
Home is where the care is?

Stories from people who need home-based care

September 2025



"Just before COVID we moved house and needed to change our GP. When we joined the GP Practice it was easy to register as housebound. I was told that I could email the practice, and this would continue for as long as I needed it. I cannot speak on the phone for myself.

This all changed post pandemic as 'new rules were introduced by the NHS' making the GPs do more face-to-face appointments. This is not possible for me. Just imagine going for an ECG and being so triggered by the experience and having a panic attack."



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Introduction

This project explored whether community healthcare services (primarily) are accessible/available to people who are classified as being housebound, their needs are being met, and what improvements can be made to better meet these needs. From speaking to people and gathering experiences via the survey it became evident that whilst the GP is considered the gatekeeper of services, people spoke about how mental health services, social care and hospitals also played a role in referring and providing care in people's homes.

This document supports the main findings report 'Home is where the care is? Home-based care September 2025'. It provides more detailed stories from 3 people about their experiences of receiving care in their home. It is written in their own words, but we have added some structure to their insights to assist the reader. We hope these detailed stories will help other people facing the same situation.

Story 1 – I have trouble communicating with the outside world

Male aged 50–64 from Guildford area

Since the pandemic and lockdown, I experience extreme difficulty with communicating with the outside world, I think everyone is out to get me. I rarely leave the house – the furthest I go is very occasionally to a neighbour by arrangement and to my refuse bins by the front door.

GP experience

Just before COVID we moved house and needed to change our GP. When we joined the GP Practice it was easy to register as housebound. I was told that I could email the practice, and this

would continue for as long as I needed it. I cannot speak on the phone for myself. I can talk on the phone as an advocate for the 3 people in my household but when it comes to myself, I start shaking and go into a panic attack. If I know that someone is going to call me that is a little easier.

This all changed post pandemic as 'new rules were introduced by the NHS' making the GPs do more face-to-face appointments. This is not possible for me. Just imagine going for an ECG and being so triggered by the experience and having a panic attack. I was told off for contacting the practice by email (you are not supposed to email us) and that I had to complete an online form which is difficult for me. I had an argument with the practice manager who I felt was not being understanding of my needs. I told them that I had a right to receive treatment under the Equalities Act.

Telephone contact is very difficult for me. My partner does this on my behalf. My partner is dyslexic and cannot access online and I complete all forms for benefits -which are long and complex.

Medical notes

People never bother to read my notes. I must explain everything every time. They are unaware of my communication preferences and phone me unexpectedly which is triggering. Texts would be much easier, but I'm not given that option. I am now under the care of a specific GP, who is understanding of my needs and preferences. The new practice manager has said they can annotate my notes, and it is not so much of a fight every time I contact them.

Treatments

I needed an ECG before I was allowed to get ADHD medication. I requested this at my GP Practice but was told that this was not possible as 'we don't do at home ECGs. An advocacy service went to the surgery and told them the reason why I need an ECG at home. They were told that I didn't fit the criteria. I felt so unworthy. I have still not had an ECG via the GP surgery. My partner needed to chase and eventually the Redwood Centre in Guildford said a

clinician could visit with their ECG and do this in my home, which they did.

I asked for a podiatry referral twice, as my ingrowing toenail has been a recurring problem. Given 2 courses of antibiotics and the infection wasn't really shifting. Then the GP made an urgent referral, and I eventually received a podiatry visit 6 weeks later. They were kind but just cut my nails and did not address the underlying problem."

Prescriptions and Pharmacy

I get most of my prescriptions delivered to my house but the one for my ADHD needs to be picked up from the local pharmacy as it is currently prescribed by my psychiatrist as he is monitoring levels. Hopefully in the future this will be taken over by the GP and I should get it delivered. We don't have ID – no passport or driving licence. It is difficult at the local pharmacy getting the ADHD medication as it is classed as a controlled drug.

Vaccinations

Around the time of COVID, I was able to get vaccinations at home. Last year I was sent an email saying I was eligible for a booster and would hear from them, but I never heard back.

Adult Social Care

We had a social worker, but she was made redundant. Someone from the reablement team has provided a stop gap and was very good. The work I did with her was going well and I was improving but then had blips with my mental health so needed to do more work. I am now waiting to be transferred to The LD and Autism team.

Borough Council

Just left us in pieces. We needed repairs on the house. They were abusive and didn't communicate with us. A person from ASC acted as an intermediary. A council worker came round to assess what work needed to be done. He was nice and aghast to hear of our experiences. Sadly, he was leaving. He identified 4 jobs that needed

to be done and put in 4 work tickets – explaining on each about communication preferences, but they didn't read beyond the first line and just turned up. There is nothing about disability or recognition of disabilities in their services.”

DWP – Benefits

I am able to advocate for the 2 adult children in my house, and I have a monthly meeting with the DWP. I experienced that the DWP laughed at me and lied to me and have been to tribunal 3 times on my family's behalf. After COVID all our benefits were suddenly stopped, and we were told that PIPs needed to be reviewed. We had no money coming in for a house of 4 adults. A week later we received a letter from Borough Council to say we would be evicted if we didn't start paying rent, but how could we? We relied on food parcels from the local foodbank. It was not enough for 4 adults, so we made sure that our adult children had all the nutrition they needed. I go to sleep each night worrying that a letter from the DWP will arrive telling us that our benefits are being stopped again. It is the first thing on my mind as soon as I wake up.

What things would improve your experiences?

- ECG at home
- Review of the criteria for people who are housebound
- Clear system to flag that someone has specific needs and adjustments.
- Practitioners and clinicians to read notes
- Not having to chase everything
- Options for communicating with GP practice i.e. text or email
- Recognition of difficulties in sharing sensitive information in pharmacies

Takeaway comment

I do understand there are things that cannot be provided in my home, such as emergency care and surgery. I am aware how much time it takes to do home visits, but I am constantly reminded by every person who visits how much extra time it takes to do a visit. I

have been told that they will come again but I will eventually have to go in.

Story 2 – I have been housebound for 10 years

Female aged 90 from Reigate and Banstead

Process for registering with GP

I have been housebound for over 10 years. I cannot remember registering as housebound so maybe someone did it for me. I always know when my carers come – 4 times a day. I asked for physio during lockdown, but I never received it. I need a cushion and new walker and was assessed in April but not received anything. I had a fall and had a visit from a paramedic who assessed that I did not need to go to A&E. I phoned my GP a few days after my fall because my eyes became bloodshot and didn't feel right. A GP called back and said I needed to go to A&E, I wasn't going to go for bloodshot eyes, I just wanted advice. GP said I needed my BP done at the surgery and I explained I couldn't. The GP did not understand and was quite short with me. The next day a Community Matron turned up.

People who have visited me at home are GP, Community Nurse, Paramedic, Optician, Podiatry (footcare), Vaccination. These visits were organised by my GP, hospital and social care. I have spoken to the GP mostly and I think my housing support comes from Social Services. My property is managed by Clarion Housing and because I'm housebound I'm classed as an emergency. I have been involved a little in decisions about my care.

Respect and empathy

I feel the system is that carers are not allowed to give me information. The manager from the agency comes. I feel there is a lack of respect from her. When I wasn't happy about the agency I spoke to Social Services and assumed it would be confidential and they would be on my side, but they emailed the agency and I was

told I could change the agency. I didn't want to do that as I was happy with the carers but had lack of respect from the senior people.

I am currently happy with the amount of care I receive. The GP generally visits if I need them to.

[What would improve your experience] Unless you can change people's personalities nothing will change! The level of respect is sometimes not there. Everything is a battle and this is very stressful."

Story 3 – my daughter is agoraphobic

Woman aged 50–64 from Guildford

Appointments

My daughter's agoraphobia started in 2020 and she was 19 at the time – although the surgery knew that she was autistic and had mental health problems, it felt quite hard initially to get the information across as it was 'new'. For example, I explained she could not leave the house so could not get out for a covid vaccine – the first response was 'can't you get her to the carpark – we can send a district nurse out to do it there'. She was unable to leave the house at all! But after a couple of emails it was sorted out and the surgery have been very understanding over the years once she was correctly registered as housebound. We have seen the GP, Community Nurse, Paramedic, Mental Health Practitioner, Optician, Audiologist, Occupational Therapist, Reablement practitioner and these were organised by our GP, Social Care and Mental Health services.

Re the mental health team – it seems to be harder to get help but I guess that is probably due to level of demand and staffing challenges. When we first tried to get help from them for the agoraphobia, they wrote offering her an appointment at a community mental health clinic! I was flabbergasted, they are the mental health professionals and they were asking her to do the very

thing that she couldn't do and wanted help with!! There was no way she could leave the house and go there. When I pointed this out to them, they did find alternatives, but I felt that I shouldn't have had to make a fuss given her diagnosis – they should have offered her an accessible appointment.

Communication

My daughter finds any communication quite overwhelming, so I have to advocate on her behalf. She is also very anxious around people. She has OCD and has additional fears around people coming into the house around contamination. She is always aware of what the plan is around care, so knows what is happening, but finds it hard to participate/be in the room. I think my daughter would rather have not spoken to the professionals at all! But I always made it clear to her she could go to her room at any time, and she was always aware of what was being discussed and what I would be saying on her behalf

Social Care have been great. We asked for respite back in 2021 – as my daughter was unable to the house there was no option apart from getting live in carers so that we could have a break. We had one bad experience with a social worker who had no understanding of autism, which was an upsetting time, but on the whole all social workers have been very supportive and understanding. One social worker arranged for an OT to visit to look at possible bathroom adaptations (my daughter has severe OCD, so not been able to flush a toilet for 16 years, thinks all taps are dirty etc) – now a Disabled Facilities Grant has been agreed so that she can have a sensor flush toilet operated from outside the bathroom and sensor taps.

I think we have been quite lucky. People have been understanding and offered alternative ways to have appointments including agencies like specsavers and the audiology team from RSCH.”

Thank you

A huge thank you to everyone who told us about their experiences and gave us permission to share them for the benefit of others.

Introduction to Healthwatch Surrey

Healthwatch Surrey champions the voice of local people to shape, improve and get the best from NHS, health and social care services. We are independent and have statutory powers to make sure decision makers listen to the experiences of local people.

We passionately believe that listening and responding to local people's experiences is vital to create health and social care services that meet the needs of people in Surrey. We seek out people's experiences of health and care services, particularly from people whose voices are seldom heard, who might be at risk of health inequalities and whose needs are not met by current services. We share our findings publicly and with service providers and commissioners to influence and challenge current provision and future plans.

We also provide reliable and trustworthy information and signposting about local health and social care services to help people get the support they need.

Contact us

Website: www.healthwatchsurrey.co.uk

Phone: 0303 303 0023

Text/SMS: 07592 787533

WhatsApp: 07592 787533

Email: enquiries@healthwatchsurrey.co.uk

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

 [healthwatchsurrey](https://www.facebook.com/healthwatchsurrey)

 [healthwatch_surrey](https://www.instagram.com/healthwatch_surrey)

 [Healthwatch Surrey](https://www.linkedin.com/company/Healthwatch Surrey)



We are proud to be shortlisted in 2025, and commended in 2024, for the National Healthwatch Impact Awards recognising our work helping to improve local NHS and social care.



We are committed to the quality of our information.
Every three years we perform an audit so that we can be certain of this.

Luminus

The Healthwatch Surrey service is run by Luminus Insight CIC, known as Luminus.

Registered office: GF21, Astolat, Coniers Way, Burpham, Surrey, GU4 7HL.