

Giving Carers a Voice

Q1 Quarterly Insight Report

What we've heard: April – June 2023



Giving Carers a Voice

Quarterly Insight Report – April - June 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.

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About Luminus CIC

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 April - June 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:

- Memory Lane, Cranleigh
- Wellbeing cabin, Royal Surrey Hospital
- Haslemere Methodist Church
- Connect group for carers and partners living with dementia
- Home-Start, Cranleigh
- We Care, Ewhurst
- Veterans drop-in group, Guildford
- The Hunter centre, Haslemere
- Dementia drop in group, Milford
- Independent Mental Health Network meetings
- Veterans drop-in group, Woking
- Action for Carers hub, Woking
- Veterans support group, Fordbridge
- All things nice parent carer group
- Leatherhead Youth project fun day
- East Surrey Hospital with Action for Carers
- Wellbeing hub, Milford
- St Peters Hospital with Action for Carers
- National Autistic Society
- Action for Carers hub, Camberley
- Young Carers National Voice event
- Dementia1st carer support group, Bletchingley
- Older people's service providers forum

Main themes we have heard from April - June 2023

The word cloud below highlights the main themes we have been hearing about this quarter. The larger text represents those themes we have heard about the most including Quality of Care, Parent Carer and Mental Health.



Where we have shared our insight

Report on Identifying as a carer

We have shared this insight with the key stakeholders, providers and the Carers Partnership Board.

The key findings of the report were:

- People being slow to self-identify as carers due to not feeling they do enough to count as a carer, due to emotional and cultural resistance and due to infrequent signposting from frontline/clinical staff.
- Understanding of the support and benefits available to carers appears to be weak for those who do not identify as carers.
- Different people have different needs and strengths and find value in different types of benefits or support.

Based on the findings we made the following recommendations:

- **Recognise that new carers are unlikely to self-identify and self-present.** Maximise “recruitment” through media such as the Action for Carers posters, GP surgery posters, ongoing engagement; by encouraging word-of-mouth among carers.
- **Ensure frontline staff “think carer”** – recognise carers, are confident in starting conversations, and know where to signpost.
- **Review the accessibility of support and benefits:** how easy are they for someone time-poor, overwhelmed or on a limited budget to find, apply for or use? How well are those “costs” balanced with the benefit to the carer and cared for person?

A copy of this report can be found on our website at [Giving Carers a Voice: Reports - LUMINUS \(luminus-cic.uk\)](https://www.luminus-cic.uk/Giving-Carers-a-Voice-Reports)

We also produced a short video to accompany the report, which highlights the key themes the carers shared with us in the report. The video can be found here:

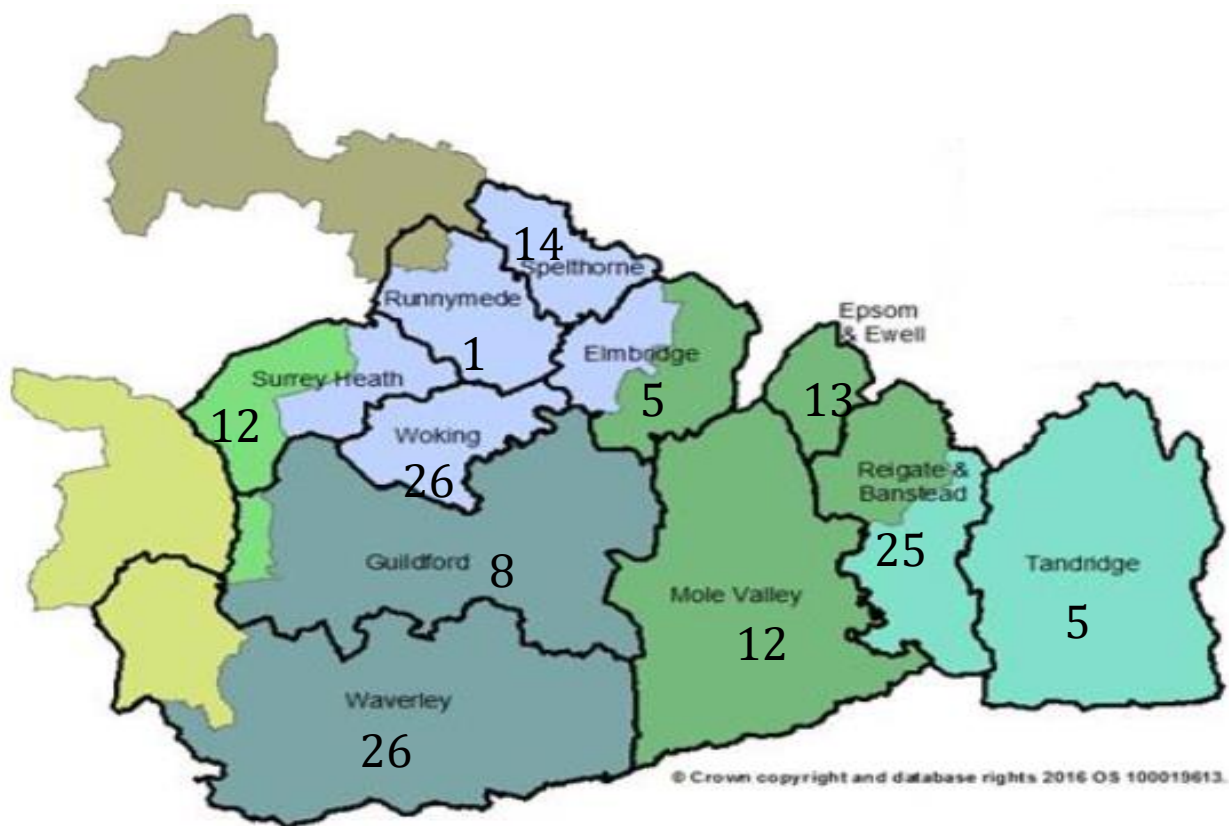
<https://youtu.be/aCINh04Fd3Q>

During 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 Heartlands QPAC – May 2023
- SABP Learning from Experience Group – May 2023
- Dementia Strategy Action Board - May 2023
- Surrey Heartlands Access Board – June 2023
- Surrey Heath Primary Care Operational Group – June 2023
- Guildford and Waverley Place – June 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 Reigate and Banstead, Woking and Waverley.



*13 Out of County
*29 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 189 carers in Q1 and over 9% (18 carers) did not identify as being a carer.

"I live with my grandson. He has mental health issues. I wouldn't use the word carer to describe our relationship but I do actually look after him more than he does me. I could manage without him but I'm not sure that he could manage without me." **189633, April 2023**

"I wouldn't use the word carer. I don't like it and I don't think that if my husband heard me saying that I am his carer, he wouldn't like that either. I'm his wife. I do know that I am technically his carer but I don't refer to myself as such or use that word." **189316, April 2023**

Quality of care – not involving the carer

Lack of communication with the carer continues to be a key issue we hear about.

"They [GP] haven't listened to me about mum's painkillers. They have just reduced them without any consultation with us or seeing her. She only gets one box now and I have to keep doing repeat prescriptions. It's such a palaver. She then runs out and tries to do the repeat prescription by herself and this causes all sorts of problems. I then have to sort it all out. I then have to buy over the counter painkillers as she has run out or she doesn't have enough." **193221, June 2023**

"It's hard to make time between caring for my husband to stay on the phone [to the GP] until someone answers. By which time, I'm frustrated and cross. I can't spend much time away from him without him becoming distressed or agitated. So much so that when I do eventually get to see the GP, I can't follow up on things such as blood tests or results etc. It would help if they understood what caring entailed and provided some sort of priority system or even just someone patient and willing to follow up on our behalf." **192110, May 2023**

"[Changing appointment time] made my wife very agitated and she then takes it out on me. Professionals should realise that when dealing with people with mental health issues, you can't just change your times as this has implications for the carer." **192107, May 2023**

We have heard from carers who are concerned about the lack of face-to-face time with medical professionals.

"As a carer I get no recognition or support. How can anyone know that I am a carer if they never see me or my wife. They can't see how much she has deteriorated or how much I have either. No one is seeing us. If we saw a Dr in person or came into the surgery regularly, both the staff and Dr could see how we were coping. I'm a carer but it means nothing. I do worry about the future. Who will help me?" **192092, May 2023**

"We hardly ever see our GP face to face so I guess he wouldn't know how much she had deteriorated and what I was doing [as her carer]. Nobody at the surgery has ever mentioned the word carer or told us about any help and support." **191950, May 2023**



We have heard how things work really well when the carer is involved.

“The GP seems to take a personal interest and it’s always flagged up when I ring up that I am a carer. It’s always pointed out which is great. GP practices do vary through the county.” **193234, June 2023**

“[Carer for autistic son.] GP very supportive. Rings me up every month and always gets back to me with any problem. Very helpful.” **193235, June 2023**

“My son got referred to the Enabling Independence Service. The service has been very very good. The lady has been very patient and very proactive. She has taken my advice that when he says no he doesn’t mean it. And she’s made a lot of difference.” **193238, June 2023**

No access to a key worker for parent carers

Parent carers tell us that they are struggling to get access to a key worker.

“Big thing that we have noticed is the absence of a key worker and a lot of parents will say this...You really lose the consistency unless there is somebody keeping it all coordinated...the big issue for me is that we used to have key worker and point of contact but that’s no longer... The social workers we have had have been worth their weight in gold. Helpful to have that back up and we now notice the absence of that back up. It feels like there is nobody out there.” **193236, June 2023**

“[carer for autistic son.] My son presents as too capable. He’s 35 and does work but I can’t get any help with a transition to independent living...Not sure that any social housing available [in our area] would be suitable but we cannot get on to special needs list because we can’t get a key worker or social worker.” **193237, June 2023**

Ongoing impact of lockdown

Carers have told us how the Covid lockdown is still impacting services.

“I’m a carer for my son [autistic]. He was receiving adult social care until the first lock down and like most people that suddenly fell off a cliff and he had nothing. I tried restarting it earlier this year but I’m still waiting.” **193260, June 2023**

"I'm a carer for my son who is autistic. He's been at home since March 2020 [due to lockdown.] We've been at home one to one all this time. He is having an ongoing mental health crisis... We are drowning... No one has been to see us from Adult Social Care so I've just been juggling things as always." **193240, June 2023**

Difficulties accessing respite care

We continue to hear about the importance of respite care.

"[Carer for husband with dementia] Respite is really important. I can leave him at the moment for a bit, but you know it will just get worse and worse.... He goes there [to a care home] once or twice a year for two weeks so I can get a break. I am self-funding and it's not cheap but I need a break." **193973, June 2023**

"I managed to have 3 weeks away and that made a huge difference to my mental health and wellbeing. Of course I had to pay for this and it was very expensive. A paid carer came and lived in the house while I was away. The only trouble is that you then come back to it all and it's physically exhausting." **189268, April 2023**

Some carers however report that they are still struggling to access any respite care.

"I'm on the waiting list for respite care through Crossroads Care but my husband is not very keen at all. I was told there is a six month waiting list." **192699, June 2023**

Carers with their own health needs

Many carers are struggling to manage their own health conditions alongside their caring responsibilities.

"It's hard to find time for your own health when you're a carer. I'm in here today for an appointment for an MRI but I can't leave him for long. My own health is getting worse as I have to prioritise his care." **192702, June 2023**

"My husband has just had back surgery. I have my own health issues (which is why I'm here) but I don't have the time to really sort myself out as I'm caring for my husband at the moment. I have to do everything for him. It is exhausting. I don't want to bother my family as they're all having issues of their own at the moment. I know that I should ring my GP but you have to ring at 8am. That's when I'm getting my husband up and dressed and making his breakfast. So that makes it

difficult. I'll need an operation but I've been putting it off until he's well but I really don't feel well at all." **193108, June 2023**

Stress and wellbeing

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

"It's extremely difficult to take care of yourself when you have an autistic child. I feel pushed to the brink of burn out. People make sympathetic noises but the reality is that you have to access therapy to help yourself. I am about to try space2byou which I got through Action for Carers. They have been very helpful to me. They are very careful with their time [and don't give you a lot of it] but I would still say they are great. It's extremely difficult to put your own needs first. I know I'm not going to go under but I do feel overwhelmed." **193239, June 2023**

"[Carer for adult autistic son.] My mental health is in absolute crisis at the moment and I don't see a way out. I've been in a bad way for a very long time and there is a limit to how much more I can take. I have been in and out of the GP surgery for years. I've taken meds on and off. Talking therapy has never helped. Nothing ever helps as it doesn't take away the fact that I'm with my son most of time. I'm worn out." **193260, June 2023**

"The thing with being a carer is that there is no time for me at all." **189269, April 2023**

"You are ignored as a carer. You go in with the person you're caring for and no one ever says how are you and how are you coping? There's no information at the GP... It's endless but I cope. I have to cope I have no choice. I can't be ill, I have to look after him. I don't go away on my own anymore but my husband comes with me. We have agreed when he's not able to come then he will go to respite sometimes so I can get a break. Going away with him is stressful anyway as I'm constantly thinking for two people." **189319, April 2023**

How caring affects the whole family

Carers have shared how caring impacts the entire family.

"The impact my daughters mental health has on my other children is unmeasurable. They see her suffering and often feel it's their fault, in particular if they've disagreed with her on something. They cannot understand her issues and

don't know how to help her. They are registered with Surrey Young Carers and have been to some of the groups and activities." **192282, May 2023**

"My son 22 is autistic, has Attention Deficit Disorder, Pathological Demand Avoidance and Oppositional Defiant Disorder. We are at our wits' end with him living in our house and abusing us daily. He needs to move out. Apparently there is nowhere or nobody to take the strain." **192380, May 2023**

"I have a [age] year old daughter that is pretty annoyed with the whole thing [older sister going through ASD assessment process, self harm, no longer in school]. She avoids having any conversations or contact with her sister. I'm working hard to try to not let this affect her but it actually is affecting the whole family and our dynamic. We can't enjoy the things that we all used to do." **192353, May 2023**

Transport and travel issues

"I do have a blue badge for parking and it would be handy to have one for him [husband] too. He loves to go and watch Woking play but the parking has been reduced from 3 hours to 2 hours. This doesn't give him enough time to park and then walk to the ground. His mobility isn't that good... Then if he gets one too, he can park nearer to the stadium and it will be free." **190502, April 2023**

"It takes about 2 ½ hours for the chemo. Her dad [in his 80s] has to drop us there as you just can't park at Royal Surrey. The stress of trying to park and having to get there an hour earlier to try to park is too much when it's already a difficult time." **189839, April 2023**

"My partner was in the Royal Surrey for a week and was only discharged a couple of days ago. It has cost me over £100 to visit her. This was spent on buses and taxis. I'm on benefits and this is very hard for me." **189602, April 2023**

Difficulties managing paid work alongside caring responsibilities

"I have to take annual leave to attend appointments with my dad. They won't offer me hybrid/flexible working. There is just no flexibility... I didn't know that I could raise this with HR as I couldn't cope with the aggravation... Those with children are allowed to do hybrid working. I'm not. They are also allowed to leave early if they have to take their children to clubs/school etc. I'm not allowed to... How is that fair? I'm exhausted and have mental health issues myself and all this stress is making it worse." **193107, June 2023**



"My daughter has an eating disorder. We were here [at the hospital] 3 weeks ago and were told that someone from the mental health team would be following up with us. It's 3 weeks later and we have heard nothing. I haven't worked for 5 years as I just couldn't. I went back to work 3 weeks ago and I think that has been just too much already." **192701, June 2023**

When employers recognise the carer and allow flexibility and support then carers can continue to work.

"Her work have actually been amazing and said she can work from home two days a week and have him home with her." **191529, May 2023**

Valued support for carers

"[Name] at Dementia 1st has been fantastic. She is my first port of call and has really helped me. She has given me lots of information. She helped me get the blue badge for my husband and helped sort out all our benefits. I wouldn't know where to start looking for information or help if it wasn't for Dementia 1st." **193974, June 2023**

"I couldn't speak highly enough of Crossroads Care – we've had 3 different people, all been fabulous. They listen to us and also make suggestions." **189254, April 2023**

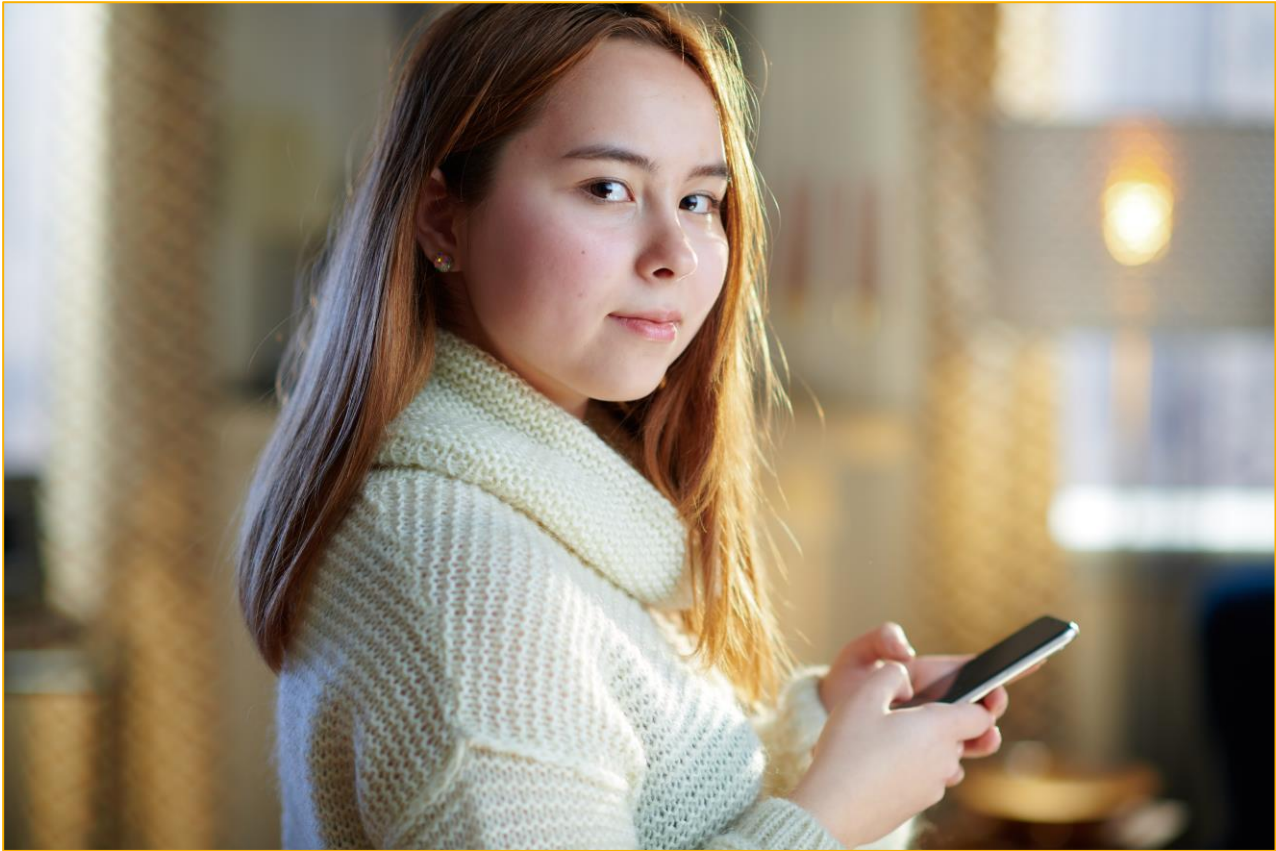
"This place [The Hunter Centre] is just amazing and it's been a lifeline for me. The staff are so good and I can come here and bring him and know that he is safe." **191508, May 2023**

Young Adult Carers

In June we held a pizza evening with Young Adult Carers; they told us they weren't currently accessing services. This was because they didn't feel there were any services that appealed to them. They told us that:

- They don't find the events appealing and/or at times they can go as they are working or at college.
- They would like a social event at a regular day/time so they could build friendships with other young carers in their area.
- They wanted local opportunities as the impact of the cost of living is preventing transport/fuel in a lot of cases.
- They would like information on what benefits and support is available to them in an accessible and easy to understand format.

Giving Young Carers a Voice Pilot – Q1 update



In May, Pam Howard joined the Giving Carers a Voice team as Engagement Officer to lead the Giving Young Carers a Voice pilot work. The first couple of months have been spent making contact with young carer support groups and attending groups to talk to young carers.

During Q1 we have met with the following organisations to discuss how we can engage with young carers and hidden young carers to help inform our engagement plans for Q2:

- MyTime4young carers
- Surrey Young Carers
- Action for Carers Surrey
- Leatherhead Youth Project
- Young Carers National Voice
- Surrey Youth Voice
- HomeStart Guildford
- GRT Forum & within their community
- Family Voice
- Surrey Youth Focus
- Youth Clubs
- Link Officers
- Community Development Workers.

This quarter we have also visited the following groups to speak directly with young carers. We spoke with **35** young carers this quarter:

- All Things Nice parent carer group
- Surrey Young Carers Sports Day Dorking
- MyTime young carers

We heard about what activities young carers enjoy at young carer groups.

"I come to Surrey Young Carers things and enjoy the activities. My sister is the person I help with, and I help my mum to do things for her. We go to church and they help us too. I like doing sports and playing games. I've enjoyed making the card and would like to do it again." **192672, June 2023**

"I come to Surrey Young Carers so my mum can spend time with my little brother. I'd like to make things; I don't like playing games like skipping and racing. I do a lot of things for my mum and little brother, like putting on the washing machine, folding clothes and making snacks and drinks. I also play with my little brother whilst my mum gets on with things." **192674, June 2023**

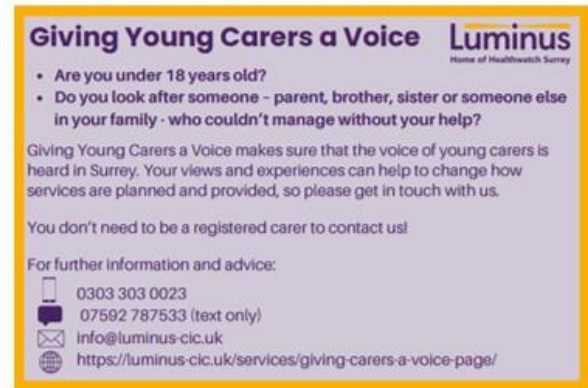
"My mum is very poorly and I have to look after my two younger sisters... I come to Mytime to see my friends and play games." **193821, June 2023**

However, some young carers told us they struggled to access activities in their area.

"My daughter who is now 16 was part of Surrey Young Carers but we found that most of the activities were either near Woking or Guildford. When they provided taxis so she could go, it often meant that she had a long journey and was in the taxi for quite a while. Now they don't provide transport and she can't get to things as I don't drive and her dad works full time. There isn't anything around here... Maybe lack of resources but it's a shame as young carers in this area are missing out." (Spelthorne resident) **192969, June 2023**

"I care for my mum who has a physical disability... I'm 16 now and I haven't heard anything from Action for Carers. So, I don't know what there is on offer. I would like more local activities as if they are not local, I have to rely on dad to drive and there is mum to look after. Regular, fun stuff would be good. Free food is also welcome." **193029, June 2023**

We worked with young carers to develop a postcard to help promote our feedback service:



During Q2 we will be continuing to engage with young carers and hidden young carers, details of where we will be attending can be found in the table below.

Where we are going July - September 2023

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

Place	Date
Surrey Youth Festival	01.07.23
Action for Carers hub, Guildford	03.07.23
Hale Community Centre	05.07.23
Dementia 1 st Carer support group, Horley	06.07.23
Living well with dementia event	10.07.23
MyTime4YoungCarers group	11.07.23
Young carers alliance forum, online	12.07.23
Nepalese elders group	13.07.23
SCAMPPS	14.07.23
Action for Carers hub, Cranleigh	17.07.23
Additional needs service showcase, Camberley	19.07.23
Dementia 1 st carer support group, Banstead	25.07.23
Young Carer Family Fun Day, Cobham	01.08.23
Action for Carers hub, Shepperton	02.08.23
Dementia group, Reigate	03.08.23
Action for Carers hub, Farnham	04.08.23
Action for Carers hub, Addlestone	09.08.23
Action for Carers hub, Hersham	10.08.23
Young Carer Family Fun Day, Horsley	15.08.23
Seniors club, Horley	16.08.23
Wellbeing support for 16-24 year olds, Mary Francis Trust	24.08.23
Action for Carers hub, Banstead	22.08.23
Action for Carers hub, Epsom	05.09.23
Action for Carers hub, Horley	06.09.23
Parkinson carers support group, Milford	11.09.23
Action for Carers hub, Caterham	14.09.23
Woking Strokeability	21.09.23
SEN parent carer group, Epsom Downs	29.09.23

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)
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