Luminus
Home of Healthwatch Surrey

Giving Young Carers a Voice

Quarterly Insight Report

What we're hearing

July to September 2026













Shining a light on what matters to people.

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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 listens 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 says something we are unsure about or concerned about, to ensure the person is 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.

This report focuses on young carers. Our Giving Carers a Voice reports can be found on our website page Giving Carers a Voice: Reports - LUMINUS.

Please note that the terminology used in this report reflects the language of the participants and may not align with the terminology typically used by Luminus.

Engagement July – September 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:

- St Peters School

- North East Surrey College of Technology (NESCOT)
- Hermitage School
- Surrey Young Carers Gatwick Science, Technology, Engineering and Maths (STEM) Centre
- Guildford Shakespeare Company Young Carers
- Surrey Young Carers, Hampton Court
- Woking College Community Inclusion event
- Guildford College Freshers Fair
- Merrist Wood Freshers Fair
- Godalming College Freshers Fair
- Special Educational Needs Stay and Play.

This quarter, we have attended the following meetings:

- Carers Trust - No Wrong Doors 2 years on
- Woking Citizens Advice Bureau Canalside Connect
- Carers Trust, Caring and Finances 2035
- Supporting Young Carers Community of Practice
- Meeting with Carers Practitioners
- South West Family Safeguarding Team meeting.

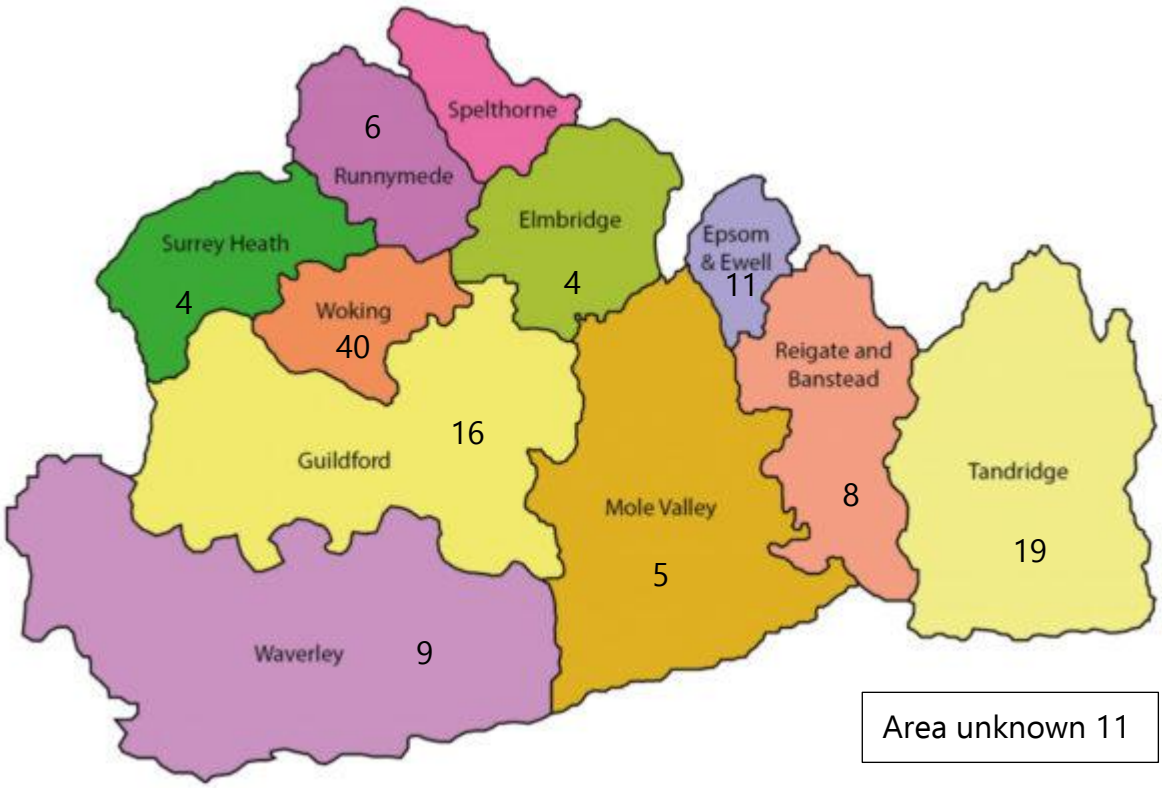
Main themes we have heard from July – September 2026

The word cloud below highlights the main themes we've heard this quarter. The most prominent words are understanding, help, awareness, frequent, support, help and advice.



Where we have heard from young carers

The map of Surrey below shows how many young carers we have heard from in each area. This quarter, we have heard the most from Woking (40) and Tandridge (19).



Key themes we have heard from young carers from July to September 2026

- Emotional impact of caring
- Practical caring responsibilities
- Educational challenges
- Young carers who were not previously identified
- Caring for family members with mental ill health
- Supporting neurodiverse siblings and family members
- Positive adaptation and resilience.

Introduction

Every young carer's story is different, but the themes are strikingly similar. Each story reflects a young person balancing their own aspirations with concern for someone they care for. These are the words of young carers, and their experiences remind us that they are not defined by the challenges they face, but by the resilience, compassion, and adaptability they demonstrate every day. They also remind us that everyone has a responsibility to recognise, understand, and support them.

The strongest message is that young carers don't necessarily want special treatment; they want recognition, understanding, and consistent support. Many are proud of the role they play in their families and have developed remarkable resilience, but they also describe lives that are often unpredictable, emotionally demanding, and very different from their peers'. Their stories highlight the importance of early identification, practical support, emotional wellbeing provision, and strengthening transitions between school, college, and adult services. Young carers don't need to be defined by their caring role, but that role needs to be recognised and understood so that appropriate help and support can be put in place.

Emotional impact of caring

The emotional toll can be watching a loved one's health deteriorate or managing uncertainty about the future. Young carers say that they have anxiety and worry about a parent or sibling's condition, sadness at seeing a once independent parent become reliant on others, fear of future deterioration or loss, feeling responsible for family members' wellbeing and experiencing stress, low mood, or poor mental health.

> "I help my mum look after my dad, who had a stroke. He can't walk without a stick and has to rest a lot. He gets depressed and angry, which causes problems at home. I prefer to be at my friend's house when he feels like that. I wish he would explain how he feels and I could help him more. He's never talked to me about it, if he did, he may feel much better, and we could talk about what he needs and who can help. I've spoken to my tutor at school and attend the support group."
> **300557, August 2026**

> "My mum has full time carers. She has motor neurone disease and is in a wheelchair. I worry about her all the time and call home several times a day. School was very good; the carers would call the office with an update, and school passed it on to me. When she didn't have carers, we had to do everything for her, which was harder then, especially as dad had to work and we were at school. It's a bit easier now we have help, but she is deteriorating, and that frightens me."
> **300702, September 2026**

> "It has an effect on my mental health seeing my dad deteriorate, and when he's been so independent and able before."
> **300712, September 2026**

> "I can't help worrying about my sister who has multiple sclerosis and the future. I just hope she gets better."
> **300711, September 2026**

> "I help my dad with emotional support and doing things around the house. My mental health has suffered from the emotional side of caring for him."
> **300710, September 2026**

"I get tired a lot. I worry about my mum. My friends do help me when I'm stressed or upset. What people need to understand is that things can be bad all the time for young carers, not just when they're asking if everything is ok."
300709, September 2026

"My dad had sepsis, which has left him blind. He also had a stroke and is diabetic. I help my mum, brother, and sister with my dad as much as I can. Some days it's harder than others; it depends on how he is and how he's feeling. He gets depressed and does very little for himself. Other days, he's upbeat and can do a lot."
300707, September 2026

Practical caring responsibilities

Many young carers take on tasks beyond what is typically expected for their age and regularly take on adult responsibilities while managing education and personal development. These include cooking meals, doing household chores, looking after siblings, reminding about medication, helping with dressing, providing food and drinks, and supporting family members with daily routines.

"Mum spends a lot of time in bed or watching films on her iPad. I help with cooking and all the chores because she finds everything difficult to manage."
300559, August 2026

"I remind her to take her meds and help her with getting dressed, lifting stuff and other bits. Mum had a car accident and now has life changing injuries. It's difficult for her. She's generally ok in the mornings, so I'm not late for college."
300646, September 2026

"I'm a carer for mum and my 3 younger sisters who are all neurodiverse. I have to help mum get dressed and stuff. I cook dinner and look after my sisters. Dad is the only one who can help out, but he is working at the moment, so he can't."
300651, September 2026

"My mum can't walk and needs a lot of help. I get as much done as I can before coming to college. When I was at school, it was harder. I have to get her dressed, get her something to eat and drink before college because she never knows what time the carers are coming in. When I get home, I do dinner and hang out the washing the carers put in the machine. In the evening, I help her get ready for bed for when the carers come because she's more comfortable in her pyjamas and can't always wait for them."
300698, September 2026

"I help with household tasks when needed and help my dad with dressing, shaving his head when he needs it."
300712, September 2026

"I help my mum with her mental wellbeing, do the cooking, chores and looking after my siblings."
300709, September 2026

Educational challenges

As the new academic year begins, young carers entering college or moving up a year face more pressure to achieve. College and school play a major role, as both present challenges and offer strong support.

"My older brother has extreme autism and ADHD. He doesn't work and is at home all day. Both my parents work, and I find his behaviour difficult when they're not there. It's hard on the family; we all struggle. I cannot concentrate on my coursework. I'll speak to the wellbeing team about the group here and possible extensions for coursework."
300691, September 2026

"It's hard to get my homework done and concentrate on anything. When she's doing her 'thing' I go off and game or go on TikTok. She tried going to college, but it didn't suit her, so she's at home now. I try to stay out of it and just put up with it."
300694, September 2026

"I would like to go to university when I've finished college. It would have to be close to home so I can look after my mum. School seems to be the only place where anyone understood what I was doing and helped me. Our lives become more challenging with studies and life, and we don't get out because of what we have to do at home."
300703, September 2026

"I've met the college wellbeing team already, and I sense they will be very helpful and seem to understand young carers. I'm hoping they will offer groups to chat and receive help/advice. I hope they have designated quiet workspaces for coursework; this is something that's difficult to find when you have things going on at home. I've already been told the college offers homework extensions, which will be amazing, as meeting deadlines can be quite stressful."
300709, September 2026

Young carers who were not previously identified

Many young carers don't recognise they're young carers until they speak about their experiences. They see caring roles as "normal family life" and therefore remain hidden from services.

> "I didn't realise I was a young carer. I mean my brother is full on, but I love him. He's my brother. I'm going to college soon, and I didn't check the box on the form about being a young carer as I didn't realise I was one. After speaking to you, I'll definitely register as a young carer with them once I get there. It would be really useful for them to know and understand."
> **300551, August 2026**

> "My sister has special needs. I don't do anything for her, so I wouldn't say I was her carer. I'll speak to the wellbeing team and join the group."
> **300693, September 2026**

> "I don't think I'm a young carer really, but maybe I am. I just do stuff for mum."
> **300646, September 2026**

Caring for family members with mental ill health

Mental health emerged as a common factor affecting young carers' lives. They mentioned unpredictability, emotional strain, increased household responsibilities and feeling responsible for a parent's wellbeing.

> "My mum has a lot going on with her health, physically and mentally, too much to mention. What would help most is for people to understand more about young carers and how we support our families when they're unwell. Young carers need more recognition, and we need more support with our families. "
> **300703, September 2026**

> "My mum has mental health issues. It's difficult because you don't know how she'll react to anything. She also drinks a lot, which doesn't help. I wouldn't say I'm her carer; I don't do anything for her. She just does what she wants, regardless of how it affects me."
> **300701, September 2026**

> "Some days she's fine and can be up cleaning the whole house. Other days I have to be around to look after my younger sister. She has vascular Ehlers-Danlos syndrome and mental health problems and aneurysms in her arms, so she can't lift much now. She's not working at the moment as she is not well."
> **300649, September 2026**

"I help to look after my mum; she has mental health issues and finds things hard to cope with. She doesn't work anymore and has become more isolated and refuses help."
300559, August 2026

Supporting neurodiverse siblings and family members

Many young carers are supporting siblings or relatives with autism, ADHD, or additional needs. Young carers manage challenging behaviour and family stress; they find it hard to concentrate at home and have limited personal space. They feel that others don't understand.

"He's calm here today, but home life can be crazy and is full on with him."
300551, August 2026

"I care for my older brother who has ADHD and autism. I have to remind him to take care of himself, like his hygiene and stuff. I have two younger brothers with autism too."
300648, September 2026

"My older sister is neurodiverse. I've found it hard to cope and have received counselling, which was only for a short time, so it didn't have much of an impact on my mental health. It's hard to get my homework done and concentrate on anything. I block out by gaming in my room. Counselling would help if it was ongoing support with someone who understands my situation and what being a young carer to someone like my sister means."
300694, September 2026

"My brother has ADHD and autism. He's very loud, and my friends are scared of him. He has outbursts, and you never know what's coming. Doing anything with him around is hard; you just can't think with all his noise."
300700, September 2026

Positive adaptation and resilience

Young carers frequently described themselves as adaptable, responsible, independent, compassionate and resourceful.

"I help to care for my mum; she has anxiety and depression and drinks a lot. Things can be tough at home, but my friends and school are great. I get a lot of support at school and the youth club that I go to. I come here every year in the six weeks holiday and have made some amazing friends who I also see at school and

the youth club. I'm quite independent and don't let things worry me; I just get on with things, and if mum needs me, I'm there for her. It was tough for dad, who left us when I was younger. I see him a lot, and he helps me with things. I'll hopefully go to college and get more independence when I start a part-time job."
300558, August 2026

"I help to look after both my mums and my brother. One mum has cancer; the other has neuropathy and multiple sclerosis. My brother is neurodiverse, with ADHD and autism. I've been a young carer all my life, so I don't know anything different. I just get on with it and take things as they come. Sometimes I find it hard, but it's what it is; I can't make them all well again and take away their illnesses."
300699, September 2026

"I had to go into foster care when I was 6 because my mum was a drug addict and an alcoholic. She was abusive, but I don't remember very much, although I'm told I was caring for her. I've been in 5 foster homes; this one for 7 years. I do see my mum, and we have a sort of good relationship. I just don't take her nonsense or put up with her behaviour. You learn to stand up for yourself. When I was younger, they were supervised visits; I can go on my own now, which I prefer. I have to leave foster care next year, and I'll move back home to help her more. I won't become like my mum, and I will help her."
300704, September 2026

"I've become more able to adapt to different things from being a young carer. I've certainly become a better cook and more willing to help others. People should know it's a constant struggle for young carers of all ages; there are ups and downs, and it's not all terrible. Our lives are unpredictable, and things can change in a moment. We are more adaptable than most people of our age."
300712, September 2026

One thing that stands out from this quarter's engagements is that young carers rarely focus on the practical tasks they might undertake. Professionals often ask them, "What do you do?" but the strongest themes are actually:

- Worry
- Responsibility
- Unpredictability
- Feeling misunderstood
- Balancing education with caring
- Wanting someone to notice and check in on them
- The future.

We have also heard of the positive outcomes young carers described. These strengths are often overlooked because the focus is on challenges and unmet needs but it should be recognised that many young carers are proud of them.

- Adaptability
- Empathy
- Independence
- Maturity
- Problem-solving skills
- Loyalty to family.

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

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Email: info@luminus-cic.uk

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