

Giving Young Carers a Voice

Quarterly Insight Report

What we're hearing

July - September 24



Giving Young Carers a Voice

Quarterly Insight Report – July to September 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 is a Surrey based independent community interest company which exists to empower people to have their voices heard. We are an enterprise driven by social value, that invests in the local community. We help organisations provide equity of access, and the best services possible, through the inclusive involvement of local people. Our vision is to create a society where everyone's voice is heard so we all receive the support we need for our wellbeing.

Initially set up as an independent, trusted partner to communities and local health and care services to deliver the Healthwatch Surrey service - ensuring the voices of all users of NHS and social care services are heard, we have built on our expertise and experience. Luminus has grown to also shine a light on the experiences of carers, young carers, those who are affected by substance use, and people most at risk of health and care inequalities. We achieve this through bespoke projects, co-design, contracts, mentoring, research, and training.

About Giving Carers a Voice

Giving Carers a Voice listen to the experiences of carers (of all ages) to ensure their views are heard in the design and delivery of the services they use.

If people look after anyone who couldn't manage without their help, they are a carer.

Engagement July to September 2024

This quarter we have visited and attended...

- Surrey Youth Focus, Coffee and Chat young carers
- Glebelands School, Cranleigh
- The Beacon Centre, Guildford
- William Cobbett School, Farnham
- Surrey Young Carers, Hampton Court
- YMCA, parent carer group, Merstham
- Loveworks Foodbank, Merstham
- Loveworks Foodbank, Reigate
- Surrey Young Carers, Painshill Park
- Surrey Young Carers, Bisley Yurt
- Surrey Young Carers, Mambo Jambo pottery
- Action for Carers, introduction to the mental health team
- User Voice and Engagement Co-ordination Group
- White Lodge Family Day
- Surrey Young Carers, Reigate Grammar School
- North Tandridge Health and Wellbeing Neighbourhood meeting
- Woking Young Carers

- Horley Health and Wellbeing Neighbourhood meeting
- Northwest Market Place, Surrey Heath Family Centre
- One-Stop Hub, Hale Family Centre
- Surrey Young Carers, Gym and Chill
- Workshop with MyTime4YoungCarers, Dorking (grant from Chair of Surrey County Council Unheard Voices micro project)
- Caring for Carers, Autism and Mental Health, Woking.

Main themes we have heard from July to September 2024

We spoke with 98 young carers. The word cloud below highlights the main themes we have been hearing about this quarter. The most prominent words are worry, talk to me, misunderstood, responsibilities, too much, expectations, anger, help, listening, regular clubs, detention, late homework, and friends.



Where we have shared our Insight

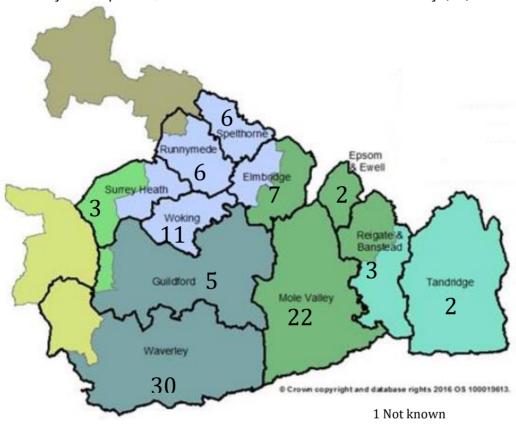
During this quarter, we have shared carer insight (key themes and young carer experiences) in the following meetings as part of our 'what we've heard' regular insight sharing meetings.

- Chair of Surrey County Council
- User Voice and Co-ordination Group
- Neighbourhood network meetings.

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 young carers

The map of Surrey below shows the number of young carers we have heard from in each area of Surrey. This quarter, we have heard the most from Waverley (30) and Mole Valley (22).



Relationships are affected by being a young carer

Young carers say their caring role affects relationships with their family and friends.

"My mum has psychotic behaviour and paranoia, which affects me and friends can't come to my house." (Carer aged 14)

218265, July 2024

"I care for my brother, who is autistic, and I prefer to spend time outside of home because he can be angry and shouts a lot." (Carer aged 11)

218058, July 2024

"I look after my mum. I cannot do things and don't like leaving her. I worry about her when I'm not at home to look after her. We don't get to do things as a family anymore, and I get lonely." (Carer aged 12)

218276, July 2024

"I care for my sister which I don't like doing. She is aggressive and annoying and I must be nice to her. I want her to leave me alone, but she won't. I want to go out shopping with my mum and have fun things to do but we can't." (Carer aged 12) **218281, July 2024**

"I look after my brother. He shouts a lot and we don't get to do things as a family because he does it when we're out too. I wish this didn't happen and we could go places." (Carer aged 12)

218289, July 2024

"I help with my brother. I have to sacrifice my free time to help my mum, but they are my family, so I have to do it because mum and dad are busy. I want to spend more time with them without my brother." (Carer aged 13)

218292, July 2024

"I care for my brother. I'd like to go places without being embarrassed by him and having to leave early because of his behaviour. We can't really have family days out or do fun things as a family other than at home." (Carer aged 12)

218295, July 2024

"My brother is annoying. He argues and fights all the time. I get blamed because mum says he doesn't know any different and I should. I'll go out and play with my friends and then he spoils it by kicking and hitting them. We then have to go in because the other mums get cross with us." (Carer aged 9)

221569, September 2024

"I'm a young carer for my brother and it can be stressful when he has meltdowns or when he makes me late for school. I get embarrassed, and sometimes, he hurts me. I would like to have more time for myself to do things I want to do, like football, without him spoiling it for me. It's really hard being a young carer and having to deal with so much." (Carer aged 12)

222833 August 2024

"My brother has ADHD. Being a young carer means I miss out on a lot, like time as a family because my brother ruins the day when we go out." (Carer aged 10) **222830, September 2024**

"I care for my younger brother and dad. I don't have time to meet my friends and I get very tired. Sometimes, I can't concentrate at school because I haven't slept. It's alright being a young carer; they're my family, but it's hard and won't change." (Carer aged 15)

222837, September 2024

Struggling at school

Young carers say they often are given detention for being late and don't get help with homework.

"My sister has autism and my dad has PTSD and depression. I read and play sports to help me manage my mental health but mostly you just have to get on with it. I know I can talk to my mum, teachers and my friends. Sometimes I'm late for school and the teachers don't really understand what I've dealt with that morning and it isn't my fault." (Carer aged 13)

218268, July 2024

"I struggle when my brother is naughty and nasty to me. Sometimes I'm late for school because of him and I shouldn't have detention when it's not my fault. Teachers should ask if there's anything wrong and can they help, but they don't." (Carer aged 9)

222842, August 2024

"My little sister is autistic. She's only 4 and doesn't understand very much yet. Sometimes I struggle with my homework because I don't have a place to do it alone at home. I asked my teacher for help and more time to do my homework but I was told she was not interested in any more excuses, so I don't do it now. I don't have many friends because they don't understand why I'm moody. I'd like more time for my homework in school, friends and teachers who understand. My sister is sensitive to noise and can become frightened. She has a meltdown if her routine is not the same every day. I love my sister." (Carer aged 9)

"I don't mind being a young carer, we get to do some really fun stuff. I'd like more help at school with my homework. We shouldn't get detention for homework being late." (Carer aged 10)

222840, August 2024

222841, August 2024

More understanding

Young carers say they want people to understand what a young carer does and how it affects them.

"I try not to think about things too much because I'll get upset. I like to know that my brother is ok or I worry about him. If he's happy, I'm happy. I think everyone should know what a young carer is so they can help us more." (Carer aged 14) **218266, July 2024**

"My older brother has autism. I don't like him very much and avoid him. It would help if others knew what young carers have to put up with and maybe they'd be nicer to us when we get frustrated because we're tired." (Carer aged 9) **218408**, **July 2024**

"My mum had cancer and has died. There's just me and dad. I don't do anything outside school. My friends know about mum but I don't think they understand when I get upset because I miss her." (Carer aged 8)

218414, July 2024

"I get embarrassed when mum gets frustrated with my brother especially when she starts shouting and mum doesn't get it." (Carer aged 9)

218419, July 2024

"People say I should be proud of being a young carer, and I don't think they understand what it's like. I like to help my brother but it's exhausting and I shouldn't have to put up with his moods." (Carer aged 10)

222830, September 2024

"I'm a young carer for my mum and dad. Because I have to do so much at home, I can often be late for school. I can forget to do things sometimes and I don't get any time to myself. It's really hard." (Carer aged 13)

222835, August 2024

"I am a young carer for my dad. It's not easy, but I try hard to do what he needs me to do. It would be better if people asked how I am and if they can help me. I wish people were nicer and everything wasn't rushed. I've asked for help and the teacher told me they didn't have time to talk." (Carer aged 14)

222838, August 2024

"Being a young carer is a bit of a rollercoaster, but if it makes my sister happier, I don't mind. I like to be funny and make her laugh. My sister is unique, and in her own world, we cannot all be the same. Being a young carer can affect my own mental health, and sometimes I need to have some space and time away from it. I don't think young carers get enough help or support from adults or in school." (Carer aged 12)

222839, August 2024

Unheard Voices Micro Project

As part of the Chair of Surrey County Council Unheard Voices Micro Project Grant, facilitated by Surrey Youth Focus, we held a workshop on 23 September to hear the voices of young carers.

With the money, we arranged an evening workshop with Rab Ferguson (author of The Late Crew, who wrote books about young carers who meet aliens) and MyTime4YoungCarers Dorking so that we could write a story with the young carers to have their voices heard more creatively. The young carers enjoyed an evening of storytelling, story writing, pizza, and snacks.

We were all delighted that Saj Hussain, Chair of Surrey County Council, could join us for the evening and speak with the young carers who enjoyed showing him their creations and ideas.



At the end of the evening, the young carers were all given a signed copy of Rab's first book.

The young carers then described and drew their aliens and explained some details of the person they cared for. Through their aliens they told us what they would like to see in an inclusive community where young carers are recognised.

With their ideas, the story below took shape and was written.

The Tri-Headed Guardian

In a distant galaxy, there lived an extraordinary alien named Vortog. Unlike any other creature in the universe, Vortog had three heads, six arms, two legs, and four eyes. Vortog could shapeshift into any support animal and become invisible whenever people who were not young carers were around.

Vortog's mission was clear: to help young carers with their chores, studies and emotions. Vortog could erase their negative energy, understanding their needs perfectly with a mere touch. A master multitasker, Vortog was always ready to lend a hand or six without ever getting tired or bored. His unwavering dedication made the young carers feel supported and cared for.

One sunny day, Vortog arrived on Earth, drawn by young carers' bright smiles and resilient spirits. He quickly became their secret friend and guardian. Whenever a young carer felt overwhelmed, Vortog would appear, invisible to everyone else, offering his many talents.

Vortog disliked bullies and crowded places, so he protected his young friends from these. He helped them build confidence, listened to their worries, and never got bored, no matter how

often they needed to talk. His healing hugs were legendary, melting away stress, anger, and hurt with a warm embrace.

When a young carer was upset, Vortog would literally munch on their fears until they felt light and happy again. He always knew when they needed him, appearing just in time to offer comfort and support. With his calming and gentle voice, Vortog would read them stories, transporting them to magical worlds where anything was possible.

Vortog loved sunny weather and enjoyed eating pizza, pasta, and chocolate, often sharing these treats with his young friends. His love for these simple pleasures made the young carers feel a sense of shared joy, strengthening their bond with Vortog.

With Vortog by their side, young carers found joy, support, and a touch of magic in their lives. His presence reminded them they were never alone, bringing a sense of happiness that made all the difference in the world.

Vortog's three distinct heads had unique personalities and colours. They were connected to a single, tall, slender body that glowed softly, reflecting its mood.

The first head, Emotia, was pink and empathetic. Emotia could sense emotions and comfort the young carers, offering encouragement and understanding.

The second head, Logicu, was blue and focused on practical solutions. Logicu helped young carers organise their tasks, create schedules, help with homework, and find resources or tools to make their lives easier.

The third head, Inspira, was green and creative. Inspira encouraged young carers to express themselves through art, music, and storytelling, helping them find joy amidst their responsibilities.

With Vortog's six arms, no task was too much for him. He often helped the young carers with chores such as washing up, putting the laundry away, making the beds, and keeping the house clean and tidy. Most of all, Vortog enjoyed playing games with the young carers and their siblings. He would shapeshift into another young person so that no one but the young carer would know who he was, making it even more fun for the young carers.

His many eyes meant he could spot things that would help the young carers and their families and could see what they needed.

Here are some of the drawings of the aliens the young carers produced.



Thank you

A big thank you to everyone we have met and who has taken the time to share their experiences of being a young carer with us. Below is a list of where we are visiting from October to December 2024. If you have a group you would like us to come along to and visit then please email us at info@luminus-cic.uk. We are very keen to hear from as many carers (of all ages) as possible from all over Surrey so we'd love to hear from you!

Where we are going October to December 2024

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

| Place | Date |
|---|------------|
| Weald School, Dorking | 01/10/2024 |
| Boxgrove Primary School, Guildford | 02/10/2024 |
| Our Shoes Young Carer training, Guildford | 10/10/2024 |
| Additional Needs Showcase, Cranleigh | 22/10/2024 |
| Shah Jahan Mosque, Woking | 28/10/2024 |
| Surrey Young Carers family day | 30/10/2024 |
| North Surrey Voluntary Support Networking event, Egham | 31/10/2024 |
| Richmond Fellowship Carers | 06/11/2024 |
| Action for Carers, Merstham Hub | 07/11/2024 |
| Home School Link Workers network meeting, Horley | 12/11/2024 |
| Get Connected Autumn Term event, Reigate | 12/11/2024 |
| User Voice and Engagement Co-ordination Group | 13/11/2024 |
| Carers Rights Fair, Farnham | 21/11/2024 |
| Leatherhead Youth Project | 26/11/2024 |
| Horley Neighbourhood Meeting | 03/12/2024 |
| Action for Carers, Epsom hub | 04/12/2024 |
| North Tandridge Neighbourhood and Wellbeing meeting | 10/12/2024 |
| Surrey and Borders Partnership, Caring for someone with thoughts of suicide | 12/12/2024 |

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

Contact us

Contact us through any of the channels below.

We'd love to hear from you:

Web: luminus-cic.uk

C Telephone: 01483 301448

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