



healthwatch
Surrey

Have your say

on health and social care

Your
voice
counts!



Your feedback

Your chance to
make a difference

#healthwatchsurrey

healthwatch
Surrey C.I.C

Giving Carers a Voice

Quarterly Insight Report – October 2022

What we're hearing about...

Table of Contents

| | |
|---|----|
| About Healthwatch Surrey..... | 1 |
| Engagement July – September 2022..... | 2 |
| Main themes we have heard from July – September 2022..... | 3 |
| Where we have shared our Insight..... | 4 |
| Number of carers we have spoken to from each borough..... | 5 |
| Not identifying as a carer..... | 6 |
| Long waiting times for Children & Adolescent Mental Health Services (CAMHS) | 6 |
| Difficulties accessing respite care..... | 7 |
| Communication concerns..... | 9 |
| Stress and wellbeing..... | 10 |
| Transport issues | 11 |
| Thank you | 12 |
| Where we are going October – December 2022 | 12 |

About Healthwatch Surrey

Healthwatch Surrey is an independent health and care champion, 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 July – September 2022

This quarter we have visited.....

- Guildford Nursery School Family centre
- Smart Tots, St Marks Church and Community Centre
- Farncombe food bank
- Action for Carers hub, Camberley
- Burpham Wellfest
- Action for Carers hub, Guildford
- Hasleway Centre Community centre
- Horley Action for Carers hub
- IMHN meetings
- HomeStart Spelthorne
- East Surrey Hospital
- Action for Carers hub, Farnham
- Action for Carers Funday for carers and families
- Samson centre for MS
- The Hunter Centre
- Eikon LGBTQ+ coffee and chat
- Action for Carers hub, Caterham
- Nepalese elders meetings, Camberley
- SABP Carers event, Farnham Road Hospital
- Cobham community centre
- Royal Holloway University recruitment fair
- Mole Valley family centre, Dorking
- Home start Elmbridge, Walton on Thames
- Farnham parent carer group, St Francis church

- Shifa (Asian women’s wellbeing group), Sheerwater



Main themes we have heard from July – September 2022



Where we have shared our Insight

Report on Children with special education needs and disabilities (SEND)

We have shared this insight with the Surrey Heartlands JIG (System Quality Group)

The key findings we reported were:

- Not being listened to
- Lack of joined up service
- Transport
- Access to mental health support
- Caring responsibilities on top of additional needs

Report on Translation Services and Support for People who are second language English

This report has been shared with Surrey Heath

The key findings for this report were:

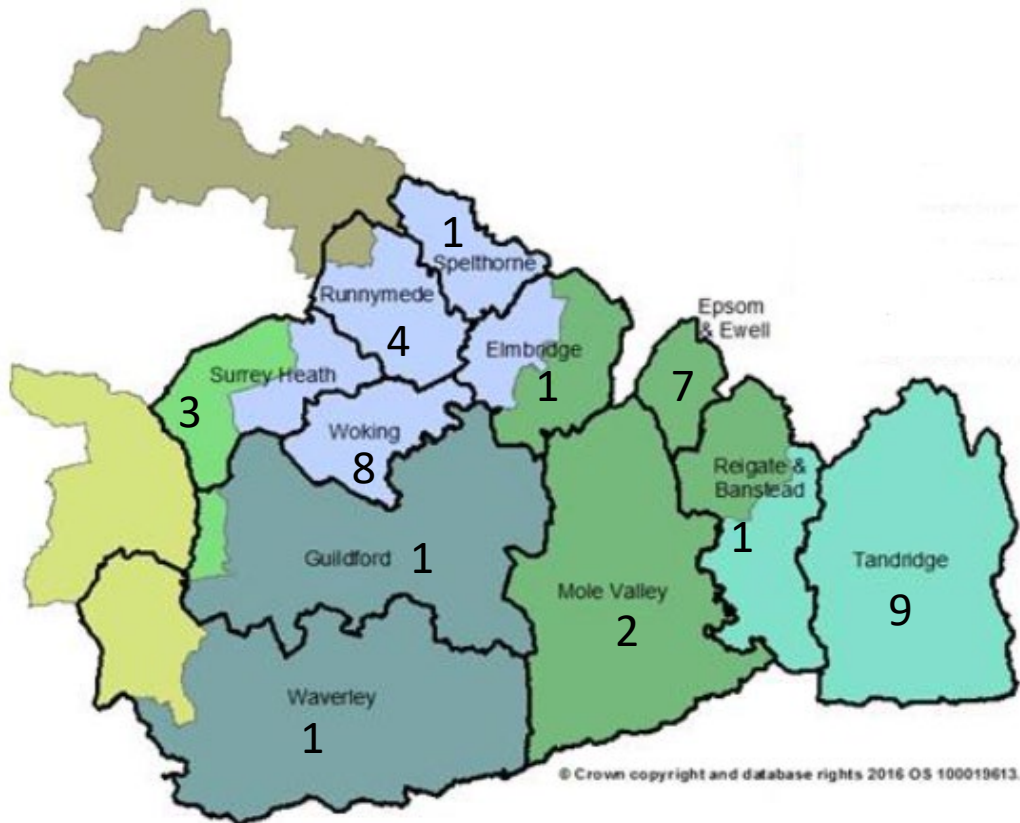
- Access to primary care appointments
- Dentistry
- Long term conditions
- Transport
- Interpreter's experience
- Financial Challenges

During Q2 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.

- Ashford and St Peter's Hospital Trust – 20th July
- Surrey and Borders Partnership – 20th July
- Surrey Heath Place – 21st July
- Surrey Heartlands Primary Care – 26th July
- Adult Social Care – 1st September
- Royal Surrey Hospital – 8th September

- Guildford and Waverley Place – 26th September

Number of carers we have spoken to from each borough:



*93 carers listed as not known as their feedback was obtained at larger events or online support groups where we were unable to capture their demographics.
*16 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 224 carers in Q2 and over 47% (106 carers) did not identify as being a carer.

"...He's my husband [has COPD] I don't think of myself as his carer. I'm not registered as a carer with my GP. I just get on with it. He can't walk far and so I have to drive him everywhere. I do have a blue badge though.

I didn't know that I could claim any benefits for being a carer." **176197, September 2022**

Long waiting times for Children & Adolescent Mental Health Services (CAMHS)

Carers have told us that they are experiencing long delays in getting appointments with Children & Adolescent Mental Health Services (CAMHS).

"My son has ADHD and ASD. The NHS waiting list is too long. CAMHS Surrey - we called monthly about a cancellation and luckily got one. We were seen within 18/24 months. The service was good, they are understaffed and the waiting times are very long even before covid. They clearly need more resources and money to support the children who need their help." **174830, August 2022**

"CAMHS have been good with my oldest son, but my younger son has been waiting for an appointment for over a year." **174532, August 2022**

"My son is a young adult carer (YAC) as I have fibromyalgia and his sister has ASD. He has needs of his own too. His sister's behaviour [ASD and self-harm] is impacting him but he has no support. [The doctor] made a referral to CAMHS last summer [2021] I then heard nothing. I contacted CAMHS in Jan and was told that they would make contact in 5 weeks. They hinted at some counselling for her but nothing happened. 2 weeks later I then got a letter saying there was a 2-year waiting list for CAMHS. From when? The point of referral? (ie last summer) or from Jan? I had mentioned that she was self-harming. She was a really good student but had been very clever at masking her ASD. Now at secondary school and

doesn't attend regularly as there is no support for her. She doesn't have an EHCP. My son had one in year 3 and went to a special school." **173438, August 2022**

Difficulties accessing respite care

People have told us about the importance of respite care.

"... I'm a carer for my 18 year old son with autism... I just feel a lack of support for myself. I have 3 kids, my 29-year-old daughter is undiagnosed autistic and struggles and needs a lot of support, my son 18 has autism and my daughter who is 16 feels very hard done by. She is very resentful of the situation and angry...Last year Crossroads care came. They come every Thursday evening and we get 3.5 hours of time out. I'm now waiting for a carers assessment to see if we can carry on with this support from Crossroads. This time we have had thanks to Crossroads has been invaluable for my daughter especially who feels really cross about our situation. The respite has really helped my daughter as COVID really set her back socially. Having that time every week is great. The carer from Crossroads is excellent and has a really good bond with my son so I have no concerns about leaving him. I am concerned if we lose this Crossroads care it will have an enormously detrimental effect on my daughter who is already suffering with poor mental health." **176450 September, 2022**

"Mum has stage 3 dementia and now lives with us. Before COVID she lived independently and used to have a little routine. She could walk from here to the community centre, then go to Waitrose and then home. It kept her moving, gave her a routine and she came here for a chat, lunch and friendship. It was really important to her and as her carer, it gave me a break. Then COVID struck and all support just stopped. I noticed that she started to go downhill and so we adapted our house to accommodate her. She also now attends The Elmbridge dementia centre in Thames Ditton. I now have a carer for mum as I found that I needed more help. We need to be able to do things as a family and husband and wife. Social care came round to assess me and said that as we had adapted so well, we didn't need any extra help. So I went private and found a carer through Elmbridge carers. She is my saviour. We tell mum that she is the cleaner as mum would refuse to have a 'carer' look after her. It's just an hour in the morning and an hour in the evening but I'm beginning to feel that I need more. We did have

crossroads care for 10 weeks for 3 and a half hours but that has all finished. I need respite care as we need a break. I currently pay for a private nursing home, so we can have a break sometimes. We're lucky to be able to do this." **176324,**

September 2022

"I get respite every Thursday for two hours through Take a Break who are based in Petersfield. I got this through the council. It's now gone up to three hours thankfully so I have time to go to Guildford and back now and get a longer break. I try to go to my pilates class also in this time. I've had this respite using Take a Break for about two years now. They came and did an assessment first face to face beforehand and met my husband. It's hard when I go to the GP as it's on the border for Surrey, Sussex and Hampshire. This makes it impossible when the GP directs you to a service which is in another county. The counties and services don't talk and the service is very disjointed. It makes it really difficult to access the right services and get the right help. It would be great if the GP provided information for similar services across the three counties." **174601, August 2022**

Some carers however report that they are still struggling to access any respite care.

"I have been waiting for help for 4 weeks now. 5 years I have been looking after my husband with vascular dementia and Alzheimer's. Now I've asked for help it's not very forthcoming. I would like respite for a couple of weeks, I don't know how I'm going to carry on but they reckon social can't find anything. I've offered to top up whatever and still I haven't heard anything. Who else do you turn to for physical help?" **172108, July 2022**

"I am a carer for my wife who has dementia... I tried to access respite care and applied back in January 2022. It took 5 months to get acknowledgement that I was eligible. Then they sent me a 40 page document to read and sign and we had to go through 2 telephone assessments. My wife can't communicate so this was challenging but luckily they were understanding that she couldn't answer their questions. I wanted to get respite care for Thursday afternoons as I play in a band. They didn't send anyone round to meet my wife and instead a carer turned up one day to do an assessment. This didn't work out as my wife has advanced dementia and can be quite challenging. They stayed for one hour. Then they sent someone else the following week who turned up unexpectedly on a different day

at a different time. There is a lack of communication and it's very hard to take care of someone with no prior knowledge of their condition. So, none of the carers were able to look after my wife due to her specific needs. They just don't seem to be trained adequately to take care of someone with advanced dementia. People need to be trained properly and be experienced to be able to take care of a person with dementia. I'm going to look at finding someone privately now as I just need a break. It's been a difficult time lately as they are trying to work out the right meds for my wife as she's quite agitated. My wife used to work in a care home herself and a lady who she used to work with sometimes pops in. I need to find some respite as my wife is entirely dependent on me and I need to get round that. I have two sons. One has recently moved back to the UK and can now visit at weekends to help me out. I like to run and cycle but I can only do this if I get up and go at 6am otherwise I can't leave the house. For too long I thought I could do it all by myself and now she's become totally dependent on me. I just need a break. The carer group at The Hunter Centre has been very helpful and a lifeline for me. My wife can't watch tv anymore or communicate and I feel isolated and lonely. I need help and respite care so that I can start to look after myself." **174602, August 2022**

Communication concerns

Communication continues to be a key issue we hear about.

"I do get frustrated when my mum goes into hospital and I can't get hold of anyone to ask how she is. She went to Frimley hospital recently and no-one answered the phone when I rang. I just wanted to know how she was. I'm a carer for my mum who is 93. My mum lives with us. I resent her for me being her carer. I really am begrudging being a carer. People see the home but they don't see the foundations. They see my mother but they don't see me (the foundations). I did get a National Trust carers card but what's the point in it as I can only use it when I am with her. I feel guilty that I want to go out and leave her so I can get a break. Mum will go into respite care if we go away but we can't often go away as it just costs so much money. It costs more than the cost of the holiday! I volunteer and the weeks away volunteering are my holiday... I am a registered carer and have been a carer for 7 years now. I haven't had my next covid booster yet as last time I got ill afterwards and I just can't afford to be ill as I have to care for my mum." **166749, July 2022**

Stress and wellbeing

Once again this quarter people have been sharing their experiences about the impact on their wellbeing from being a carer.

"I feel like a complete prisoner. I am a carer for my mum who is in her 90s and has dementia. I just feel so miserable and so resentful at having to be her carer. I have been a carer for about two and a half years but things really got worse since October 2021. You don't initially realise you're a carer then you realise most of your week is taken up looking after someone else's needs... There just isn't any support for carers. The only support I get is from Action for Carers and they have been so supportive whenever I have rung them. It's great to have somewhere to ring. Mentally I have been to some really dreadful places but I realise now that I have got to look after myself. I am really worried though about what I would do if I got ill? I'm on my own caring for my mum with no back up. My mum refuses to have any additional help or support so I have to do everything on my own. I need to get an emergency plan in place just in case something happens to me or I get ill. There are times where I just feel like I need to get out but she won't have anyone else to help her. She would never go into respite care or a care home. I don't see what choice I have got, I have no choice. " **166738, July 2022**

"I feel very down and low. I love my son [who has autism and ADHD] but I feel down and am struggling to come to terms with who he is. I am not well myself... Coming here [to the community centre] is a safe space and at least he can run free here and the people are so kind and understanding and helpful." **176554, September 2022**

"My mum cares for my dad who has dementia. They are both 81. Dad's dementia is getting worse. I am really worried about mum as she gets no time off and has no break from it. I just don't know what to do. I have to work full time and I feel so guilty every time I visit them and then I have to leave. I have told mum to register with the GP as dad's carer but she hasn't done it yet. They go to a dementia group every Tuesday morning. They both go. Mum sits on one side of the room with the

other carers and dad sits on a different table with the other dementia sufferers. It's not much of a break but it's all mum gets." **174237, August 2022**

"My GP [Caterham Valley medical practice] have been great. They told me about the carers assessment, attendance allowance and I have had money for a carers break. Social services don't seem to give a damn about my mental health, they don't seem to want to help me. I have been caring for 4 years now. My wife has Alzheimers. I would like her to go into a facility where she is cared for. My GP is supportive but there are barriers with Adult Social Care. They don't seem to want to help me... I am suffering from tension in the back of my neck, anxiety and lack of sleep. I don't take any medication at the moment. I have seen a friend of mine get ill caring for his wife for over 10 years. I've only been doing it for 4 years and I don't want to end up like him. He has a bad back from carrying her up and down the stairs. Maybe if I exaggerated how I'm feeling they might take more notice of me." **175505, September 2022**

"...I have been a carer for my daughter since she was 15 years old and she's now 31. It's very hard being a carer for someone with mental health issues. When you're in the middle of the road in terms of your mental health problems that's when you get no support. You have to be very severe or very very bad or you just get no support or help. As a carer, you just can't switch off from it. You don't get help and the school didn't help when she was younger, they just said she's got a good method of coping in other words ... me ! As soon as she isn't coping, she rings me. It's a lifetime job being a carer for your child." **176400, September 2022**

"I think as the parent of a child with additional needs you realise very early on that you are alone. It's all on you and you have to do everything alone. You have to fight for everything and realise that you're just on your own. I don't really react to things anymore good or bad, I just feel flat. I do keep busy and in my spare time I do things to feed my soul such as crochet, playing the piano and baking cakes." **176450 September, 2022**

Transport issues

"My son cares for me [mental health and physical disability] and I care for him [Autism/ADHD] He belongs to Surrey Young Carers [Action for Carers] but I can't

get him to some of the activities as I can't drive and can't even get on a bus/train due to my mobility issues. They [SYC] will provide a taxi for some of the activities that they put on but not for everything like the drop ins. He would love to go as his friends go. He used to have a taxi and he loved going but that stopped. They are so good for his mental health. He comes back in high spirits and this makes me feel better as I can't do a lot. I also don't have to rush around as someone else does that for me." **176498, September 2022**

"We have moved 1 mile down the road and now the council won't pay for our son [with SEN] to have a taxi. They say it's under the 3 mile limit (as the crow flies). They say that he can walk to school. This will take him an hour." **173480, August 2022**

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 October to December 2022. If you have a group you would like us to come along to and visit then please email us at carers@healthwatchsurrey.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 October – December 2022

| | |
|--|-------------------|
| Guildford Nursery School family centre | 3/10/2022 |
| Over 18s youth group, Woking | 3/10/2022 |
| Surrey University volunteer fair, Guildford | 4/10/2022 |
| Linklight Mental Health Forum | 5/10/2022 |
| Homestart family group, Godalming | 11/10/2022 |
| Action for Carers hub, Addlestone | 12/10/2022 |

| | |
|--|-------------------|
| Action for Carers hub, Knaphill | 17/10/2022 |
| Carers support group, Spelthorne | 17/10/2022 |
| End of Stigma Launch Surrey | 19/10/2022 |
| Patient Engagement event, Camberley | 22/10/2022 |
| St Davids GP Surgery, Spelthorne | 25/10/2022 |
| Wellbeing centre, Royal Surrey Hospital | 31/10/2022 |
| Action for Carers hub, Shepperton | 2/11/2022 |
| Action for Carers hub, Cranleigh | 7/11/2022 |
| Action for Carers hub, Horley | 9/11/2022 |
| Veterans and families group | 14/11/2022 |
| Alzheimers café, Camberley | 21/11/2022 |
| Epsom Hospital with Action for Carers | 23/11/2022 |
| East Surrey Hospital | 24/11/2022 |
| Homestart group, Elmbridge | 29/11/2022 |
| The Samson centre, Guildford | 30/11/2022 |
| Frimley Park Hospital | 5/12/2022 |

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



healthwatch

Surrey C.I.C

Freepost RSYX-ETRE-CXBY,
Healthwatch Surrey,
Astolat,
Coniers Way,
Burpham,
Guildford,
Surrey,
GU4 7HL

- 🌐 www.healthwatchesurrey.co.uk
- 📞 0303 303 0023
- ✉️ Text/SMS: 07592 787533
- ✉️ enquiries@healthwatchesurrey.co.uk
- 🐦 @HW_Surrey
- 📷 @healthwatch_surrey
- 📘 /healthwatchesurrey
- 📍 Healthwatch Surrey