

Giving Young Carers a Voice

Quarterly Insight Report

What we're hearing

January to March 2026



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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. We achieve this through bespoke projects, co-design, contracts, mentoring, research, and training. Our vision is to create a society where everyone's voice is heard so we all receive the support we need for our wellbeing.

About Giving Carers a Voice

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

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. These experiences form the basis of this report.

The lived experiences quoted in this report are in people's own words and therefore reflect their personal perspective and perception, not the views or opinions of Luminus as an organisation.

When we are engaging with people and the individual has incorrect information about a provider or service, we endeavour to provide them with up to date, correct information. We also offer signposting for other local support services and organisations where relevant and appropriate.

We check in with the group leader if someone has said something we are unsure of or concerned about to ensure that the person is being supported and not alone. We also ensure that support services are aware of appropriate treatment pathways and local support available. 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.

We have signposted young carers to the following places:

- Surrey Young Carers
- College Wellbeing Leads
- Mindworks
- Eikon
- Young Minds
- Home School Link Workers
- MyTime For Young Carers
- Surrey Youth Voice.

Engagement January – March 2026

This quarter we have visited the following places to speak to young carers and hidden carers to hear their experiences and to signpost to the relevant services where needed/appropriate:

- Merrist Wood College
- Surrey Young Carers - Be Me Project session
- Godalming College Wellbeing Fair
- Surrey Young Carers – parent and young carer wellbeing session
- Furzefield School
- The Hive Youth Café
- Howard of Effingham Wellbeing Festival
- Warlingham School
- Farnborough College Health and Wellbeing Fair.

Some photos from engagements

1. Surrey Young Carers Be Me Project session
2. Surrey Young Carers Be Me Project session
3. Howard of Effingham's Wellbeing Fair
4. The Hive Youth Café
5. Surrey Young Carers, Young Carers in Bunnyland session
6. Surrey Young Carers and Parent Carer wellbeing session.



This quarter, we have attended the following meetings:

- Redhill and Reigate Health and Wellbeing Partnership meeting
- Professional Briefing Webinar about Adult Social Care changes at Surrey County Council
- Carers Trust - What devolution will mean to unpaid carers
- Surrey Wellbeing Partnership showcase
- Carers Trust - Local Government Reorganisation, devolution and local carer support
- Surrey Schools Young Carer Network Meeting
- Children and Young People Participation Group.

Key themes we have heard from young carers from January to March 2026

- Young carers of siblings with neurodiversity
- Young carers with multiple caring roles
- Young carers and parent carers need time together
- Stronger together
- Each day can be different
- The need for more understanding from others.

Young carers of siblings with neurodiversity

Young carers of siblings with neurodiversity report experiencing stress, anxiety, and worry. Some will take on the role of an adult and provide emotional regulation support during meltdowns or periods of distress, while others avoid their siblings to prevent conflict and to manage their own wellbeing. These young carers often find it difficult to identify or express their own needs and may feel overlooked compared to their siblings with additional needs.

"I care for one of my sisters. She has ADHD and autism. She hurts me sometimes, and the other sister hibernates in her room. One of my older sisters doesn't want to go to school every day. She refuses to go. My sisters can be annoying, and we fight, but I care about my sisters, and I love them. I enjoy the caring club at school."

Carer, 7, 300283, March 2026

"I have two autistic and ADHD sisters. It's really hard for me."

Carer, 9, 300286, March 2026

"Dad left, and mum is working full time, so I guess I'm maybe a young carer for my siblings. I don't know. I mean, I don't do it full time as I'm at college. I cook for them, I clean, I help them get washed and stuff. My sister has ADHD, autism and lots of other things. I have to remind her to take her medication, or we all suffer if she doesn't. I haven't told college about me being a young carer. I'm not registered with Surrey Young Carers (SYC) either. [How are you coping/looking after yourself?] It's hard, but I battle through it. A fair future for me would be having the opportunity to get a degree, but without the money and time to do it, it's impossible."

Carer, 16, 300294, March 2026

"I help look after my younger brother, who has autism. I stop him from going into the kitchen, or he will hurt himself or burn himself or something."

Carer, 12, 300304, March 2026



"I help care for my sister, who is autistic. She's 26 and lives at home. She likes and needs to have her own space, so I get out of her way most of the time."

Carer, 11, 300311, March 2026

"I'm a carer for my younger brother, who has ADHD. Mum works nights, and he struggles to sleep, so I stay up with him, read to him, and help him fall asleep. I'm tired, but I battle on. No, school don't know I'm a young carer."

Carer, 11, 300312, March 2026

"I'm a carer for my younger brother with autism. If he gets deregulated or overwhelmed, I help him to ground himself. If we're out at a family event and he gets overwhelmed, I take him to another room, talk to him and ground him. If something has upset him, I try to take away whatever has upset him to help calm him down."

Carer, 15, 300317, March 2026

"I'm a carer for my younger brother, who has autism and ADHD. I am registered at school as a young carer. Sometimes he has meltdowns, and it's very difficult."

Carer, 16, 300340, March 2026

Young carers with multiple caring roles

Young carers looking after multiple family members often face cumulative and intensified challenges. Managing several caring roles places them under ongoing emotional and practical strain, raising the risk of poor mental health, chronic stress, and exhaustion. They may also experience educational disruption, reduced concentration, and physical health issues such as fatigue and sleep disturbances.

"I look after my mum, who is dyslexic, and my sister, who has ADHD, Tourette's, and autism. I help mum with reading, and I help to calm down my sister when she starts ticking. I like singing, dancing and drawing. I like this group in school as they are all really kind and they help me with stuff."

Carer, 11, 300288, March 2026

"I care for my nana and younger sister. My nan is very old and can't remember stuff. My sister has autism, ADHD, PDA, a sleep disorder and a short temper. She's very sensory with food and clothing, so I have to help her calm down. Sometimes she gets mad at a game, so I take things out of her hand and give her a cuddle."

Carer, 10, 300292, March 2026

"I look after my mum, who has a mental health issue, and my nan, who lives with us and is in a wheelchair. My mum can become angry and emotional. My school knows, and I go to the young carer group there. Eikon also visits our school, and I often talk to them about what worries or upsets me. It would help if there were



other places I could go where people understood me and what I have to do at home. I've been bullied because of my mum."

Carer, 11, 300295, March 2026

"I help my nan and grandad, who live with us. They're forgetful, sometimes it's frustrating, I don't argue with them because they don't know they've forgotten, and sometimes it's amusing. Mum is with them all the time, and it affects her more. I don't go to SYC anymore; I went to a couple of things, but there wasn't anyone I knew there, and I'd prefer to be with people I know."

Carer, 13, 300297, March 2026

"I don't have a choice but to help my siblings, who all have ADHD. I'm at a different school now, so I do get a break from them. I haven't been to the young carer group at school or Surrey Young Carers, and I will think about it."

Carer, 12, 300298, March 2026

"I'm a carer for my dad and my younger and older brothers. My brothers have autism, but on a more severe scale. My dad has numerous physical and mental issues. It is tricky."

Carer, 17, 300341, March 2026

"I saw you here last year. I'm still looking after mum and dad at home. Things have got worse, and I'm having to do a lot more now. I am an only child and at home with mum and dad. My parents are older. I have to help them out so that things can run smoothly at home. I sort of manage everything to make sure things happen. I am not coping well. Mum is more unwell now too, and now that means I'm going to have to take on more medical stuff as she will need help every day. I am struggling. I feel alone and overwhelmed. I'm very stressed."

Carer, 17, 300347, February 2026

Young carers and parent carers need time together

When young carers spend time with their parent away from caring duties, it helps keep their relationship strong and supports the young person's emotional wellbeing. It reminds them they are children first, not just helpers, and brings them closer to their parents.

"My daughter is 2 and has Down's syndrome; she hasn't been sleeping unless she's in my bed, so I'm not sleeping very well either. My wife left me, and my two children and our son will not speak to her. He refuses to go with her on the day she has access and clings to me. I worry about him because he's so quiet and timid. He told me he's seen you several times and has spoken to you about his sister, so you know how much he loves and will protect her. It's been good to come along with him and spend time with him, other parents and the other young carers and those who support them. There are no groups for dads, but it's been



good to come here today and meet some mums who have been so welcoming and have given me loads of information and advice on getting my daughter to sleep at night. I don't get any breaks from the children, not that I want any, and my family are supportive; they will always help, and they look after the children if I need to go somewhere. My sister is looking after my daughter today, and they have a great time doing girlie things."

Parent Carer, 300273, February 2026

"Both my children are neurodiverse. My son goes to a Special Education Needs (SEN) school, and we're trying to get my daughter in there too. I had to give up work because it was all too much for me. I help my husband, who is self-employed, with his accounts. I was diagnosed with ADHD, too, and although I come across as confident and chatty, I dreaded coming here today and meeting strangers. I'd like to meet other mums who have neurodiverse children, and one of the mums (here today) and I have swapped numbers to keep in touch. I think it would help if there were more groups that parents could come to, not just mums, but dads too."

Parent Carer (attended with daughter), 300274, February 2026

"I have enjoyed making a new friend and spending time with my mum. Her mum and my mum have swapped numbers and so have we."

Carer, 9, 300275, February 2026

"It was a great day for us. My daughter made a great friend and will now more than likely attend outings if her friend is attending, they have Face Timed every day since. I've also been in touch with the other mum, and we'll be meeting up."

Feedback via email, February 2026

"I've enjoyed coming here today with my mum; we've had great fun."

Carer, 9, 300276, February 2026

"My mum has ME and osteoarthritis. She's in constant pain. What would help me most is somewhere I could go as a young carer where my mum could come along too. She doesn't get out because she looks after my gran. We don't have much time together. My friends know how hard it is for me and support me so much. They always check in on me and ask how I'm doing. We talk a lot, too. Caring for my mum has given me skills that you don't see on paper. It can't be fully explained or understood unless you've gone through it yourself."

Carer, 15, 300296, March 2026

Stronger together

Young carers benefit from peer support and shared understanding with others who have similar caring responsibilities.



"I'm a carer for my mum, who has chronic fatigue and long covid, and also my brother, who has severe special needs. He can't go to school because there is nowhere that can meet his needs. So, he's at home with mum. It's quite hard. I go to MyTime every other Monday. It's good, I like it. My friend, who also looks after his mum, and I help each other."

Carer, 14, 300308, March 2026

"My mum has ME. But she doesn't have it as bad as my friend's mum does. Luckily, we're good friends, and we help each other out. It can be tough."

Carer, 14, 300309, March 2026

Each day can be different

No two days are the same, as a person's condition can change, placing emotional and practical demands on the young carer.

"I'm a carer for my brother, who has a brain tumour. He was diagnosed with the tumour 5 years ago. Things change every day, so what I need to do to help him changes every day. I'm the youngest in the family, and the rest of my siblings have moved out, so I bear the brunt of all the caring as it's just me at home with mum, dad and my brother now. I am registered with Surrey Young Carers, and the school does know I'm a young carer."

Carer 16, 300315, March 2026

The need for more understanding from others

Young carers often face complex and challenging circumstances, yet their needs are frequently misunderstood or overlooked. Greater awareness and understanding are essential to ensure they receive the right support.

"I wish teachers understood that young carers are always tired. We struggle to balance things going on at home and college. We also struggle with friendships because life can be unpredictable for us."

Carer, 16, 300346, February 2026

"It's been good to talk. I worry a lot [about my mum]. I get bullied because of my [family situation]. I've enjoyed doing the mood board and having my hands massaged. I get very angry and lash out. My teachers don't understand; they just ban me from their lessons, which makes me angrier. The school knows what has been happening, so why do they punish me for the way I feel?"

Carer, 11, 300272, January 2026

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!

Our Giving Carers a Voice report is for carers over 18 and can be found on our website page [Giving Carers a Voice: Reports - LUMINUS](#).



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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