

Luminus

Home of Healthwatch Surrey

Giving Carers a Voice Quarterly Insight Report

What we're hearing

January - March 2024



● Shining a light on what matters to people.

Giving Carers a Voice

Quarterly Insight Report – January - March 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 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 and Giving Young Carers a Voice listen to the experiences of carers 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.

Giving Carers a Voice

Engagement January - March 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:

- Family Voice Surrey ASD/ADHD parent carer group, Woking
- St Mark's Church food club, Tattenham
- Action for Carers hub, Woking
- Parent carer group, Learning Space, Redhill
- Home-Start, Pirbright
- Lived experience conference, Surrey and Borders Partnership, Dorking
- Dementia friendly launch, Spelthorne
- Making Melodies dementia group, East Horsley
- Action for Carers hub, Guildford
- Action for Carers hub, Epsom
- Action for Carers hub, Haslemere
- Parent carer group, National Autistic Society, Ashted
- Banstead dementia aware information day
- Carers Café, Cameo Day Centre, Sunbury.

Main themes we have heard from January - March 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 quality of care.



Where we have shared our insight

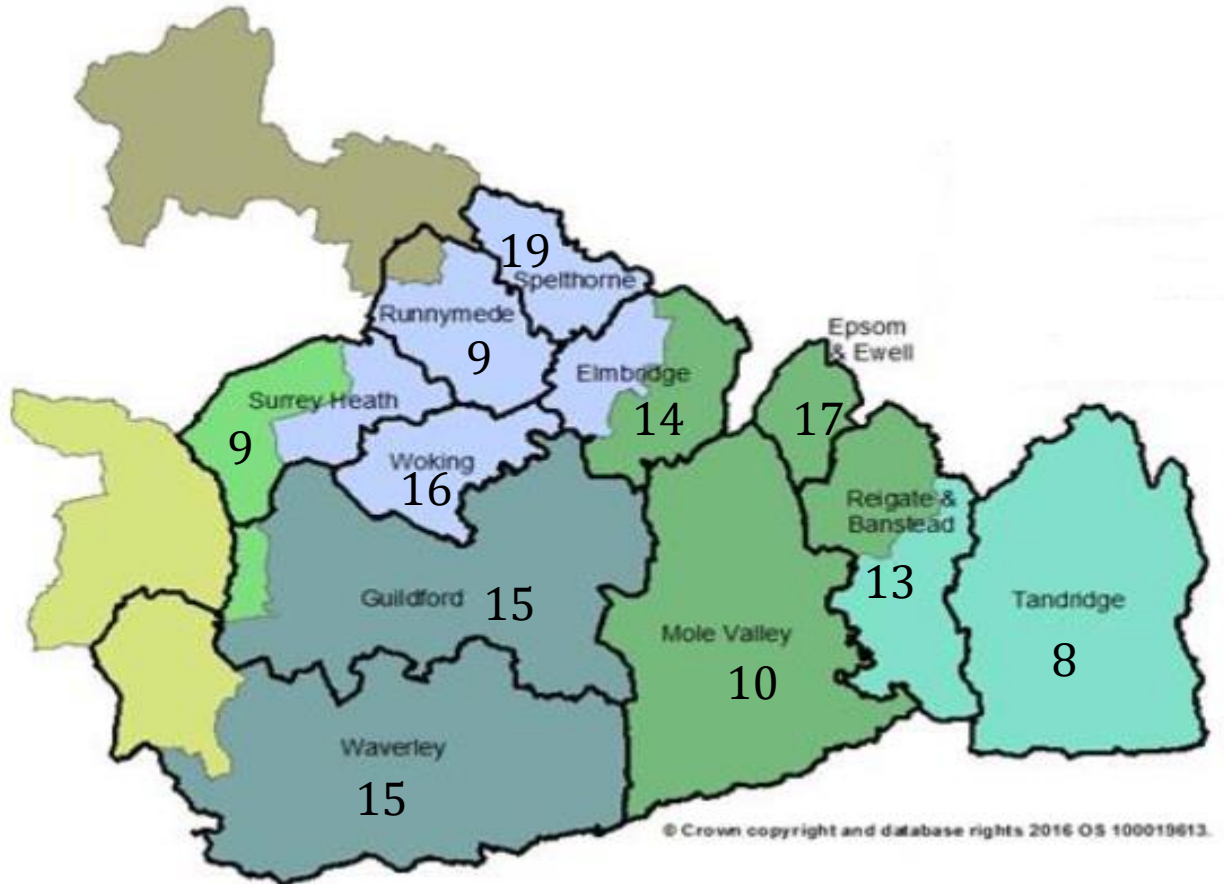
During Q4 we have shared carer insight (key themes and carer experiences) in the following meetings as part of our 'what we're hearing' regular insight sharing meetings.

- What we're hearing – Surrey Heath – February 2024
- Carers Partnership Board – March 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 month, we have heard the most from Spelthorne, Epsom and Ewell and Woking.



*6 out of county

*46 carers listed as location not known

Not identifying as a carer

We are continuing to speak to carers who do not realise that they are carers. We spoke to 188 carers in this quarter and many still do not recognise themselves as carers.

"Listening to this conversation today, it makes me realise that I am an unpaid carer for my husband. He is not very mobile and his illness has progressed. I help him with day to day tasks and also all his medical needs. I used to think this was just being a wife and partner but it has become more these days. You realise gradually that things shift and now my husband wouldn't be able to cope without me."

212325, March 2024

"I'm a carer for my husband. He had a fall at work 5 years ago and suffered a brain injury... he needs my help every day. I also have a son with special educational needs too. I just care for them all as it's my duty. No one else is going to do it and

they wouldn't allow anyone else to help them. So it's up to me. What can I do? My husband wouldn't accept any help from anyone except me."
211705, March 2024

Stress and wellbeing

Once again, carers have been telling us about their mental health concerns and the impact that caring has on them.

"I do need some respite as I have my own health issues too to deal with... I'm quite down. Being at home is lonely. He can't chat."
208314, January 2024

"My sister has been sectioned many times, which is heartbreaking. I feel helpless, and there's very little support for people like me. I get worried she may do something to harm herself. It's hard to concentrate when she is upset before I leave for college and I worry most of the day. I ring and text her throughout the day and rush home to ensure she's safe. I don't have many friends because they don't understand when I cancel plans due to my sister. My parents are very good at supporting her, but sometimes they forget my needs out of concern for her. Thank you for listening to me and for caring."
211219, March 2024

"We haven't had the house specially adapted and I have hurt my back lifting him [husband] when he fell once. It's all exhausting. I have my own health issues as well which I'm trying to get the GP to investigate further... Before this I was on anti-depressants but now, although I still suffer from anxiety, I'm not on medication anymore. I worry about him all the time and I neglected my own health for 4 years."
212249, March 2024

"I'm working, I've got a family to look after, a daughter with bipolar who we support and a father-in-law in a care home. I have so much paperwork to do and I have to spend my time visiting my mum and my father-in-law. All of us are maxed out at both ends. We are caring for children and elderly parents with dementia. I think that is what really puts the pressure on as you are squeezed from both sides."
210319, February 2024

Quality of Care – listening to the carer

We have heard how things work when the carer is involved and listened to.

"My daughter... has an uncommon neurodiverse condition. In 2023 she was due to go into Royal Surrey [County Hospital] for some dental work. I completed the pre surgery form and entered a lot of detail under the special requirements section. It

was a small box and I added lots of detail. I shared my daughters trigger points and anxieties and things that would help i.e. her favourite music. The team at Royal Surrey read what I had written. They put her in a side room as there were babies crying and put my daughter's favourite band on when she was anaesthetised and when she was waking up. The team were fantastic."

209496, February 2024

"Recently my son has had a better experience with the home treatment team... They've made proper use of me, checking in with me [as his mum and carer] to see is there anything they need to know before they go and see him, asking me what is the best way of contacting him etc. The proper human touch."

210313, February 2024

Quality of care – not communicating with the carer

Communication continues to be a key issue we hear about.

"... he was sectioned at home. Yes, that is a thing as there were no beds. The system will know when a bed will become available but this isn't passed onto the carer... You need information in a crisis and it just isn't given to you. It's just assumed that you're there to deal with the crisis... Then without any notice, he was given a bed... No notice, nothing. Again assuming we can suddenly drop everything and get him to hospital. If we had known that there wouldn't be a bed available for 3 days, we could have coped. But just being left in the dark with no information isn't helpful and very, very stressful for the carer. Just tell me."

210975, February 2024

"My wife is in hospital at the moment with a broken pelvis... Yesterday there was a meeting in the hospital about her care and apparently a decision was made that carers would be popping in in the morning and afternoon. What does that mean? They haven't even visited the house to assess it, so how can they possibly know what her needs are? I wasn't present at the meeting as I wasn't told about it. I had to keep asking for the details... They don't know what a carer is and what they have to do."

211233, March 2024

"We just don't know what to expect next as no one has told us anything. I'm worried about what will happen when he comes home [from hospital] and how mum will cope. She can't drive and so I take her everywhere. I suppose when he does come home, he might not be able to drive for a while and so I'll have to take him to hospital and doctor appointments."

212063, March 2024

"My wife has early onset dementia, Lewy body... I went in to visit her [in hospital] on Monday this week, only to be informed that she was going to be discharged to



a care home on Tuesday morning... No one has discussed this with me or thought to ask if this was ok. Not one person has asked if I'm a carer or how I'm coping. I have really just been ignored... I have seen her and been with her all the time and know what she is like, yet nobody has asked me... I am a professional, intelligent man and this whole process and lack of any help or transparency has left me exhausted. I'm used to stress in my professional life but this is different. No one talks to you and no one tells you what the next stage will be... I feel completely lost and alone in a system that seems to want to confuse you and ignore you."

212068, March 2024

Worrying about the future

We have heard from carers about their concerns for their future and the future of those they are caring for.

"I'm a carer [in his 80s] for my son who has schizophrenia. He was diagnosed aged 19. He lives with me... I am worried about what is going to happen to him as I am [in my 80s] now. It is a worry. It's a worry for both of us. He does read articles about people who have died recently in their 70s and 80s and it's worrying and frightening for him too. I've sorted out my will but it's the practical side that I am concerned about. He can't live on his own and I would worry about him living with other people with mental health illnesses as I'd worry they could take advantage of him. I don't know what to do."

208313, January 2024

"My problem is now I'm being asked to contribute to his care and it's all so confusing. I'm worried that I'll have to move him as I can't afford the home he's in now. I come to this group to get advice... I just need it explained to me, so I know what to expect and what I have to do. I was just told that I would have to pay now and that was that. Nothing more. No help, just leaving me with all the worry."

212239, March 2024

Struggles for parent carers

Children being out of school for long periods of time

"What's missing are any services to help with my son. He has spent a year being bounced around and continually filling out forms only to be told that there is nothing that they can offer him. Referrals are then closed. His school did apply for an EHCP [Education, Health and Care Plan] but this was refused. They said in their decision that his needs could be met by the school. If they were, why isn't he in school? He's [a teenager] and hasn't been to school for a year. He now won't engage or speak to any professionals or leave the house. He is still waiting for an ASD/PDA [Autism Spectrum Disorder/Pathological Demand Avoidance]



diagnosis... it does make it very difficult for me as his mum as it means that I have to be at home all day too as he is very needy at the moment."

211456, March 2024

"I've got a son who was diagnosed with autism in 2016. I think he possibly has ADD [Attention Deficit Disorder] too and maybe PDA profile. We've been in dire straits for some years. The EHCP is not worth anything and we've got quite specific circumstances around him and his sleep which has really not helped him to go to school. He's only ever had one school placement so he has lacked most of his secondary education. He's [a teenager] with no qualifications and he can't access anything he'd like to do... I don't know what the future holds for him at the moment... I haven't been able to work for 5 years... My son was out of school for over 2 years."

208375, January 2024

"My son did start in education in September 2023 but only lasted 6 weeks and has been at home ever since... It was the stress of everything that led to me having a relapse and having to go back on medication. I'm a single, working mother. I was so depressed that I was given 3 months of CBT [Cognitive Behaviour Therapy] sessions. It was after this that everything got more joined up. I'm self employed, I'm very stressed and I'm with my son every day and he's not going anywhere. I have scoliosis which affects my mobility and sometimes I'm bedbound. The health of the family is a lot on the parents. Parents go through a lot of stress themselves. When things are not fine, I will be in bed, my son will end up being in bed with me and he's not being fed properly then or having a shower etc. When you add mental health in, depression and anxiety it's awful. Caring impacts you."

208382, January 2024

Issues with Education, Health and Care Plans (EHCP)

"I'm tearing my hair out. We just had the EHCP through for my younger son and that took one day short of 42 weeks. Trying to deal with all the appointments and paperwork for everything is very challenging."

208372, January 2024

"My child was issued an EHCP but they left off a load of provisions. I need this sorting out as at the moment they are saying my child will be fine in mainstream. I know he won't and if that happens, he just won't go to school anymore. My child is suffering because of this incorrect EHCP and it's exhausting for him and for me."

211998, March 2024

"My eldest son is on a level 4 course currently. We were told that as he is on a level 4 course he no longer needs his EHCP. When you're on a level 4 course apparently the EHCP ceases. He doesn't have an EHCP for his academic studies, he has it as he



has special educational needs and is vulnerable. He is academic but he needs his EHCP for his social skills and development. I would not have let him go on to the level 4 course if I'd realised that it would mean his EHCP would stop."

212008, March 2024

Long waiting times for diagnoses

"I'm waiting for an ADHD diagnosis [for my daughter]. The waiting list is very long and in the meantime, my daughter is self-harming."

209726, February 2024

"I am exasperated that I have been told we will need to wait 2-3 years for an assessment for my [age] son for ADHD even after he has passed all the triage tests and is scheduled for an assessment."

211789, March 2024

Lack of support groups for parents caring for adult children with mental health problems

Carers have told us how they would value support groups targeted at parents who care for their adult children with mental health problems.

"A gap in services that I feel should be addressed is for a group for parents who are still carers but are caring for adult children. There used to be one when there were carers support groups in each borough. So, we'd like a group that meets to talk about adults looking after adult children. The problems are different to other parent carers who are looking after under 18s. Some groups also have a high profile like dementia for example and there are plenty of support groups for them but not for us."

211236, March 2024

"Most people think about carers of people with dementia when they think about what a carer is. Mental health still has such a stigma to it and it's under the radar completely. Respite care for carers like us is impossible. It's emotional support that our son would need so respite is just not possible for us. It's just not out there. There is a whole missing area of support that needs to be worked on... We don't want to go to dementia groups. We want specific groups for carers of people with mental health problems. These groups just don't exist. We want groups where we can speak to professionals to get help and support and talk."

210318, February 2024

Valued support for carers

"Hospital visits have become the norm in our family now, and I would be lost without the support of this Home-Start group."

209485, February 2024

"I come to the [Cameo Day Centre] Carers Cafe and sit and talk to others in the same situation. If I can help someone else going through the same thing, that's great. It's nice just to have a chat and share things. You pick up all sorts of ideas and tips about services and what helps."

212250, March 2023

Influence and Impact

- A review of continence products is being undertaken at Surrey Heartlands following Giving Carers a Voice highlighting these issues.
- Feedback from a carer we met: "Thanks for all this information. It's been good to talk about it and know that there is help and support if I need it."
- We heard from one parent carer group that, following our visit, the carer had looked into applying for additional benefits that she may be entitled to and was successful. She was very grateful for the signposting given to her by the Giving Carers a Voice team and she even received backdated money too. The carer went on to share this advice with other families in a similar situation.

Giving Young Carers a Voice pilot – quarter 4 update



We spoke with 47 young carers this quarter. We have visited the following groups to speak directly with young carers:

- Boxgrove Primary School
- Phoenix Youth Centre, YMCA Tadworth
- Gosden House School

- Carers Action Group
- The Hive youth club, Guildford
- Godalming College
- Better Together event and AGM, Surrey Youth Focus
- My Time for Young Carers
- St Mark's Church food club, Tattenham
- Scouts.

During quarter 4, we have met with the following organisations and individuals to discuss how we can engage with young carers and reach hidden carers.

- Preston Partnership meeting
- Action for Carers Surrey
- National Autistic Society
- User Voice
- Young Carers National Voice
- Surrey Youth Focus
- Learning Space, Redhill.

We also attended the following events:

- Surrey County Council Young Carers Action Day awareness event, Woodhatch
- Surrey County Council Young Carers Action Day awareness event, Woking
- Godalming College, Wellbeing event
- Young Carers Alliance, Young Carers Rights webinar
- Carers Trust, No Wrong Doors webinar
- Carers trust, launch of Young Carers Covenant webinar



We have heard how valuable school support is to young carers.

"School is somewhere I forget about things at home. I did go to Surrey Young Carers but I didn't know anyone there, it made me anxious because I didn't know what to expect. I didn't enjoy it and I haven't been to anything else. Yes, I would

go again if the person in charge could spend time with me and introduce me to other young carers but they were too busy. I'd prefer to do things at school."

211210, March 2024

"We all have lots of fun at choc and chill and we can talk to [name] anytime if we're worried or scared about something. School is my favourite place because I have lots of friends and people who I can play with. My mum cannot walk and we have to help her do things. I have a lot of brothers and sisters and we all care for her."

211203, March 2024

"My daddy is poorly and cannot play with us which is really sad because I would like to play football with him. We don't go out very much so it's nice when we go on school trips. I like coming to this group [at school] because it doesn't matter if we are happy or sad - [name] understands and cares about us."

211206, March 2024

Young carers have told us how important it is to have someone to talk to and support them.

"I met you at my school. My sister has mental health problems which makes me very sad because I don't know how to help her. Sometimes she gets angry and lashes out and doesn't like herself afterwards. She often says she doesn't want to live which makes me worry when I'm not there. [Name] is really kind and helps me. I enjoy coming to My Time for Young Carers because everyone is kind and I know I can talk to people if I'm worried. We also get to eat here as well as play games, do crafts and have lots of fun."

212411, March 2024

"My mum has Fibromyalgia and needs my help when she has a flare-up, as she cannot do anything when that happens, which is quite often. I do all the gardening as well as help mum with cooking and cleaning. There aren't enough youth groups for young carers. I telephoned Surrey Young Carers and was told that Action for Carers Surrey lost their funding and does not offer support once you turn 16. I'm 17 and left with no support at all. It doesn't have to be in a hall; a coffee shop would be just as good. I enjoy cycling, and it would be nice if a cycling event could be arranged for young carers to take part in."

211213, January 2024



Where we are going April - June 2024

The following table shows, in the first column the places and the second column the dates, of our upcoming visits.

| Place | Date |
|--|------------|
| Action for Carers hub, Cranleigh | 15/04/2024 |
| Action for Carers hub, Shepperton | 17/04/2024 |
| Dementia carer support group, New Haw | 22/04/2024 |
| Keep living the life you want event with Age UK | 23/04/2024 |
| Action for Carers hub, Hersham | 25/04/2024 |
| Arty crafty chitty chatty group, Hurst Green | 30/04/2024 |
| Sight for Surrey, Oxted | 08/05/2024 |
| Dementia carers information afternoon, The Hunter Centre | 14/05/2024 |
| Carers café, Royal Surrey County Hospital | 15/05/2024 |
| Memory lane café, Cranleigh | 20/05/2024 |
| Action for Carers hub, Camberley | 28/05/2024 |
| Dementia friendly carers café, Leatherhead | 31/05/2024 |
| Home Instead Pub and Pastries, Windsor | 03/06/2024 |
| East Surrey Hospital with Action for Carers for Carers Week 2024 | 11/06/2024 |
| Carers stand at Surrey County Council for Carers Week 2024 | 12/06/2024 |

Please note these dates are subject to change and additional visits may be added.

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. 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!

Contact us

Contact us through any of the channels below.

We'd love to hear from you:

-  Web: luminus-cic.uk
-  Telephone: 01483 301448
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