June 2024**

“My son is constantly having a mental health crisis. I am... really stressed with life. He is 17 and 3 weeks off being 18 and because he is about to move under Adult Mental Health, it feels like no one will help. I can't cope with him. I am struggling. I wanted to go into a refuge but they wouldn't take me and my son, just me. He is slitting his wrists.”

**214176, May 2024**

## **Importance of separate groups for children with additional needs**

“There is nothing out there for parents like us. I came to this group and I found my people. At this group, I can be myself, the kids can be themselves. I'm not judged, and I can speak to other people who are going through similarly difficult situations with their kids.”

**217121, June 2024**

“I need to come here because it gives me a chance to chat with other parents (of children with additional needs) and understand that I'm not alone when it comes to fighting the system.”

**216968, June 2024**

“I come here every week because there isn't anything else where I can take my son where he won't be judged for his behaviour.”

**217417, June 2024**

“We cannot go to other groups because I've been told he's too naughty and parents complain.”

**217418, June 2024**

## **Carers with their own health needs**

“[Carer for son with additional needs] I have a spinal injury, so I struggle to pick my son up now... He's [age] but already he's quite tall and very sturdy. I'm a single mum and I'm not very tall myself but when he falls to the floor, I have to pick him up so I don't have time to worry about my back, you just do it. If it's in the road, I just have to act, I don't have time not to.”

**213399, April 2024**

“I'm [in my 60s] and care for my husband who has COPD and cancer. I have osteoarthritis and find looking after him very difficult as I'm in a lot of pain and my mobility is poor... I wasn't aware there was support out there for me... My husband



refuses to have social services involved because he would be self-funding, and he won't pay for help coming in, although he can see I'm almost on my knees. I can't give up work because we couldn't afford to do it without eating into our savings. I get up early and prepare him refreshments and food for the day; although he's pretty capable of doing it for himself, he just won't."

**217408, June 2024**

"I can't get her into the car as I need to support her weight as she can't weight bear... This is becoming more and more difficult and it's really hurting my back now... She hasn't had a bath/shower for a year. I feel terrible saying that but she's in so much pain, I can't get her in and out and she can't stand anyway. She has got worse. She is also becoming incontinent and that's really upsetting her. I'm changing the beds and her clothes all the time. It's horrible for her and so tiring for me. We're both now at the point where we're struggling. I've always done everything, but I think we're both coming round to the idea that we might need some help. I haven't let anyone know how bad it is but with you having to help her, I'm realising that I can't do this on my own... My own back is now going and physically I'm feeling it."

**217214, June 2024**

"Four weeks ago I had a breakdown, I was suffering with my mental health whilst visiting mum in the ward as it was all getting too much for me being here 12 hours a day, 7 days a week without a break, it feels relentless. That time staff in A&E were brilliant, they understood what I was going through, very empathetic and said that I could go back up to the ward and they would call me when there was a doctor ready to see me to discuss my condition. This was really helpful and made me feel that they understood."

**216944, June 2024**

## Difficulties getting to morning support groups

We have heard how getting to morning carer support groups is a real struggle for many carers.

"I can't get to morning things as it takes time to get mum up, washed, dressed and have breakfast. I expect that most dementia carers will say the same thing... Why don't they do any afternoon ones? ...So, if I was to say about gaps for dementia carers, I would say, can we have more groups that are in the afternoon please? ... I would like to see some exercise classes too for my mum - chair ones so she can build strength and hopefully prevent her from falling."

**215141, May 2024**

"I'm [in my 50s] and care for my mother who has dementia... but I cannot attend support groups because they're during the day and I work."

**217409, June 2024**

"I can't get him out of bed in the morning. It's not that he can't, it's that he doesn't want to... it makes it difficult to attend things that are in the morning, as by the time I get him up, dressed etc, it's late morning... We don't go to any other groups. They are usually in the morning and as I said, we can't make those."

**213656, April 2024**

Carers have also told us how they would like more specific support groups.

"I would like to go to groups that are illness-specific and not generic, I would find those most beneficial."

**214190, May 2024**

## Valued support for carers

"This group (Arty Crafty Chitty Chatty group) has saved me many times, it's somewhere I can come, chat and get the help I need."

**214190, May 2024**

"I still come here (Runnymede dementia carers support group) every week even though he's in a care home as I enjoy the company and it's good to keep busy. I've made good friends at this group. It's been a real lifesaver for me."

**213584, April 2024**

"I wouldn't be here today if it wasn't for the help and support that I have had from Action for Carers Surrey."

**213838, April 2024**

## Influence and Impact

- Experiences gathered by the Giving Carers a Voice team regarding the cultural aspect of caring are being used as part of Surrey and Borders Partnership NHS Trust carers awareness training.
- We were involved in discussions about carers and what information they need when the person they care for is in hospital. This was led by Surrey County Council and Action for Carers Surrey. A leaflet will be co-produced with carers.
- We were invited to talk to the Learners' Single Point of Access (L-SPA) team at Surrey County Council and were able to dispel some myths and hear about what they offer families.

- A review of continence services was carried out at Surrey Heartlands. They found nothing unusual as such in their provision however they have stated that they do want to make improvements and think about how personal health budgets are used.
- We had some lovely feedback following a recent visit to a dementia group.  
"It was a pleasure seeing you [the Giving Carers a Voice team] again as I find you are so patient with carers and such a help to them."

## 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 2024. If you have a group you would like us to come along to and visit then please email us at [info@luminus-cic.uk](mailto: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 July - September 2024

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

Place	Date
Autism Carers Support Group, The Lost Sheep, Caterham	03/07/2024
Carers group, Phyllis Tuckwell Hospice, Farnham	16/07/2024
YMCA parent carer group, Reigate	17/07/2024
Loveworks foodbank, Merstham	17/07/2024
Loveworks foodbank, Reigate	18/07/2024
Knights garden centre, Godstone	19/07/2024
Surrey Young Carers family fun day, Painshill	01/08/2024
MHA dementia friendly club, Redhill	16/08/2024
Muslim women's group, Redhill	05/09/2024
Carers Café, Royal Surrey Hospital	23/09/2024
Action for Carers hub, Caterham	26/09/2024

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](http://luminus-cic.uk)
-  Telephone: 01483 301448
-  Text: 07592 787 533 (SMS only)
-  Email: [info@luminus-cic.uk](mailto:info@luminus-cic.uk)

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