

Giving Carers a Voice Quarterly Insight Report

What we're hearing

October - December 2023



Giving Carers a Voice

Quarterly Insight Report: October – December 2023

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.

Contents

| | |
|---|----|
| About Luminus..... | 3 |
| Engagement October – December 2023..... | 3 |
| Main themes we have heard from October - December 2023 | 3 |
| Where we have shared our insight..... | 4 |
| Report on Carers Replacement Breaks | 4 |
| Where we have heard from carers..... | 5 |
| Key themes for quarter 3..... | 5 |
| Not identifying as a carer | 6 |
| Stress and wellbeing..... | 6 |
| The impact that caring has on the whole family..... | 7 |
| Carers neglecting their own health needs | 7 |
| Worrying about the future..... | 8 |
| Lack of respite care..... | 8 |
| Struggles for parent carers | 9 |
| Issues with Education, Health and Care Plans (EHCP)..... | 9 |
| Delays in accessing services for children with Special Educational Needs (SEN)..... | 9 |
| Lack of specialist training to support children with Foetal Alcohol Spectrum Disorder (FASD)..... | 9 |
| What carers would find useful..... | 10 |
| Valued support for carers | 11 |
| Giving Young Carers a Voice pilot – quarter 3 update..... | 11 |
| Influence and Impact..... | 13 |
| Where we are going January - March 2024 | 13 |
| Thank you | 14 |
| Contact us..... | 15 |

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](#).

Engagement October – December 2023

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:

- Maybury support group, Woking
- Community café, Camberley
- Linklight mental health forum, online
- Surrey Minority Ethnic Forum autism awareness event, Woking
- Home-Start, Guildford
- SCAMPPS (Striving for Children’s Additional Medical, Physical and Personal Support)
- Parent carer group, Camberley
- Home-Start, Pirbright
- ASD/ADHD support group, Epsom Downs
- Hongkongers, Guildford
- Rare dementia group, Tadworth
- Age Concern dementia group, Banstead
- Womens group, Woking
- FASD (Foetal Alcohol Spectrum Disorder) support group, online
- Carers rights fair with Action for Carers, Cranleigh
- Carers rights fair with Action for Carers, Camberley
- Carers rights fair with Action for Carers, Caterham.

Main themes we have heard from October - December 2023

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

Report on Carers Replacement Breaks

We have shared this insight with providers, commissioners and the carers that took part in the survey.

The key findings we reported were:

- Breaks from caring duties are highly valued and appreciated, to relieve stress and allow carers to rest but also as stimulation for the cared for.
- For some the carer replacement breaks service was an introduction to paid-for care.
- Despite many positive comments about aspects of the service, only half our sample thought the service met its objectives well.
- There were challenges around: structure, timing and flexibility of the care provided.
- Also around the ability to match more unusual/challenging needs with specialist carers.
- A 10 week service cannot be seen as 'preventative' and no one described it as such.
- Information and support for post service care is wanting, with the knowledge that the service is short term coming late for some.

A copy of this report can be found at [Luminus-Carers-Replacement-Breaks-report-December-2023.pdf \(luminus-cic.uk\)](#).

Following the initial report, we have convened a co-production group which includes carers, commissioners and providers. This group will work on generating ideas for what the future

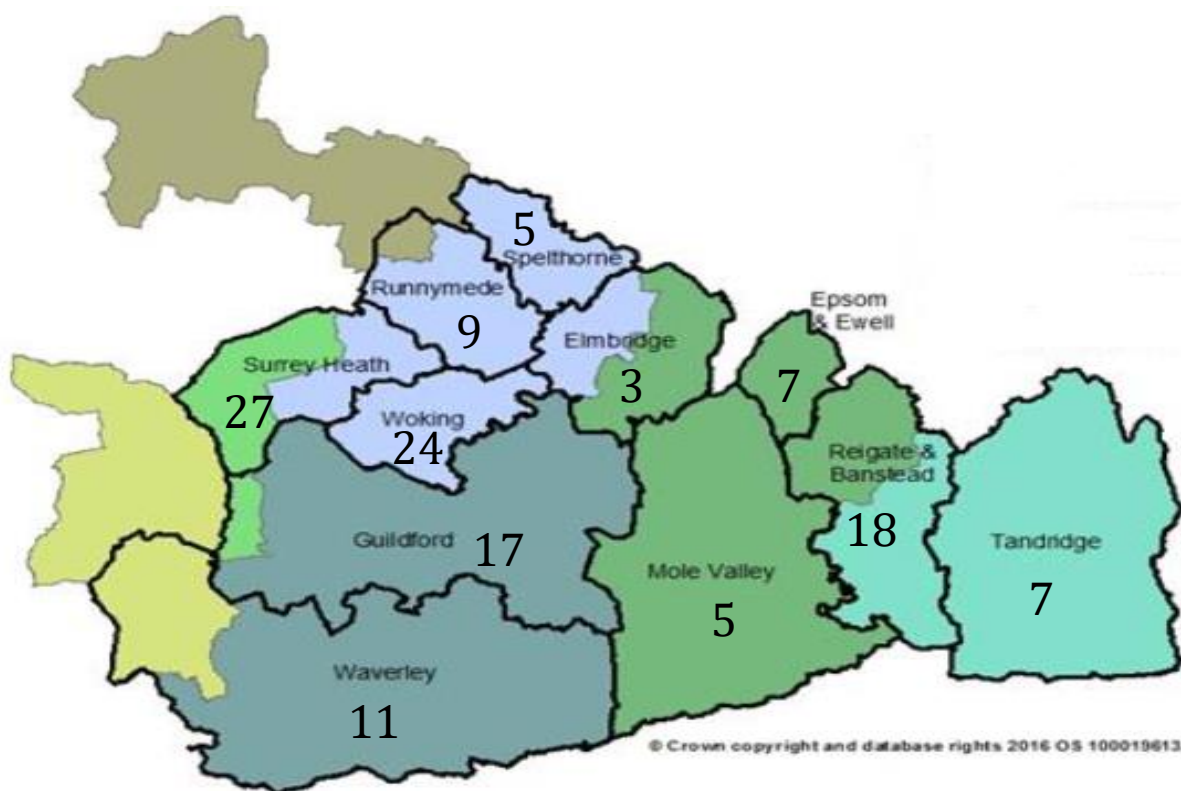
breaks service could look like and the ideas will be shared with the wider group of carers for feedback as they are developed.

During Q3 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.

- Joint Intelligence Group, Surrey Heartlands – November 2023
- What we've heard – Guildford and Waverley – November 2023
- Carers Partnership Board – December 2023

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. The areas we have heard most from are Surrey Heath, Woking and Reigate and Banstead.



*6 out of county

*30 carers listed as location not known

Key themes for quarter 3

- Not identifying as a carer
- Stress and wellbeing
- Carers neglecting their own health needs
- Worrying about the future
- Lack of respite care

- Struggles for parent carers
- What carers would find useful
- Valued support for carers.

Not identifying as a carer

We are continuing to speak to carers who do not realise that they are carers. We spoke to 169 carers in Q3 and many still do not recognise themselves as carers.

"I don't see myself as a parent carer. I am their mum but I do realise that I am doing more things for them than other parents of children of the same age."

203474, November 2023

"I hadn't thought of myself as a carer at all. I came here today to translate for my parents."

203505, November 2023

"I make appointments for my wife too – she doesn't speak English, only Urdu. Sometimes we get offered an interpreter, but not always... I suppose in that way I am her carer because she can't do this without me."

206825, December 2023

Stress and wellbeing

Once again this quarter, people have been sharing their experiences about the impact on them and their family's wellbeing due to being a carer.

"One of the worse parts of being a carer is that I have nobody to talk to. She just sits there, so it's very lonely at times."

201940, October 2023

"I need a break, I need respite. I can't leave her with friends and neighbours. I couldn't ask them to get her up in the morning. It's just too much to ask of people. She can't go out unescorted now....My wife is getting worse and worse. She is totally dependent on me and I don't see any light at the end of the tunnel."

205058, November 2023

"It's so tiring and lonely being a carer."

204628, November 2023

"I am very stressed and don't know what to do. I feel like crying just talking about it. It's never ending [being a carer]."

204618, November 2023

"It's very lonely being a carer. There is no point trying to chat as he can't chat."

203999, November 2023

"I'm a carer for my son [in his 30s] who has complex needs. It's cruel the way carers are treated. We're not listened to and are ignored. In the end you just give up asking and get on with things."

201883, October 2023

"My daughter had a breakdown with all the stress [that being a carer] has caused her. It's been just terrible."

203478, November 2023

The impact that caring has on the whole family

"[My daughter] can't really have friends over for playdates because of her sister's behaviour which can be a bit frightening if you're not used to her. We can't do things like go swimming or to the cinema as a family because of her sister. I don't want her to start resenting her sister because of this. She has started to say 'Why can't we do this?'. Family time is important. She did have friends over and they saw her sister's nappies and started laughing. She explained that they were for her sister. She thought this was normal but she's beginning to realise that her sister isn't like other sisters."

202007, October 2023

"My son... has mental health issues. My two daughters are greatly affected by his behaviour and need support. I don't know where they can get any."

204875, November 2023

Carers neglecting their own health needs

"I'm so tired. I am so stressed. I am not looking after myself, it's all too much. My daughter does nothing all day and can't do anything. It is awful."

205045, November 2023

"I am neglecting my own health needs but it's good for losing weight."

205063, November 2023

"[Carer in his 90s] All my kids live far away so I have no local support. It's been a bad year for me... I've gone downhill but she's the same... I had to get an ambulance out for me a couple of days ago... I had to take her to the hospital with me as I couldn't leave her at home. I just can't cope and I am struggling. I keep feeling panicky. I have no time to myself... It's me who needs the help not my wife."

203997, November 2023

Worrying about the future

Carers have told us about their concerns for the future and what will happen to those they care for if they can no longer care for them.

"I feel a great deal of responsibility and pressure but I am at the point where I feel I can't do it anymore... If I don't appear, what will happen to him? I have my own health concerns to worry about too."

205061, November 2023

My daughter is [in her 40s] and lives in supported living. My worry is that now I'm not getting any younger, who will look after her... Although she lives in supported living and copes well, she comes home every weekend and I'm the one who organises the taxis and I'm the one who sorts out everything if her carer doesn't come. Who will do those sorts of everyday things? I have all the financial things in place for her but it's the everyday practicalities that worry me."

205310, November 2023

"I'm a carer for my grandson who has autism... I need something in place for when I can no longer care for him. I'm on my own at home with him as my husband died. So it's all on me now. He won't leave the house unless I am with him. He is very anxious...He is at home 24/7 and he doesn't sleep...I've not had any break, I would like a break."

205052, November 2023

Lack of respite care

"[Parent carer]. We are really struggling as we have no breaks or respite or any time alone together. What even is a date night?"

202007, October 2023

"We do have respite care with Crossroads Care Surrey... It's only 3½ hours and for 10 weeks, we've reached the 7 week point... It feels like I'm dropping off the edge of a cliff... The respite care has been a lifeline and I'm dreading when that goes. It's almost cruel to have this lifeline for 10 weeks and then to have it snatched away."

201940, October 2023

Struggles for parent carers

Issues with Education, Health and Care Plans (EHCP)

"He's been in and out of school since year 7 and because he was not in school, I was told he couldn't get an EHCP. But he wouldn't go to school because he didn't have the help he needed which he would have got through an EHCP. When the 3rd inclusion officer came round to my house they asked me why he had no EHCP. He's finally just got it and has it now for college."

201554, October 2023

"Even after... having the EHCP agreed... They just ignore what is written in it. It's been a year... and I'm still battling... to get the things that were agreed put in place for my son."

203471, November 2023

Delays in accessing services for children with Special Educational Needs (SEN)

"The main thing... is the lack of services for children with SEN. They are put on the pathway for diagnosis and they need this to be able to have support put in for their child when they start school, but there is a long waiting list. So the child starts school with no diagnosis and therefore gets no help.."

201912, October 2023

Lack of specialist training to support children with Foetal Alcohol Spectrum Disorder (FASD)

"Professionals and teachers need to be trained. They need to know that children with FASD will respond differently from children with autism and other conditions. The occupational therapists and speech and language therapists didn't know what I was talking about when I said FASD. When I mentioned FASD to the occupational therapist, she told me she understood as she'd worked in primary schools and knew loads about Autism Spectrum Disorder (ASD). I had to explain I meant FASD not ASD. I think training is critical. Staff need to understand our children [with FASD] do respond in different ways. Unless they understand why, they say this child won't engage and they discontinue the service. Mental health services say they won't engage so poor families are just left on their own holding some unbelievably traumatic life situations."

204619, November 2023

"All the interventions are for ASD and ADHD. They aren't trained in FASD."

204622, November 2023

"...there is a social worker coming next week to assess her. The social worker had barely heard of FASD. So I'm sending her some stuff. She's had no training and then she's coming to assess my daughter with FASD. It's ludicrous."

204624, November 2023

"The battle has been with infant school. They had training on autism and Pathological Demand Avoidance (PDA) but nothing on Foetal Alcohol Spectrum Disorder (FASD). I've had to keep explaining to them why she behaves how she behaves... It's a constant battle. I keep going to the EHCP and saying it needs to be worded differently and changed to reflect her FASD. The school is fantastic and the Special Educational Needs Coordinator (SENCO) has been fantastic but it is so centred on autism and ADHD... I need to know that the one to one with her has FASD knowledge. I need that written into her EHCP. I want a teaching assistant that knows."

204625, November 2023

What carers would find useful

"I would love a local group with mums of kids with similar needs. If I speak to other mums whose kids aren't like mine, they don't understand and they make you feel bad and different. The support of other mums is so useful."

201712, October 2023

"...having someone at [carer] groups who knows about Parkinsons, would be really useful to me... We also need proper exercise groups for people with Parkinsons."

205306, November 2023

"It seems to me that if you have complex needs and difficulties, then you have services but what about those who don't? Those who are middle of the road so to speak, like my daughter. She isn't physically disabled but has some mental health issues and there doesn't seem to be groups for her to socialise... my daughter would love a group that has young people of her age but also understands her issues."

205043, November 2023

"Everything with being a carer is not joined up... you constantly have to repeat yourself. When you're a carer you don't have much time and they give you so much paperwork and forms to fill in. It would be really useful to have a clear list of what you need to do and clearly written leaflets. There is too much to look through."

204594, November 2023



Valued support for carers

"[Name] from Age Concern has been fantastic... She's been so helpful, she's spoken to me and my wife on the phone and contacted Adult Social Care and our doctors for us. I don't know what I'd do without her help. I have no one else."

203997, November 2023

Giving Young Carers a Voice pilot – quarter 3 update

We spoke with 154 young carers this quarter. We have visited the following groups to speak directly with young carers:

- Burpham Junior School
- SCAMPPS (Striving for Children's Additional Medical, Physical and Personal Support)
- Broadwater Youth Club
- Weald School
- Surrey Young Carers Croc Adventure, Dorking
- Surrey Young Carers, Sayers Croft
- Guildford Grove School
- Action for Carers hub, Woking
- Young carers pizza evening, Guildford
- Action for Carers hub, Camberley
- Surrey Young Carers Drop-in, Tadworth
- William Cobbett School
- Surrey Young Carers Junior Group, Ashford
- Surrey Young Carers Senior Group, Shepperton.

During quarter 3, we have met with the following organisations and individuals to discuss how we can engage with young carers and reach hidden carers:

- School nurses
- Surrey and Borders Partnership NHS Trust
- User voice engagement & participation group
- Preston partnership
- Woking young carers
- Carers practitioners meeting
- North West Surrey supporting unpaid carers
- Carers Advisory Group
- Home-Start Surrey
- Community link officers
- Young Carers National Voice
- Young Carers Alliance
- The Children's Society
- Mindworks Surrey
- Crossroads Care Surrey

- Gypsy, Roma and Traveller forum
- School link workers
- Carers Partnership Board
- Woking mosque.

We also attended the following events:

- Black History, Salfords village hall
- Surrey Safeguarding Children Conference
- Carers rights fairs
- Substance use in young people
- Children and Young People Marketplace, Surrey Heath
- Young carers pizza evening, Guildford.

We heard about the importance for young carers to have support in school.

"I like coming to the young carer group at school because I get to see my friends who are different too. [Name] is kind and she cares about us. She looks out for us and we can come to her anytime we need to."

204862, November 2023

"I like being at school and coming to this group where I can talk."

204871, November 2023

Young carers told us about the value of one-to-one regular contact and regular support groups:

"When my sister has had a meltdown in the morning, my mum rings [name of teacher] and she comes for me in class and we go to the quiet room to talk. I feel better afterwards and [name] is very kind... The kindness club is somewhere where we are safe and we can talk about our feelings and share... I don't go to any other groups."

204769, October 2023

"Being a young carer does affect my mental health, I'm anxious and don't like to be in unfamiliar situations. Speaking to someone on a regular basis about my anxieties and situation would help me enormously. I attend a group that's run every other week. It's nice to know that it's on the same day and at the same time and the same staff are there. We have guest speakers, and we enjoy snacks and socialising with like-minded people. I like this as I suffer from anxiety and I like to know where I'm going and who's going to be there. I like meeting the same people."

206738, December 2023

“It would be nice to have someone to talk to about things that are affecting me... I would prefer groups that meet regularly and do something – bowling, a meal out. Just to socialise and have a chat with other people who would understand what you’re going through.”

206740, December 2023

Influence and Impact

- Surrey County Council Carers Commissioners have been informed about what we have heard that young adult carers need. They have met with Action for Carers to see how this can be achieved.
- Further work has been commissioned with Surrey County Council as a result of the report on carers replacement breaks.
- Issues with carers assessments have been brought to the attention of Adult Social Care who are looking to develop more training around this for all their staff.
- Continence issues that carers have been experiencing (only being offered pads and not pulls ups) was raised at the Joint Intelligence Group meeting in November 2023. This is now in the action log and the place leads are taking this forward.
- Feedback we received from a carer we met: “I just wanted to say thank you so much for your time yesterday, it was great to meet a couple of people with so much experience, who are also carers and who, if anything, are more passionate than I am about giving carers a voice, alongside access to and signposting to relevant services.”

Where we are going January - March 2024

The following table details our upcoming visits (first column details the place and the second column the date). Please note these dates are subject to change and additional visits are still being planned.

| Place | Date |
|---|------------|
| ASD/ADHD parent carer group, Home-Start, Woking | 18/01/2024 |
| Action for Carers hub, Woking | 22/01/2024 |
| Parent carer group, Learning Space, Redhill | 26/01/2024 |
| Home-start, Pirbright | 30/01/2024 |
| Carers group, Spelthorne | 19/02/2024 |
| Action for Carers hub, Guildford | 26/02/2024 |
| Action for Carers hub, Haslemere | 11/03/2024 |

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
-  Text: 07592 787 533 (SMS only)
-  Email: info@luminus-cic.uk

Our address is:

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

