

## Giving Carers

a voice

Do you support  
someone who  
couldn't manage  
without you?

I just do a bit of  
shopping.  
But I'm not their carer.

I just go to their hospital  
and GP appointments with  
them.  
But I'm not their carer.



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# Giving Carers a Voice

Quarterly Insight Report - April 2023

# **Giving Carers a Voice**

## **Quarterly Insight Report – April 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 Healthwatch Surrey

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Healthwatch Surrey is an independent health and care organisation, empowering the residents of Surrey to have their voices heard. We seek out people's experiences of health and care services and share these with service providers and decision-makers, to support services to improve and tackle health inequalities. We believe that health and social care providers can improve services by listening to people's experiences.

We also provide advice and signposting to help the people of Surrey find the care that best suits their needs. Any urgent or concerning experiences within this report have been escalated to the appropriate teams. All appropriate information and advice and signposting to complaints processes has already been given.

## Engagement January – March 2023

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This quarter we have visited.....

- Churches for Horley foodbank
- Action for Carers hub, Guildford
- Home-Start, Farnham
- Action for Carers hub, Epsom
- Wellbeing café, The Hive Guildford
- Nepalese women's group, Camberley
- Eikon LGBTQ+ group, Guildford
- Ukrainian hub, Woking
- Independent Mental Health Network meetings
- National Autistic Society parent carer group, Ashted
- Action for Carers hub, Hersham
- Substance misuse carers group, Guildford
- St Davids GP Surgery, Stanwell
- Hale Community Centre
- Young adult carers group, Guildford College
- Dementia café, Reigate
- Parkinsons carer group, Milford
- First Community Health and Care Annual Quality Improvement day
- ATLAS youth group

- Making Time for Young Carers event
- Spelthorne parent carer group
- Action for Carer hub, Caterham
- Action for Carer hub, Haslemere
- Caring for children with additional needs group, Farnham

## Main themes we have heard from January - March 2023

The word cloud below highlights the main themes we have been hearing about this quarter.



## Where we have shared our Insight

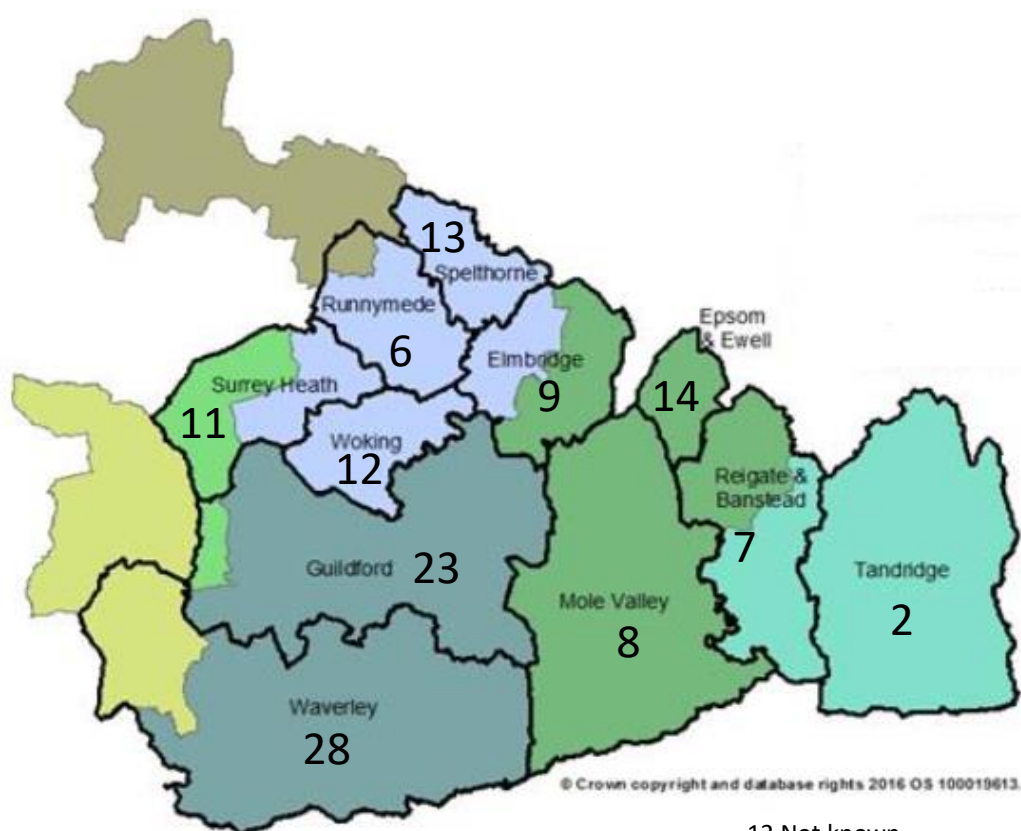
During Q4 we have shared carer insight (key themes and carer experiences) in the following meetings as part of our ‘what we’ve heard’ regular insight sharing meetings.

- What We’ve Heard Surrey Heath – 31<sup>st</sup> January
- Adult Social Care What We’ve Heard – 14<sup>th</sup> February
- Public Health What We’ve Heard – 27<sup>th</sup> February
- East Surrey Place What We’ve Heard – 28<sup>th</sup> February
- What We’ve Heard Surrey Heartlands – 20<sup>th</sup> March

- Surrey Heartlands Quality and Performance Assurance Committee – 23<sup>rd</sup> March
- CQC Inspection report – March 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 between January – March 2023. This quarter we have heard from 150 carers.



12 Not known  
5 Out of County

## Not identifying as a carer

We are continuing to speak to carers who do not realise that they are carers. We spoke to 150 carers in Q4 and over 15% (23 carers) did not identify as being a carer.

“I don’t view myself as a carer as it’s just parenting. It’s the word carer – whatever they’re going through you just do it.”

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**185278, January 2023**

"I wouldn't register as his carer as he is a very proud man and would not want that...I may consider registering as his carer but he would not like that and would be embarrassed and humiliated. [when it's suggested she is a carer]... that word isn't very positive or useful. And when the person you help is of sound mind it's quite derogatory to them in some cases."

**187307, March 2023**

"At first I didn't want to admit that I was his carer. It was like I was accepting that there is something wrong, even though we haven't got a diagnosis. I think it would have been easier and I would have accepted that I was if we had received a formal diagnosis. We were also frightened that the dynamic and our relationship would change if I said that I was his carer. He still wants to take care of me. He is a proud man and has always taken care of me."

**187483, March 2023**

## **Stress and wellbeing**

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This quarter we have heard, once again, about the impact that caring has on a person's mental health.

"Being a carer and being a wife means I don't have my own time. I can't go out when I want to go out. I don't have my own life anymore and I have no free time. I have to make all my plans according to my husband and his condition. My husband had a stroke 5 years ago and his mobility is getting worse and worse. I feel really cut off from the community. Being a carer is isolating."

**185795, January 2023**

"Being a carer doesn't get easier, it's so unfair. Life is so hard and it won't get easier and it's endless. It all feels so hopeless. It's the longevity of it, my eldest is nearly 18 and I am going to be a carer for the rest of my life for my four children. People judge me."

**186664, February 2023**

"I just feel drained... I can't read at home now as she wants me to sit with her and be with her so we watch endless mindless television. I feel trapped and helpless... I haven't had a night out of the house for over four years now. I'm struggling and I feel trapped. I am struggling a bit with my own health and have issues with my knees. I used to love running but I can't now due to my knees but I can't leave my wife for that time either."

**188692, March 2023**

"It's very frightening caring for someone at home. As carers we're wearing ourselves out. I have no freedom as you can't leave them alone. It starts when you feel you can't walk out of the house and then you can't even walk out of the room."

**188193, March 2023**

"Because of all this [caring for son with ASD and mental health issues] I've had to reduce my hours of work. I'm now on anti depressants, have sleepless nights and just feel so aged and weathered."

**188802, March 2023**

"I'm starting to feel very stressed about things. I had a chest infection recently and last week I had norovirus and I'm worried about what will happen to my husband if I get ill. I have my own health problems. When I'm stressed and not sleeping it just all catches up with me. I am finding things very hard. Now I'm stressed as my husband has started falling."

**185318, January 2023**

## **Quality of Care – Not involving the carer**

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Communication continues to be a key issue we hear about. Many carers feel they are overlooked and not included.

"I feel like people just don't listen to the carers and actually ask what we think they need and what we think would help them and help us. I feel constantly undermined."

**186664, February 2023**

“They don’t speak to us as carers and find out what they [the people we are caring for] are like on a daily basis and what we have to do.”

**188193, March 2023**

“I live and breathe my son’s condition every day. I know him best and even things that were recommended by his psychiatrist I don’t implement. They just don’t understand his behaviours – I do. They should listen to the carers more.”

**185394, January 2023**

“[the hospital] said that they would be putting the sides on his bed and I told them not to as he would then try to climb over them. They didn’t listen to me as his carer. When he was discharged I was phoned and told that he had to be collected at 9am that morning. They said that transport wouldn’t be provided even though I tried to explain that I didn’t drive. There was no compassion or understanding... It’s all about treating people with respect and understanding. I didn’t sign up for this life and nobody at the hospital/GP has shown any interest in how I am as a carer or asked how I was.”

**188205, March 2023**

People have told us how as a carer they do not feel valued.

“I see myself as a 'carer' albeit the word doesn't feel correct. The word 'carer' smacks of a low level unskilled job when actually it is a highly demanding role for which we get no training or preparation. To be honest running my design practice was child’s play compared to the stress and challenges of looking out for someone with mental health issues. I don't... have another title but there needs to be some recognition of the enormity of the task...”

**187306, March 2023**

“I cared for 10 months for my niece... I cooked for her, take [sic] her to all the appointments, paid for her food and upkeep etc. I went to



all her oncologist appointments and nobody has asked me if I am ok or if I could cope. I registered with my GP as carer and have not received anything not even an acknowledgement. Also ... I have mental health problems of my own and they did not even think of calling and offering any help or see if I am ok.”

**187466, March 2023**

## **Carers with their own needs**

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This quarter we heard from carers who are struggling to manage their own health needs alongside their caring responsibilities.

“I am exhausted. I need to have an operation but it’s worrying me about how everyone will cope while I am in hospital. I have had to organise everything.”

**188194, March 2023**

“I have a daughter [12] who is autistic. She has only just been diagnosed in the last year. She’s really struggling. I am really struggling also as I am also autistic. I’ve only just been diagnosed recently myself too. It’s a lot to cope with. It really hit me last week that I may be a carer. I have so much to do for my child and so much to cope with. It’s more than I can cope with.”

**186490, February 2023**

“I do have my own needs [Fibromyalgia] and this can make caring very difficult. I’m a work in progress. I suffer from chronic fatigue and so I have to pace myself and ensure that any stress is kept to a minimum.”

**185526, January 2023**

## **Impact of long waiting times for referrals**

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Carers continue to tell us about the impact of long waiting times for referrals on themselves and those they care for.

"We have been waiting 1.5 years for ADHD assessment for my son. How is this acceptable? His school don't have enough staff to help, they 'can't' recruit teaching assistants and without diagnosis there is not funding for the help he needs. This is impacting our family life."

**187515, March 2023**

"He is incontinent and I am having to change his sheets daily. It's exhausting and it's costing a lot to use the washing machine so much. The continence nurse was due to come in October 2022 but her machine was broken so they rescheduled and are now coming in May 2023."

**188194, March 2023**

"I am concerned about my son 17, turning 18 in the summer. Over the past few months he has become significantly depressed. I have been struggling to get him out of bed, he has not been attending college and he has made frequent comments about wanting to take his own life. I went to the GP for help. My son is rejecting therapy at this point, as he has difficulties trusting anyone. I requested anti-depressants as an interim. However, the GP is unable to prescribe medication until he becomes an adult (when he turns 18) but he made a referral to CAMHS. We attended an initial meeting with CAMHS, during which I stated that my son was threatening to take his own life and that medication was needed as a matter of emergency. I was told by CAMHS that my son's case needed to be reviewed and discussed and that this could take 6-8 months."

**186571, February 2023**

## **Different cultural attitudes towards caring**

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Caring is an expectation in some cultures and considered a natural responsibility.

"I am the sole carer for my mother who is 74 and is physically disabled since 2014.... Although I have a brother and a sister, I have

no family support from them and so I have nobody to fall back on and no break from caring for mum... Taking responsibility for my mother is a cultural thing [carer is Pakistani]. I am the eldest and as I am not married and have no family, this falls to me... We don't like to say that we are taking care of someone in the family. Disability is not a good word. When asking someone from my culture, if they might be a carer, you need to be sensitive and ask 'what support do you need?' Ask what the person does to SUPPORT the person you think they are caring for. 'What do you do?' 'How can I help you?'. Never use the word carer. My family would say that I'm not a carer. When I said this to my sister she laughed. I'm not seen as a carer as I'm her daughter. Caring for family is not seen as a caring role... I used to call myself, my mums support, not her carer. I won't ask or seek help as it's like saying that my mum is a burden."

**186597, February 2023**

"It's a big stigma within our culture (Sri Lankan) There is no word for carer at all or mental health – you are just mad... I have had no support as a young adult carer as nobody recognized that I was one. I'm 24 now and it was only a couple of years ago that I realized that I was a young adult carer."

**187123, February 2023**

## Difficulties managing paid work alongside caring responsibilities

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We have heard from many carers this quarter who are struggling to stay in employment whilst managing their caring responsibilities.

"[My son] is now 12 and has not been in full time school for 3-4 years now. I have given up my job and I feel like I have lost everything."

**185020, January 2023**

"My whole world revolves around my son. I don't have any time to do anything else. I can't work anymore. Mentally it's very hard looking after a child with autism."

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**187225, February 2023**

“My employer had no policy in place for carers. I worked for them for 10 years. I had to take annual leave/make up time and go without pay if I had to take mum for appointments during work time. They only gave compassionate leave for parents who needed to look after a family member. Not someone in my position. There was no flexibility for me to work from home either. So, in the end I left as I couldn’t juggle looking after mum and working full time.”

**186597, February 2023**

“My daughter has cerebal palsy. I first realised I was her carer when I had to give up my job to look after her.”

**185317, January 2023**

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## **Valued support for carers**

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“Homestart is amazing. I self referred. This group is a godsend for me. It’s so nice to meet other mums. I have children [of various ages] and it’s been hard for me to make friends with mums who have younger children. This is a really good group for peer support.”

**185223, January 2023**

“Action for Carers are very helpful. They helped me get £150 for a carers break. Intermittently I go to the Action for Carers hubs. I’d like to go more but it’s hard to get out and I would prefer to go alone so I can actually talk to people but that’s not usually possible.”

**187305, March 2023**

“I have been coming to this [parkinsons support] group for about 11 years now. I have learnt so much from everyone. They are so supportive. People take the time to listen. Professionals don’t. They don’t even explain the medication and possible side affects. I have learnt it all from this group. I have also learnt about other support and private help and diagnosis. The correct diagnosis is so important so they get the correct medication .Makes all the difference, not only to your loved one but also to me as his carer.”

**188199, March 2023**

“Any questions I have, I just bring it to this group [National Autistic Society parent carer group]. They are a lifeline. Where else could you go to get information and help? There is nowhere for parents of children with autism.”

**186497, February 2023**

## 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. Below is a list of where we are visiting from April – June 2023. If you have a group you would like us to come along to and visit then please email us at [carers@healthwatchesurrey.co.uk](mailto:carers@healthwatchesurrey.co.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!



## Where we are going April – June 2023

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

<b>Place</b>	<b>Date</b>
Dementia Open Day	01.04.23
Memory Lane, Cranleigh	03.04.23
Wellbeing cabin, Royal Surrey Hospital	05.04.23
Methodist Church, Haslemere	12.04.23
Connect dementia group, Effingham	13.04.23
Home-Start, Cranleigh	18.04.23
Veterans and carers meeting, Woking firestation	19.04.23
Veterans and carers meeting, Guildford firestation	27.04.23
Action for Carer hub, Leatherhead	28.04.23
Woking Strokeability group	29.04.23
Young adult carer group, Guildford College	02.05.23
The Hunter Centre, Haslemere	09.05.23
Action for Carer hub, Woking	22.05.23
Surrey Heartlands staff carers network learning event	23.05.23
SEN parent carer group, Epsom Downs	26.05.23
Joint event with Action for Carers at East Surrey Hospital	05.06.23
Milford wellbeing hub	06.06.23
Joint event with Action for Carers at St Peters Hospital	08.06.23
Dementia café, Reigate	08.06.23
Action for Carer hub, Camberley	13.06.23
Action for Carer hub, Banstead	20.06.23

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

## Healthwatch Surrey – Contact us

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