

Giving Young Carers a Voice

What we've learned from young carers

January 2024



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Insight Report – January 2024

What we're hearing

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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. Luminus continue to deliver the [Healthwatch Surrey](#) service and we 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](#).

Introduction

Young carers are remarkable individuals who shoulder significant responsibilities at a tender age. They make valuable contributions to society by providing care and support to family members who have chronic illnesses, disabilities, mental health issues, or substance abuse problems.

Young carers may experience stress, anxiety, and feelings of isolation due to their caring roles, often sacrificing their childhood and social opportunities. Caregiving responsibilities can affect a young carer's education, leading to absenteeism, difficulty concentrating, and lower academic achievement.

The demanding nature of caregiving can limit a young carer's participation in social activities, leading to feelings of loneliness and disconnection from peers. The strain of caregiving can negatively impact a young carer's mental and physical wellbeing, increasing the risk of depression and other health issues.

There are many estimates of how many young carers there are in England. The 2021 ONS census reported around 120,000 young carers under 18, while the school census 2023 suggested that there were 39,000 young carers in the country. Surrey is estimated to have 1,946 young carers; 1.2% of the school population.

One thing is for sure: many young people across the county have caring responsibilities, and all should be recognised and supported with their unique needs to maintain healthy mental wellbeing.



Claire Kendall, a BBC News analyst, suggested in November 2021 that nearly 180,000 children in England who care for a relative may be missing out on support because they are not known to their council.

[Young carers: Thousands of children left unsupported - BBC News](#)

Challenging assumptions about young carers – who they are and the care they give

When we think of young carers the picture that tends to spring to mind is that of an underprivileged child carrying out practical household tasks beyond the norm for their years.

Listening to our local young carers we heard that young carers come from a wide range of households and circumstances:

“My mummy has a poorly brain and sometimes she can get angry and upset. She has to go into hospital when that happens, and my granny looks after me then... Walking and cuddling my dog make me happy. I like riding my horse.”

204787, October 2023

“I care for my sister. She can't do a lot but I like to make her laugh. I like playing football with my dad. I like Christmas, Easter and Halloween. I like going horse riding, fishing, riding and music.”

204793, October 2023

“I care for Gizmo (cat), mum, dad, brother and Sparkles (cat). Riding my horse makes me happy and going on hikes with my family. Seeing my little brother when I've been on a school trip makes me happy too.”

204783, October 2023

Many young carers are undertaking practical tasks at home:

“I have to come home after school, look after my brother and sister, and cook dinner. I don't have time to go to things.”

204837, October 2023

"I do lots of things with him, like play games when mum is busy. I help to feed him and hold his hand when we're out walking. I'm going to teach him to ride his bike."

204805, October 2023

"My mum drinks a lot, and this makes it hard for me. I have to do all the cooking."

200488, April 2023

"My mum has Ehlers Danlos Syndrome (EDS), which I have too. I share the cooking and other chores with my sister (also at the youth club) but she's going to Uni next week. So, it will be just me at home."

200487, September 2023

"I help to care for my sister. I don't like doing it, so I come here to escape."

196352, July 2023

But much of the care being provided is psychological, emotional or social support:

"My mummy has a poorly brain and sometimes she can get angry and upset... I give mummy lots of cuddles and tell her I love her to make her feel better." **204787, October 2023**

"I have a little brother, and we live with my mum and dad and Tinky the cat. I do things which make my brother happy because he gets very sad, grumpy and unkind but I love and want to help him."

204764, October 2023



"My dad is dead and my mum is sad so I look after her."

204786, October 2023

"I sometimes have to speak for [my brother] when someone is asking him a question because he doesn't always understand, or the person gets impatient with him. That can make him angry. I do lots of things with him, like play games when mum is busy."

204805, October 2023

The impact of being a young carer – activities of daily living and emotional wellbeing

Being a young carer often impacts a child's ability to enjoy a normal childhood:

"I sometimes don't want to come to school because my brother has kept me awake screaming and I'm tired. My teacher is very kind, and so is [name], and they look after me."

204773, October 2023

"My brother has autism and he becomes angry, takes my things and won't let me have them back. He plays on the iPad a lot and won't let me use it. He takes the remote for the telly too."

196282, August 2023

"I help with my sister who has autism. She's intimidating because she's tall and strong. She eats a lot, so she's heavy... My mum bought me a Jellycat Avocado, and my sister pulled out all the stuffing. Mum has repaired it, but it's not the same. Things like that upset me, and then I don't want to be near her. She comes into my room and breaks all my things. I know she can't help it, but it's unfair."

196293, August 2023

"My brother is autistic and I don't know what I can tell you, except he can be violent and naughty. I sometimes can't think because I'm upset..."

204790, October 2023

"My mum can't spend time with me because my sister cannot be left alone except when she's in school. When my sister has had a meltdown in the morning, my mum rings [name] and she comes for me in class, and we go to the quiet room to talk. I feel better afterwards, and [name] is very kind. I spend a lot of time in my room and my sister comes in and breaks things which isn't very nice. I try to play

games with her to make her happy but when she gets angry, I go to my room.”

204769, October 2023

Unsurprisingly, young carers often talked about the negative impact on their emotional stability and mental health:

“I care for my mum, who has a lot of health problems, including mental health. It causes me anxiety and depression. I’m not attending school because of my anxiety; my school is very supportive.”

193814, June 2023

“We help my dad care for Mum. She's in a wheelchair... Sometimes mummy gets cross, and daddy gets upset because it's hard work looking after her. This makes us cry, and we go to our room.”

195197, September 2023

“My mum drinks a lot and this makes it hard for me... I get very angry. ”

200488, September 2023

“I help to look after my brother. He wants to fight all the time and won't let me play. I get upset and cry a lot when I'm at home.”

204760, October 2023

Young carers told us about the impact of their lives on friendships, including stigma, embarrassment and exclusion:

“I can't have my friends come to our house and have sleepovers like my other friends. It's so unfair.”

204769, October 2023

“[My daughter] did have some [friends] over a while ago when my other daughter was at a playscheme. Her friends saw the nappies that her sister uses and started to giggle, laugh, and ask why there were nappies in the house if there wasn't a baby. She had to explain that they were for her sister. I think she's just beginning to understand that our family is slightly different from others.”

204778, October 2023

“I cannot bring my friends to our house because we don't know how my sister will react. She doesn't like strangers, and if she became angry, it would embarrass and upset me.”

196293, August 2023



"Our friends know that we do things to help mummy, sometimes they laugh at us, and we don't get invited to things."

195197, September 2023

"My friends don't like to come to play because he frightens them."

204805, October 2023

Young carer support – why, and what works?

Young carers told us how important it is to have a consistent support group – whether these are helpers they are familiar with and can trust, or friends who are also young carers:

"I get very angry and it's good to have a place 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. We tease each other and can be silly. I'm glad you came back because I was grumpy last time, and I didn't mean to be rude to you. I hope you'll come back now that we know you."

200488, April 2023

"I like seeing my friends every week. I don't go to any other young carer things. I like doing my art and don't want to go anywhere else."

196352, July 2023

"[Name] helps me and takes me somewhere quiet to talk when [distress at home] happens. Maybe if you come again, I can talk to you then."

204790, October 2023

"My mum likes [support worker] too and says she's very kind. I don't go to any other groups. School is where I like to be. The teachers know me, and I have my friends here."

204760, October 2023

"We know it's here every week at the same time and it's always the same people who come; some volunteers were young carers once. They know what it's like for us and can give us advice and support. I've made some really good friends here, and we have lots of fun."

196351, July 2023

They also told us how valuable they find respite and the distraction of therapeutic activities that often can't be enjoyed at home.

"I need to come here to get away from my mum and dad. If I didn't come here, I would be alone and unable to manage at home."

196351, July 2023

"I do drawing, colouring, painting and cutting shapes because it calms me down, and I can switch off to whatever is upsetting me. People at school say I'm strange and not very good at art, but it doesn't matter, that's not why I do it, but I'd like to do it better. Animals are cute, and they help me not to be anxious."

200486, April 2023

"I like school to see my friends, sewing is something I like to do but don't get to do it very much, I like to read and draw, like we're doing with you."

204764, October 2023

Unfortunately, some young carers told us they struggled to access support activities in their area:

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

195197, July 2023

"My daughter 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 she had a long journey. Now they don't provide transport and she can't get to things."

192969, June 2023

"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."

193029, June 2023

Key messages we've heard and their implications

1. Young carers may not be where we expect them to be – we need to listen to engage with the full range of children and young people to ensure our insight is representative of all young carers.
2. Schools are invaluable for identifying young carers and supporting young carers. They deserve acknowledgement and support for their young carer programmes. Some

schools we spoke to felt support was lacking and there is concern the support may have to end if funds run out; "It would be helpful for schools to have some funding for these sessions. At the moment they are being paid for by local charities and being staffed by volunteers."

3. Young carers are giving psychological and emotional care as well as practical care. This kind of care may be harder for those around them to see and recognise. Specific young carer training is needed for health professionals so they understand the different types of caring responsibilities they have to deal with and the different ways these might impact on young carers.
4. Consistency, familiarity and trust are crucial when providing support to young carers – long term solutions need to be in place, a few weeks is not long enough. And young carers shouldn't have to tell their story repeatedly.
5. As young carers are under 18 building relationships with their families too, so they trust us, is key. Parents can be wary and if we don't build that trust they may withdraw their child from services. Diplomacy and transparency with all parties is vital, as is providing feedback to all involved.
6. Young carers need more detailed information from doctors from a younger age about which services are supporting their family, treatment/medication (e.g. what it's supposed to do, side effects etc) and what to do when things go wrong (like when family members have seizures or mental health crisis).
7. Young carers need crisis and discharge plans for the cared-for that are written in an accessible language they can understand, so they know what to do before a crisis happens. They also need quicker responses to crisis situations - they shouldn't have to cope with crises on their own.
8. Referrals to activities, support groups and days out for the cared-for decreases their isolation. Doing this helps decrease young carers' isolation and caring burden.

Engagement and Networking May - December 2023

Leatherhead Youth Project	Epsom Family Centre
Mary Francis Trust (16–24-years) event	William Cobbett School
Surrey Youth Voice summer party	Woking young carers
Royal Surrey Hospital open day	Action for Carers hubs
Home-Start Surrey, Guildford family centre	School nurses
Burpham Primary School	North West Surrey supporting carers network
SCAMPSS (Striving for Children’s Additional Medical, Physical and Personal Support)	Mindworks Surrey
Parent carer groups	User Voice and engagement co-ordination group
Preston Partnership Meeting	South West Surrey carers network
Broadwater youth club	YMCA
The Weald School	Family Action
Weydon Primary School	Caring Together
Surrey Young Carers croc encounter	Centre 33
Black History event	Sheerwater Community Centre
Guildford Grove School	Reigate and Banstead Community Centre
The Hive Youth Club	Young Carers National Voice
Surrey Young Carers - a day of cricket	Community Link Officers
William Cobbett School	Carers Practice Advisers meeting
Children and young people's marketplace	Carers Partnership Board meeting
Young Adult Carers pizza evening	Woking Mosque
Dorking Schools Link Workers meeting	Carers Rights Fair, Woking
Woking young carers club	Gypsy, Roma and Traveller Forum
Surrey Young Carers Juniors circus skills	Substance Use in Young People – Surrey County Council
Surrey Safeguarding Children Conference	Young Carers Alliance
Surrey Youth Focus	Learners’ Single Point of Access (L-SPA)

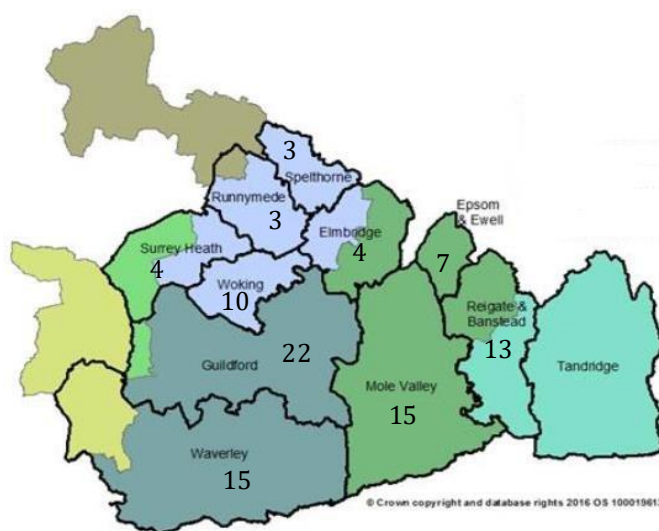
Main themes we have heard from May - December 2023

The word cloud below highlights the main themes we have been hearing from young carers. The most prominent words are friendships, school, anxiety.

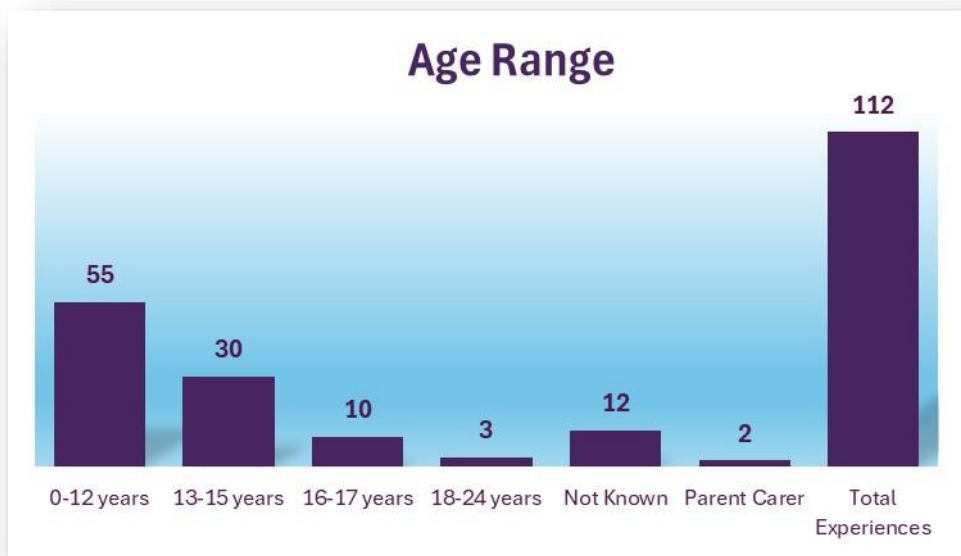


Where we have heard from young carers

We engaged with 248 young carers and took experiences from 112 young carers. The map below shows the number of carers we have heard from in each area of Surrey.



14 Not known



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. If you have a group you would like us to come along to and visit then please email us at carers@healthwatchesurrey.co.uk. We are very keen to hear from as many young 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: luminuscic.uk



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Text: 07592 787 533 (MSonly)



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