



healthwatch
Surrey C.I.C

Giving Carers a Voice

Quarterly Insight Report – July 2022

What we're hearing about....

Table of Contents

About Healthwatch Surrey.....	1
Engagement April - June 2022	2
Not identifying as a carer	2
No access to a point of contact	3
Difficult in accessing GP services	4
Stress and wellbeing.....	5
Mental Health Report.....	6
Where we are going in Q2.....	7

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 April – June 2022

We have been to the Camberley carers hub, Richmond Fellowship Carers Coffee Break in Epsom, Sight for Surrey in Godalming, Surrey Charities Roadshow, St Marks Food Club, Andy's Community café, The Hive at Park Barn and Brockham surgery talking to carers.

Not identifying as a carer

Over 30% of the carers we spoke to did not recognise that they were carers.

"I'm popping in to drop something off for my Dad today, it's the fourth time in four months and it's looking like another urine infection which is completely miserable for him. They are following up on it, he has an ultrasound booked in at Dorking in 6-8 weeks... I can't get involved in that part of his care, I don't want to step on his toes and he is very proud in managing his own care. Dad will wait and will not push it forward or contact them until the full 8 weeks have passed, they [my parents] are very polite and don't want to push.

I'm not Mum and Dad's carer, Mum and Dad [both in 80's] look after each other at home, but I do drop in with shopping and take them to any appointments and things. He's very good at doing all his own admin and books his own appointments, he is online, which is a godsend really as he can do all those things for himself but he can't drive now and where they live is quite rural, so I drive them around to what they need otherwise they would be quite cut off." **159827, April 2022**

"What's the definition of a carer? Oh that might be me as he can't manage without me but I wouldn't use that word. I'm his wife. I don't know what other word we could use. I'm not registered as a carer with my GP. I'm fine, I just get on with it. He knows where everything is in the house. Sight for Surrey have been great about helping us with things. Our children help out sometimes. I did manage a walking holiday on my own and the children came and helped their dad." **162795, June 2022**

"I don't really identify myself as a carer. I'm his wife. I don't use that word really. I'm not registered with the GP as a carer but I have been in touch with action for carers. They sent me a pack of stuff to read and register with them. I haven't had the time to do this. I go out once a week to a needlecraft group. He doesn't go out. He's lost his confidence since COVID and relies on me to be his eyes and ears. This

gets very tiring. I wish he'd listen to the radio or an audio book as then he'd have something we could talk about. Even if he would go to a day centre for a while, perhaps where there is a men's group. I have some information about a couple in Farnham. I'll have another look at them. We used to belong to the National Trust and visit Wisley but he says there's no point in going as he can't see anything and I get tired having to describe things all the time. We used to go away but we can't be bothered now. It's such a palaver to drive somewhere and then it's not really a break for me as I'm doing exactly the same things but in a different place. A place that he's unfamiliar with, so I actually end up doing more.

I fell over and broke my pelvis. That was a difficult time as I was in hospital for 5 days. Then my daughters had to come and help but they don't live nearby. I can drive again in 3 weeks' time. We still rely on them to do the shopping. Naughty I know but we can't get on with online shopping. There was never a slot during COVID and then we sort of gave up. " **162793, June 2022**

No access to a point of contact

People have told us about the importance of a point of contact and ideally seeing the same person or group of people where possible. In some cases this is working well and carers value the continuity of care.

"...There is one Parkinsons nurse at Frimley but she covers a huge area. I'm worried that she will become overworked and overwhelmed and then leave. It's great having that one point of contact.

When you first get a diagnosis it would be good to get some information. We got nothing in the beginning. We're 15 years down the line and I have done most of the research into what help and support we can get..."**162802, June 2022**

"I am a carer for my dad who is in his 90s and has dementia. I also used to be a carer for my mother who died three years ago and also other family members and friends. Initially I didn't recognise myself as a carer and I just thought "let's just shed whatever else is going on in my life and this is what I do now." Looking back I have probably been a carer for about 20 years. I wish I had a point of contact that I could ring to ask for advice and reassurance. I worry daily about my dad thinking "is he safe? Is he happy?". I would love to have someone to ask those questions to and to know at what point should I be concerned and how to recognise changes in his behaviour. We used to have dementia navigators but these now seem to have disappeared unfortunately as they were useful. I used to contact the GP as my point of contact but they are so overloaded with work now. I

just want a number I can ring or to see someone who knows my dad and can help me when I question if his condition is changing or deteriorating.

I use Fitznells Manor Surgery who are excellent and have always been very helpful. Also I found the cottage hospital in Epsom to be fantastic when one of my family members was there. It's like a one stop shop and a great place to be assessed and to recuperate with so many services under one roof." **162836, June 2022**

Difficulty in accessing GP services

Carers have told us of the difficulties of making GP appointments online.

"The surgery turn their forms off if full so you can't get an appointment. When you go to the GP there are always people trying to get an appointment, but they get told to go home and go online. Well not everyone can, I can't go online. All my friends experience the same issue! Staff are not friendly at all.

Husband got diagnosed with Alzheimer's before Covid. After diagnosis at Epsom, it's pretty much ended there support wise. Had no Dementia navigator or nurse assigned to me. We have gone private to get the help we need." **159787, April 2022**

"I came in today to make an appointment. I am not very good with computers as I am [Age 80's] so I do find the system now more difficult to make an appointment. Pre-COVID I thought the systems were manageable. I did try to register for the online service but we have one computer at home and my wife registered and then it couldn't register two people from the same computer.

The individuals at the surgery are very, very good. Although they do seem to have a lot of bank staff, so you see different people each time.

For example, my wife has been seeing a particular doctor but when she tried to get an appointment, she couldn't see them for 15 days. Because she has sciatica and it had come on she needed to see someone more quickly than that so she saw another doctor. They were very good but it's not consistent.

I am due to have a cataract operation at Ashted hospital. I saw the consultant in January and they said I should have the operation mid-March. I contacted them at the end of March to chase it (they had given me his name and the phone number of the hospital). They said they would let me know when and explained that consultant only does a few these days and they don't know when he's available. I asked them to check as I thought they must have a waiting list and have some idea of when. They said maybe mid-April or could be May. They have added me to the cancellation list but I'm not very impressed. I get the feeling that

the guy is either not very good or is very busy. We're now into April and I still haven't heard anything. I'm concerned as it's a pretty drastic operation if it goes wrong. I don't mind waiting but just feel they should have some idea about how long I might be waiting." **159877, April 2022**

"I'm with St Johns practice in Woking. I'm not able to make a GP appointment, I cannot see a doctor. You call and get triaged and then get a phone call. If you are not online it's very difficult. I'm still able to manage medication etc.

I care for my son who is in his 40's, he has a mental illness and needs regularly checking on. He is seen every 4 weeks by CMHRS Woking. System working well, but no requests for feedback – do they really care?

I go to Action for Carers hub at the Vyne centre in Knaphill, it's good." **160514, June 2022**

Stress and wellbeing

People have been sharing their experiences about the impact on their wellbeing from being a carer.

"I'm pleased to be back here today [AFC group] I was attending a parent/carer group in Ash but that hasn't started back up again, I've felt a bit down about not having somewhere to go, one of the parents there started up an informal social coffee which I went to for a bit which helped... I started some volunteer work at Frimley park Hospital, just to get out whilst my children are at school and have found helping others has really helped me to feel better... I really hope the parent/carer group will be up and running again soon, caring for 3 autistic children is really challenging, one is very violent and I've had him at home with me a lot as his school will call me to get him at the first sign of trouble. He's been through 4 schools and so I need him to stay at this one, so I will go and get him, but it means I don't have a life, I can't go very far as I might have to be back to pick him up. I think they realised what a strain it is, as I picked him up and had a complete meltdown, I have definitely had less calls since then. I said look you will have to find some strategies at school too, it can't just be me picking up every day. I have been so down, depressed but I won't talk to the GP as they will just give me meds and I don't want medication." **161816, June 2022**

"... I'm on my own now after my husband died last year, I cared for him at home for a long time, he had dementia and he ended up at Abbeywood care home, both he and I liked it there. It's not easy now he's gone. Whilst my husband was alive we

were getting some benefits, I gave up my job to care for him and now I am having to cope with everything on my own, figure out all the money and everything is so expensive now. I miss him but he wasn't like he was before, it's been lonely, I've lived in this area for 12 years and it has been hard to make friends as there is nothing to do, nowhere to meet. I thought I would try the café today with my friend, we met going to the same club." **162862, June 2022**

Mental Health Report

Healthwatch Surrey was commissioned by Surrey County Council to work with carers of people using mental health services in Surrey with a view to helping redesign support services. After a series of initial workshops just with carers, we brought together the carers with relevant stakeholders and providers in order to capture their experiences and insight with a view to reshaping mental health support services in Surrey. The report was published July 2022 and is available on our website - [Report-Designing-support-services-for-carers-of-people-using-mental-health-support-PDF-1.pdf \(healthwatchsurrey.co.uk\)](https://www.healthwatchsurrey.co.uk/Report-Designing-support-services-for-carers-of-people-using-mental-health-support-PDF-1.pdf)

Key findings

- **People not identifying as carers.** In particular parents of children under 18 were the least likely to recognise themselves as carers. All the carers agreed, it would be useful to have this flagged up to them at the first point of seeking assistance or advice so they can begin to be supported with information and advice from the beginning.
- **Accessing information and services.** Carers told us how they felt bewildered trying to find out what support services were available to them. They found the information was very scattered and difficult to find and often too detailed to process. People told us that access to clear, concise information from a single point of contact would be very useful.
- **Carer assessments.** Out of the carers we spoke to, the majority had not been offered a carers assessment. Most were unaware what a carers assessment would entail and what the benefit would be for them to have one. Carers welcomed the opportunity to have a carers assessment that would look at their situation, the situation of the person they care for and the family unit as a whole with a view to the carer being provided with more relevant information, support and signposting where applicable going forwards.

- **Access to and continuity of practical support for carers and for their wellbeing.** Carers expressed the importance in having an individual or an organisation that knows their background and situation and whom they can contact for support and advice. Carers told us they find it frustrating having to retell their situation repeatedly.
- **Working with professionals and communication.** Often carers felt excluded from discussions with professionals about the person they are caring for. They believe that in many cases they hold insight and knowledge about the person they care for which could be very useful to the professionals involved. They welcomed more inclusion and more open discussions with professionals. Carers were concerned how the level of inclusion and information diminishes when the person they care for turns 18.
- **Stress and wellbeing.** Carers talked about constant stress and the impact that caring has on their physical and mental health. Carers felt unsupported and many felt very anxious a lot of the time.

Where we are going in Q2

This quarter we are planning to visit Guildford nursery school family centre, Westway community carers hub, Burpham Wellfest, The Hive community centre, Hasleway community centre, East Surrey hospital, Farnham Action for Carers hub, Wayside Surrey, YMCA Horley family centre, Camberley Nepalese Elders group, Frimley CCG carers organisation meeting, SABP carers action group, The Hunter centre and Home Start Elmbridge.



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