

Giving Carers a Voice

Quarterly insight report

What we're hearing

July - September 2023



Giving Carers a Voice

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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. We continue to deliver the [Healthwatch Surrey](#) service and 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 July - September 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:

- Burpham Wellfest
- Action for Carers hub, Guildford
- Hale community centre
- Dementia 1st carer support group, Horley
- Nepalese elders group, Camberley
- SCAMPPS (Striving for Children's Additional Medical, Physical and Personal Support)
- Action for Carers hub, Cranleigh
- Additional needs service showcase
- Dementia group, Banstead
- Action for Carers hub, Leatherhead
- Action for Carers hub, Shepperton
- Dementia group, Reigate
- Action for Carers hub, Farnham
- Action for Carers hub, Addlestone
- Action for Carers hub, Hersham
- Seniors club, Horley
- Action for Carers, Banstead
- Wellbeing support for 16-25 year olds with Mary Frances Trust
- Horley food club and café
- Action for Carers hub, Epsom
- Action for Carers hub, Horley
- Parkinsons support group, Milford
- Sight for Surrey drop in coffee morning
- Include Choir, Epsom

- Include Choir, Redhill
- Royal Surrey County Hospital open day
- Forget me not café, Horley

Main themes we have heard from July - September 2023

The word cloud below highlights the main themes we have been hearing about this quarter. The larger text represents those themes we have about the most including quality of care, dementia, mental health and respite care.



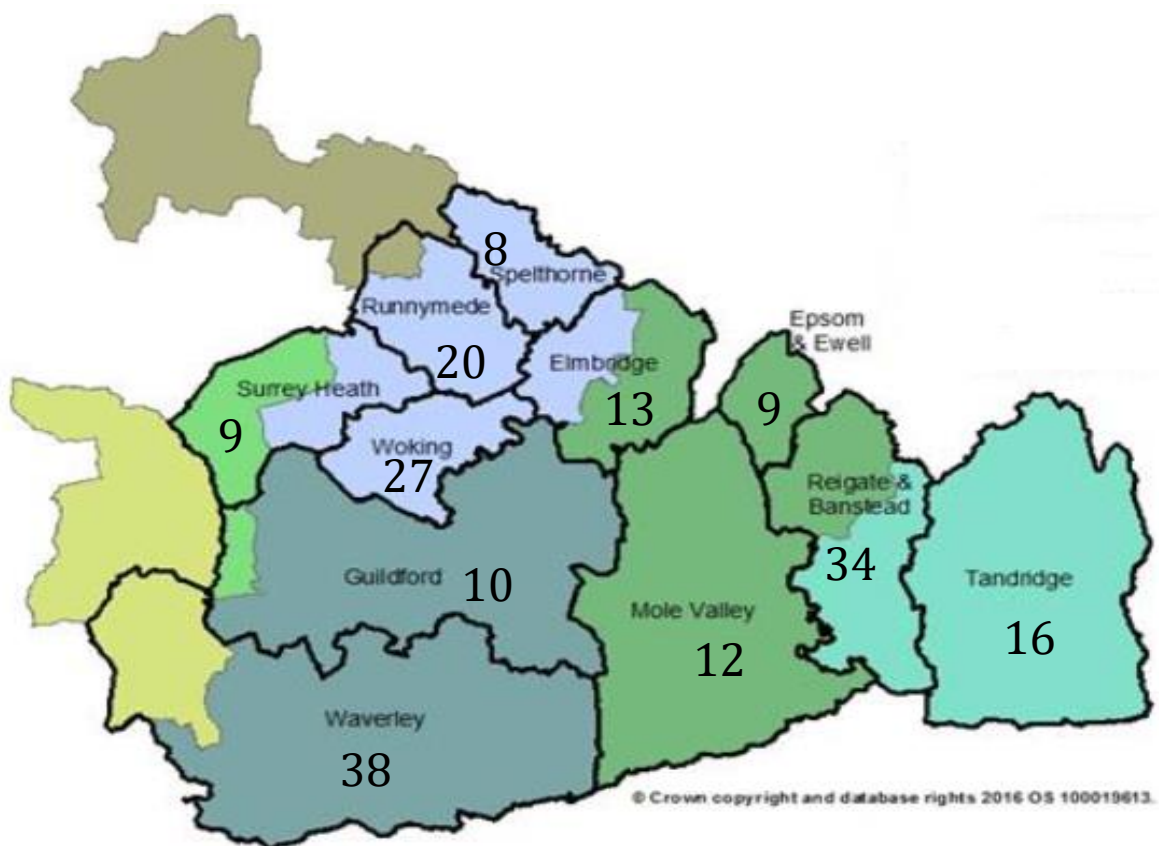
Where we have shared our insight

During quarter 2 (Q2) 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.

- Surrey Safeguarding Adults Board – August 2023
- Carers Partnership Board – September 2023
- What we've heard Adult Social Care – September 2023
- What we've heard Public Health – September 2023
- What we've heard Mental Health – September 2023
- Surrey Heartlands Primary Care Commissioning Committee - September 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 Waverley, Reigate and Banstead and Woking.



*5 out of county

*78 carers listed as not known as their feedback was obtained at larger events or online support groups where we were unable to capture their demographics.

Key themes for quarter 2

- Not identifying as a carer
- Quality of care – not speaking to the carer
- Difficulties accessing respite care
- Lack of choice with incontinence service
- Navigating dementia
- Stress and wellbeing
- Carers with their own health needs
- What carers would find useful
- Valued support for carers
- Giving Young Carers a Voice pilot – Q2 update
- Influence and impact
- Where we are going October – December 2023

Not identifying as a carer

We are continuing to speak to carers who do not realise that they are carers. We spoke to 279 carers in Q2 and many still do not recognise themselves as carers.

"We've only recently realised that we are all carers - we are all related and because we all have health issues, we just look after each other [mum, daughter and gran]. We care for each other and it didn't occur to us to say that we are carers. We all live near to each other too. How do people who don't have family cope?"

196815, August 2023

"I'm his mum, so does that count? I'm not being paid to do this...If you hadn't been here I don't know how long it would have been before the penny dropped [that I'm a carer]... I'll take some leaflets for my friends at school as I don't think that any of them think of themselves as parent carers... I also think my daughter might benefit from attending a group to meet other children who might have a brother or sister like hers. Her home life is different as it all revolves around my son and what he can do and how he reacts to different situations."

201156, September 2023

"I never thought of myself as a carer as although we both work, my wife deals with most of the paperwork and things like that. I don't think that she thought of herself as a carer either. It's just not a word either of us would use or associate with. As my son has got older I now realise that being a carer is more than the physical and practical things, but it's emotional too."

200122, August 2023

Quality of care – not speaking to the carer

Carers tell us that they feel invisible.

"As a carer the hardest part is starting the conversation - can you help me? How lovely it would be if someone had said to me 'what help do you need? Not much to ask is it?"

194417, July 2023

"No one there [at the GP practice] has ever asked me how I am as his carer. They always ask how he is but never me. They never ask how I'm coping."

194488, July 2023

"Nobody ever asks me how I am."

200500, September 2023

Difficulties accessing respite care

People have told us about some of the challenges with respite care.

"I usually use a care home for respite care if I go away as he does need that extra help if I'm not there to do it...The problem is that you now have to book so far in advance and there doesn't seem to be any beds locally...Where can you send them if you need to go away on holiday? I did find a local one this time but they couldn't confirm that they had a bed until the week before. This then adds to the stress that I already have as his carer."

196810, August 2023

"Respite care has been a real issue. I had a holiday booked in February 2023 and tried to book [a care home] as [my husband] had been there before and was happy there. I called them and they said that they no longer did respite. I had to cancel my holiday."

201152, September 2023

Carers tell us how vital having a break from their caring responsibilities is.

"I now pay for someone to come in and sit with my husband who has Alzheimer's... I didn't recognise myself that I needed help until a friend pointed out that I did. The signs were there though - losing weight, not eating. I thought that I had something seriously wrong with me. It was the stress of caring for my husband. Now that I can leave him and I know that he is ok, I feel that I have got my life back."

195985, August 2023

Lack of choice with incontinence service

We continue to hear that people are only being offered incontinence pads rather than being offered the choice of pull up pads.

"The incontinence nurse offered her sanitary towels which looked like logs. There is no way she could use these. She uses the pull up incontinence pads. We were sent one box worth but she can't use these so I gave them to the district nurse and we've said no to anymore. We just pay for her pull up incontinence pads. Why can't they provide these ones instead as most people want those not the sanitary towel ones?"

199626, August 2023

"My wife is 76 and suffers from dementia. She is doubly incontinent and I buy her the pads and pull ups that she needs. You need the pull ups, to put the pads into... They said they would give me pads but not the pull ups. What use are these without the pull ups too? So I'm funding both myself. I didn't find this service helpful at all... It has put me off asking again and I can't be bothered going back

to the next appointment. I'd rather carry on paying. The double incontinence goes with the dementia and there's not a lot that anyone can do about it. It would have made life easier for me as I can't really afford to carry on paying for them but I'll manage."

194496, July 2023

"Pull ups would be much better. I do now buy them as the pads don't stay in place."

201351, September 2023

"The pads that they give you just aren't suitable for my husband. They don't stay in place and the net pants are useless. Pull ups would be ideal and much easier for me to change. It must be horrible for him to have a pad. They move around and just don't do what they should. Having these anyway for him is an indignity in itself, pull ups would be so much better as they are more like pants and he would understand the concept of pulling them up and down which would help me."

201369, September 2023

Navigating dementia

We have heard about the impact of dementia navigators on carers.

"We lost [name], the dementia navigator, now which is a real pity, a real shame. Now we're on our own and have no idea who to turn to if we need help. [Name] was so helpful when my wife had her stroke."

201281, September 2023

"I really wanted just to say how wonderful the dementia navigator that I have is. My wife has Alzheimer's and they have been a lifeline for me. They are absolutely fantastic...The dementia navigator is in regular contact with me and WhatsApps me, visits us at home and even emails me on her day off. This makes such a difference to me as a carer. Knowing there is someone to talk to and ask questions about things as the illness progresses."

196133, August 2023

Carers have told us about feeling alone after the dementia diagnosis.

"You're just left [after diagnosis] and the carer is relied upon to watch out for signs that their other half needs more help. I'm not medically trained - how can I tell if she needs more medication?"

195723, July 2023

"There are now no regular check ups or any back up... There doesn't seem to be any further treatment for her. She's just left and I'm just left looking after her."

195720, July 2023



Carers have told us about the challenges of caring for someone with dementia.

"I am so tired of all the constant questions. He asks me the same question over and over again. It's so draining and irritating."

196623, August 2023

"People don't understand dementia at all and what carers have to do."

194496, July 2023

Stress and wellbeing

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

"Our life is dictated by our daughter and her routine and appointments. I don't switch off at all and hardly sleep."

195986, August 2023

"As a carer you really are just surviving."

196749, August 2023

"I'm the carer for my [age] autistic son who... comes to me from 8am every morning... I'm 87 and find having to deal with his problems and being up so early in the morning very difficult. He doesn't understand and I'm worried that there would be no one to help him when I'm gone... My son becomes agitated and angry easily which he has always done but now I find I can't cope with it."

197071, August 2023

"[Carer for husband.] I miss having my husband, he made the decisions and looked after the finances which is on me now."

196746, August 2023

"My [age] year old son has autism and ADHD. I have never, ever thought of myself as his carer. I am just his parent. My journey to get him help and support has been horrendous. I'm on anti depressants and have felt suicidal."

194428, July 2023

"I do feel that I'm just a whisker away from bursting into tears [all the time]."

194489, July 2023

"I'm isolated, I don't feel supported or listened to and I'm very stressed. I think the GP should at least check on patients when they know they are unpaid carers. Just knowing that someone will check in on you relieves some of the stress."

195509, July 2023

"You're not a widow, you're not a wife. Everything changes when you're a carer."
200689, September 2023

"[Carer for husband with dementia] I miss my husband; we have been together [number] years and I grieve for him as he was every day... I miss doing things, like going to the theatre with him, it's not the same going with someone else. We did so much together before he became ill. I would like to have some respite to recharge."
195768, July 2023

Carers with their own health needs

"My own health has gradually deteriorated due to my caring for my husband over the years. We could do with a wet room and it's difficult getting him in and out of the bath. His walker is also heavy and I have hurt myself putting this in and out of the car over the years... it's actually getting difficult [for me] to move around."
195987, August 2023

"I don't want to keep bothering my sons as they both work and have families. I have health needs of my own and have a hospital appointment coming up. But what do I do with my husband? If I take him with me, I'll have to watch him all the time. I don't really want to ask either of my sons as they would have to take time from work to either come with me or sit with my husband."
196196, August 2023

"I'm a carer for my husband who has Parkinsons. I am having to pay about £2000 a week for my husband to go into a care home as I need to have an operation. I have breast cancer so he has to go in there while I have my operation until I am ready to manage again. I help him with everything and I am not sure how long it will take for me to recuperate but I can't afford to keep him in there for very long. I am worried about how this will affect my recovery."
199625, August 2023

What carers would find useful

Carers say it would be helpful to have more evening support groups.

"I work full time as well as caring for my 86 year old mum who has dementia...[I would like to find] an evening group that I can go to, without mum and be able to talk openly about how it is caring for someone with dementia. It would be so nice to meet others who are in the same situation...I don't want to do zoom as that's what I'm doing all the time for my job. I would like to get out of the house and talk to people face to face."
200489, September 2023

Other carers are looking for support groups for carers looking after people with similar conditions.

"I wasn't bothered that they were mostly women or their age but it would have been nice to talk to someone who was caring for someone with a physical disability. It would have been more relevant to me."

200500, September 2023

Valued support for carers

"We've been to the forget me nots group about four or five times now. It's really great. I had planned on leaving my wife here but it's really good fun so I stay too. It's useful and there is no pressure to join in with anything you don't want to."

201281, September 2023

"We come here [Dementia 1st Tuesday club] as I know my wife can come, it's safe, and the volunteers who run it are wonderful. I can talk to others who are in the same situation and my wife is talked to and included. We all have lunch and it's really sociable."

195683, July 2023

"This is my first time at the [Action for Carers] hub and it's been lovely to talk about my situation and realise there are other people who understand. It's also interesting to hear their stories and pick up very helpful advice about self funding and other things."

196753, August 2023

Giving Young Carers a Voice pilot – quarter 2 update



We spoke with **69** young carers this quarter. We have visited the following groups to speak directly with young carers.

- My Time young carers
- Surrey Young Carers family fun day, Painshill Park
- Surrey Young Carers family fun day, Horsley Place
- Surrey Youth Voice young carers youth club, Goldsworth Park.

During quarter 2 we have met with the following organisations and individuals to discuss how we can engage with young carers and reach hidden carers:

- Surrey Youth Voice
- Family Action
- Caring Together
- Young Carers Alliance
- Young Carers National Voice
- Centre 33
- Carer practitioners
- Community link officers
- Surrey Family Voice
- L-SPA (Learners' Single Point of Access).

We also attended the following events:

- Surrey County Council youth arts & cultural event, Staines
- Community wellbeing event, Bellfields
- Mary Francis Trust wellbeing event, Tadworth
- Surrey Youth Voice summer party, Reigate
- Royal Surrey County Hospital open day.

We heard about the importance of having a safe space to go to and having access to appropriate adults to talk to.

"I enjoy coming to My Time. We do lots of fun things. I've made lots of friends. [Names] are kind and look after us. I know I can talk to them about things and they take time to sit and listen."

194672, July 2023

"I get very angry and it's good to have a place [young carers youth club] I can come to once a week to be with people who understand and to have adults who can help and advise me. I've made a lot of friends here and we are all close."

200488, September 2023

However some young carers told us they are unable to access activities and support in their area.

"We used to go to Surrey Young Carer things but we can't get there anymore."

195197, July 2023

"I tried to get my son on the trampolining with Surrey Young Carers but there were no free places. They get booked up very quickly and it would be nice if they did a couple of trips so no one is left out."

197018, August 2023

Upcoming pizza evening 5 December

We are having a pizza evening for young carers (aged 16-24) on Tuesday 5 December from 6-8pm. Invites are going out at the end of October. If you are a young carer and would like to come along or you know some young carers who would be interested in coming then please email Pam.Howard@luminus-cic.uk for more details.

Influence and impact

- We heard about unsafe hospital discharges and unsatisfactory treatment of patients with Parkinson's at Royal Surrey hospital. As a result, the hospital has now looked into the risks of being discharged by taxi and has commenced use of a standard to ensure patient safety upon discharge. Parkinson's medication is to now be audited throughout the hospital trust to assess the issues raised by Luminus. The findings of experiences in 2 wards has been escalated and actions have been agreed to ensure improvements.
- A carer reported how her carer's assessment was stopped and restarted twice. We were able to involve a carers practice advisor at adult social care who found out the carer's social worker was on maternity leave yet no one had informed the carer. The senior carers practice advisor has now recommended the carer's assessment for this carer. The senior carers practice advisor has intervened to ensure the assessment will now be completed.
- Many carers were unaware that they should register with their GP practice as carers. Giving Carers a Voice fed this back to the commissioners. Surrey County Council have now recruited 2 people to cover GP practices in Surrey to raise awareness of carers and to ensure that they are registered and offered the correct help and support. This was as a direct result of our feedback of carers' experiences.

Where we are going October - December 2023

As shown on the front page photo, when you and others see us at different events and engagement sessions, you might notice something different about our leaflets, banners and tablecloths. We now have new branding following the name change of our Community Interest Company from Healthwatch Surrey CIC to Luminus Insight CIC (known as Luminus).

Luminus is home to all of our services including Healthwatch Surrey, Giving Carers a Voice and Combating Drugs Partnership Public Involvement.

Some examples of our new branding:

Young Carers

Giving Young Carers A Voice

Luminus
Home of Healthwatch Surrey

- 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?

Giving Young Carers a Voice makes sure that the voice of young carers is heard in Surrey. Your views and experiences can help to change how services are planned and provided, so please get in touch with us.

You don't need to be a registered carer to contact us!

For further information and advice:

0303 303 0023
07592 787533 (text only)
info@luminus-cic.uk
<https://luminus-cic.uk/services/giving-carers-a-voice-page/>

Giving Young Carers a Voice

Thank you

Thank you for speaking with us today.

Do you have anything more to add? Please get in touch with us.

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Giving Carers a Voice

Luminus
Home of Healthwatch Surrey

- Do you provide care or support to a relative, friend or neighbour who couldn't manage without that help?
- Are you getting the support you need to carry on caring?
- Would you like to help improve services and support for carers in Surrey?

If you provide unpaid help or support to anyone who couldn't manage without that help, then you are a carer and we would like to hear from you.

We want to hear from you about both your good and bad experiences of the support and services you have received, or if you have had problems getting services or support.

As an organisation that holds a number of voice contracts including Healthwatch Surrey, we are experienced in gathering people's feedback and using this to help service providers and decision makers know what they are doing well and what might need to change.

For further information and advice:

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Giving Carers a Voice

Luminus
Home of Healthwatch Surrey

Thank you

I just interpret for them, but I'm not their carer.

I just help to calm my child down when they're angry or upset, but I'm not their carer.

Providing unpaid help and support to anyone who couldn't manage without your help, means that you are a carer.

Thank you for speaking with us today.

Do you have anything more to add? Please get in touch with us.

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info@luminus-cic.uk
<https://luminus-cic.uk/services/giving-carers-a-voice-page/>

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

Place	Date
Maybury support group, Woking	03/10/23
Community café, Camberley	04/10/23
Linklight mental health forum, online	04/10/23
Surrey Minority Ethnic Forum autism awareness event	09/10/23
Home-start, Guildford	12/10/23
SCAMPPS	15/10/23
Parent carer group, Camberley	16/10/23
Home-start, Pirbright	17/10/23
ASD/ADHD support group, Epsom Downs	03/11/23
Hong Kongers group, Guildford	04/11/23
Dad matters, Home-Start group, Shepperton	06/11/23
Rare dementia group, Tadworth	07/11/23
Age concern dementia group, Banstead	08/11/23
Womens group, Woking	15/11/23
FASD support group, online	17/11/23
Carers rights fair with Action for Carers, Cranleigh	20/11/23
Carers rights fair with Action for Carers, Camberley	21/11/23
Carers rights fair with Action for Carers, Caterham	23/11/23
Hope café, Egham	29/11/23

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

Our address is:

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

