

What are we hearing about Adult Social Care?

November 2020

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1. One of the statutory duties of Healthwatch Surrey is to listen to the views of local people about their health and social care and to share these views with the organisations who make decisions about local services.

How do we listen to the views of local people?

2. Healthwatch Surrey receives feedback about Adult Social Care via two routes: - through agenda-free engagement, and targeted project work:
 - a) We gather Surrey residents' health and social care experiences via **agenda-free engagement**. Pre-pandemic, this would have been through our engagement team (staff and volunteers) visiting GP surgeries, hospitals and holding events in shopping centres for example. During the pandemic we have pivoted our engagement activities, for example we have joined virtual engagement events and sent out bespoke flyers. We also gather insight by people pro-actively sharing their experiences with us, via our partnerships with Local Citizens Advice services, our telephone Helpdesk, our website and by post. We also hold the Independent Health Complaints Advocacy contract. We mainly hear about NHS services through these routes; social care only accounts for 4 % of the experiences that we hear in this way. As we do not hold the Advocacy contract for social care users, we do not have that route for gathering intelligence.
 - b) Because most of what we hear through our agenda-free routes is related to healthcare, we undertake **specific targeted project work** to help us hear more about Adult Social Care. As the number of older people living in care homes is set to rise, Healthwatch Surrey has made it a priority to amplify the voice of older people in care homes. We believe that care home residents are not very likely to come to us to give feedback, so we need to go to them. If we do hear concerning feedback (through our normal channels) about a care home, we will always talk to CQC about whether a visit would be beneficial. We have

statutory powers to conduct Enter and View visits. However, due to the pandemic, we are currently unable to use Enter and View powers to go into care homes and speak with residents and families about their experience of care. We have challenged our system partners about how they are ensuring that resident and family voice is sought and remains at the centre of decision-making. We continue to try to find ways to reach care home residents (e.g. via remote engagement).

How do we share local views with decision-makers?

3. Healthwatch Surrey have quarterly meetings with the Adult Social Care team where we share what we have heard from local people. This feedback is in the main not comprised of “formal complaints”, but rather issues which service users have chosen to share with Healthwatch, as a safe place to raise their concerns. Where appropriate, we always signpost people to formal complaints processes. However, much of the insight that is shared with us is sub-complaint level. People will often share their experience in the hope that the learnings will help improve services for others; or they want someone to listen to them; or they want to know if there’s anything more they can do to help a loved one.

Why does feedback matter?

4. It is very seldom that these ‘grumbles’ turn into a formal complaint, but we believe this is a vital part of the feedback jigsaw. We know that many people are unwilling to complain; Healthwatch England research in 2014 (*Suffering in Silence*) showed that fewer than half of those who experience poor care actually report it.
https://www.healthwatch.co.uk/sites/healthwatch.co.uk/files/complaints-summary_0.pdf
5. The routine gripes of dissatisfied patients/service users are what Sir Robert Francis (now Chair of Healthwatch England) called “the early warning signs that something requires correction”. It was the failure to take patient feedback seriously that led, at the Mid Staffordshire NHS Foundation Trust, to what Francis described as the “appalling suffering of many patients” (*Public Inquiry into the Mid Staffordshire NHS Foundation Trust*).
6. We believe that sharing the insight local people report to us with Adult Social Care commissioners is a key component of any early warning system so that issues can be nipped in the bud. Collating and taking the learnings from this insight about services across social care is very valuable. Some insight is held by Healthwatch Surrey, some by third sector partners such as Age UK, Action for Carers and Surrey Coalition. Some is held by providers, who are very often the first port of call for feedback and potential complaints. A key challenge for a system which wants to improve is to actively encourage, listen to and act on this feedback.

7. With this in mind, we monitor our database on a weekly basis, and if we see any concerning cases, these are escalated to providers and commissioners. We see our relationship with Adult Social Care as being a critical friend, for example we have highlighted the need for complaints and feedback mechanisms to be obvious in printed literature.
8. The Healthwatch England report in 2019 “Creating a Learning Culture in Social Care” reviewed local authority complaints reports from across England. Within this, Healthwatch England highlighted that in most complaints reports that they reviewed, the emphasis was on the number of complaints received in a year and the timeline within which they were reviewed. Having more complaints than the previous year was often seen as a ‘worse performance’. *“As Healthwatch has emphasised previously, having more complaints can be an indication of a more open culture around feedback and a negative view of complaints is not helpful for complaints managers or service users”*. The Healthwatch England report also commented that while many of the LA complaints reports referenced learning from complaints, only a handful referenced the **actual learning outcomes**. We welcome Surrey’s focus on putting things right with complaints and sharing learning outcomes.
9. The Healthwatch England report can be found here:
https://www.healthwatch.co.uk/sites/healthwatch.co.uk/files/20190822%20Creating%20a%20learning%20culture%20in%20social%20care_0.pdf

Key Findings from our project work

10. In recent years, our specific targeted project work has looked into areas such as Care Home residents’ mealtimes, Care Home residents’ advance care plans, and more recently the voice of domiciliary care users.

Mealtimes in care homes

11. We used our Enter and View powers to conduct research into care home residents’ mealtimes. In this research, residents and their relatives told us that care home staff are often under pressure and this seemed to lead residents to moderate their requests and expectations. Residents were often seated in the dining room for some time before meal services began; sometimes without a drink, and always without anything to occupy their time.
12. Residents gave mixed responses about the availability of choice. Menus, which enable choice, often had small writing unsuitable for anyone with poor eyesight. Relatives and members of staff pointed out the importance of having visual prompts to enable residents to choose. Many initiatives were found which demonstrated the commitment of care homes in seeking to involve

residents, make mealtimes enjoyable and improve wellbeing e.g. residents arranged flowers for the tables.

13. The report can be found here:

https://www.healthwatchesurrey.co.uk/wp-content/uploads/2017/06/HWSy_What-I-want-within-reason_FINAL_no-bleed.pdf

Experience of advance care planning in care homes

14. More recently, we asked Care Home residents to share their experiences of advance care planning, in line with Surrey's Health and Wellbeing Board strategy to "help people die well".

15. Here we heard that people who had put advance care plans in place - whether for themselves or for a loved one - were all happy that they had done so.

16. We heard about the barriers in creating an advance care plan, and furthermore we heard that the creation of an advance care plan is triggered by a medical event, or by healthcare professionals/care staff.

17. The full report can be found here: <https://www.healthwatchesurrey.co.uk/wp-content/uploads/2020/01/ACP-Care-Homes-Report-November-2019.pdf>

Hearing from users of domiciliary care

18. As well as hearing from care home residents, we also seek out care at home users. We conducted qualitative research in 2019 (*"Can you hear me? Amplifying the voice of people receiving care at home"*).

19. This was a vital piece of research which helped us understand the sub-complaint concerns which service users have, and the challenges they face when they are raised.

20. We found that most domiciliary care users who we talked to did feel that they are listened to; there is a well-developed listening landscape, and many felt that when they have expressed their needs, this has resulted in improvements in their care.

21. Care workers provide a powerful conduit for the system to understand what users want and need: intimate, frequent, repeated contact with care users means they are uniquely well placed to understand what their clients want and need, and can feed this information back to their agency managers. Some agencies take full advantage of their care workers' insight into their clients. Agency staff are well motivated to listen to care users and respond to their needs: the emotional desire to do a good job is partnered with a business need to deliver good service and a requirement to conform with regulations. Surrey County Council require their commissioned care agencies to report regularly on

measures intended to reflect whether agencies are listening effectively to people using their services.

22. However, and importantly, there are some domiciliary care users who are less willing or able to express their needs:

- a) People who are not able to engage with the system, do not have an emotionally engaged advocate (parent, child, spouse) to engage on their behalf, or who don't know where to get independent advocacy support from.
- b) Clients who have reason to be scared of losing their care (e.g. special needs, scarce resources) which they and their families rely on. This finding is reinforced by recent feedback from Surrey Coalition: ...

*Our main concern is the very real fear that people have of raising complaints. We have had numerous examples of people sharing their fears that care will be cut, or that they will be 'punished' in another way if they complain about their care or about their package or adult social care more generally. This was really highlighted in a recent focus group we ran to support ASC commissioning (of home-based care) where members were reduced to tears describing their fears over raising a complaint. **Surrey Coalition of Disabled People November 2020***

23. Age UK Surrey have also reported that clients often feel demeaned and dismissed as being confused or too 'old' to know what they are talking about, they describe themselves as being patronised.

d) Age UK Surrey tell us that people are confused as to who they should complain to, the care provider or ASC. When they do complain, the agency or ASC blame the other and refer them back. They feel that no one seems willing to take responsibility for looking into complaints. This is illustrated by the following feedback from Surrey Coalition:

*An older person contacted us because her care was being delivered in a way which meant she was often hungry (because visits were being conducted in a very short time period, leaving the rest of the day/night with no support to eat). In that specific case, the person had no knowledge of who the right person was to contact to make a complaint and what the process is and what protections there are for her in this process. **Surrey Coalition of Disabled People November 2020***

We raised a range of additional concerns:

24. Care workers do not always feel it is their responsibility to feed informal information back to their agency about the care their users receive. Few would consider raising a safeguarding alert without going through their agency management, or even know how to do this.

25. Some agencies' systems for capturing verbal client and care worker feedback are very informal and can be vulnerable to error and oversight.
26. Some agencies do not include care worker feedback or insight when reassessing or reviewing care plans for their clients.
27. Some care folders do not contain an accessible complaints procedure; some contain no information on safeguarding for either care user or care worker; some contain out of date information.
28. While Surrey County Council does include Engagement measures in its care agency Key Performance Indicators these do not explicitly cover quality of listening. The data generated in these KPIs around Complaints is subjective and may not be comparable across agencies.
29. The full report can be found here: <https://www.healthwatchesurrey.co.uk/wp-content/uploads/2019/09/Care-at-home-report-web.pdf>

Our recommendations

30. We recommended that commissioners should identify service users who cannot advocate for themselves, and have no emotionally involved advocate early in the care journey and be prepared to offer them additional support. Commissioners should enable access to funded advocacy and identify and support an organisation that could be tasked to represent domiciliary care service users.
31. Our recommendation to providers was that they should take the additional needs of these service users into account and provide appropriate and sensitive listening opportunities.
32. Care workers are not always confident of the value of their insight or empowered to use that insight on behalf of their clients. Not all agencies have robust systems for soliciting and recording care worker feedback or including them in care reviews. But care workers are the eyes and ears of the care system with unparalleled insight into their clients' needs: the system needs to ensure this insight is used to benefit care users. Tools and processes intended to enable people to make their voice heard - such as care folders and recording systems within agencies - are not always robust. Commissioners and providers need to ensure these tools are fit to support the people they serve.
33. Via our Helpdesk, we have recently heard from a care at home user whose experience resonates with what we heard in our 2019 research, with the user experiencing negative repercussions after complaining:

"Client had problem with one of the carer, this went on for over three weeks. Client complained to owners but was told to talk directly to the carer in question. This she did and resulted in carer responding to client in a non-pleasant manner and she left the house. Client is unable to carry out her basic needs. She has meals delivered but needs daily attention, she cannot use her legs and is unable to bend. However, client

is articulate and able to communicate and express her thoughts in an articulate way. After this incident the care company sent other helpers but they arrived unannounced and she was left with no help for a day or two". **124655, August 2020, Telephone (Helpdesk).**

Key findings from our agenda-free conversations.

34. The following are a selection of confidential case studies from the conversations Healthwatch Surrey has had with people over the last year.

Personal details have been removed to protect the anonymity of individuals.

All appropriate information and advice and signposting to provider complaints process has already been given by our partners.

35. Key areas where Healthwatch Surrey has recently heard insight which we feel is important for system learning are around care homes - visiting and isolation; rapid discharge from hospital; and the impact of the pandemic on carers.

Visiting guidance

36. Throughout the pandemic, we've heard of the detriment to physical and mental wellbeing caused by not being able to visit loved ones in care homes. As restrictions have eased people are beginning to question the fairness and implications of care home visiting policies:

37. *"In the early days of lock-down we were in agreement with our son not returning home as we thought this was a sensible approach. However since restrictions have been lifted we don't understand why he can't visit for an afternoon without being threatened with quarantining, or why we can't meet him in a public place without being supervised assuming that social distancing and face protection is in place."* **128029, September 2020, Waverley CAB**

38. *"A lady was told that she was not allowed to visit her mother in her care home at all until November as the home was going to 'shut down'. She is aware that the residents need protecting but she feels that she should be allowed to visit her mother outside or talk through a window (her mother has a garden room). She feels staff could enable visiting in a safe way."* **129960, October 2020, Telephone (helpdesk)**

39. *"I don't think NHS/policy makers understand the cognitive impact of no visits and the emotional impact on relatives.... We are on course to be severed from our partners on a semi-permanent basis..."* **126048, September 2020, Engagement Event**

40. Healthwatch Surrey comment: Care home residents have the right to autonomy and control over their private lives, they cannot be deprived of their liberty, and are entitled to make judgements on how to balance risks. But at the same time, they are not entitled to put others who do not have the same

risk appetite in harm's way. This is a dilemma for care homes and policymakers alike, but it is a problem that is likely to be with us for many months to come.

Isolation in care homes

41. We have heard about residents having to self-isolate in their rooms for two weeks at a time/ and that residents are anxious and not leaving rooms. They are therefore missing out on social interaction with other residents, they are eating alone in their rooms, with no activities.
42. *“On her return (from an outpatient hospital visit) her mother was informed that she had to completely self-isolate in her room for two weeks. The daughter thinks this was excessive and that one week would be more appropriate”.* **129960, October, Telephone (helpdesk)**
43. *“It's been really tough. I see my [family member] she will appear at window a few times a week but it's not the same. Before lockdown I had just settled in well and liked living here, I got to leave a lot and it was lovely. I now see hardly anyone, mainly my care worker and she is lovely. My [family member] visits now in the courtyard but we can't hug or touch and to be honest I'd rather not see her as it hurts. I miss our private chats in my room and of course she can't go in there now because of Covid. The communal areas are so quiet, nothing goes on. I miss interaction so much. We used to do exercises together and play chess. There was a lovely man who came into do reminiscence sessions and I miss him terribly. He was a volunteer and not allowed to visit and we don't do these things on computers. I eat on my own most days The others are so anxious they rarely leave their room now. I have hardly any conversations or stimulation”.* **124407, August 2020, Other Engagement Event**

Rapid discharge to home

44. A recent Healthwatch England report, derived from 590 people who had been discharged from hospital during the pandemic reported that:
- 82% of respondents did not receive a follow-up visit and assessment at home and almost one in five of these reported an unmet care need.
 - Some people felt their discharge was rushed, with around one in five (19%) feeling unprepared to leave hospital.
 - Over a third (35%) of people were not given a contact who they could get in touch with for further advice after discharge, despite this being part of the guidance.
 - Overall patients and families were very positive about healthcare staff, praising their efforts during such a difficult time.
 - Around a third (30%) of people faced an issue with delayed COVID-19 test results, potentially putting family and carers at risk, or in a care home, other residents and staff.

45. https://www.healthwatch.co.uk/sites/healthwatch.co.uk/files/20201026%20Peoples%20experiences%20of%20leaving%20hospital%20during%20COVID-19_0.pdf

46. We have heard similar experiences in Surrey, and we are aware that Action for Carers have also heard from carers about lack of support following discharge. We therefore believe there is a need for more evaluation of how the process is working locally.

47. *"The client is carer for her husband who has Parkinson's and dementia and she fell and broke her neck and was admitted to St. George's and her son moved to care for her husband whilst she was in hospital. The client was then discharged after major neck surgery five days later with only four days of medication and no assessment of the home situation. The hospital was aware of her caring duties and that her son did not live at home but was only staying to look after his father - he has young children of his own and needed to get back to them. There was twenty minutes warning that she was being sent home. Whilst there was a discharge note there was no wound care instructions, no request for district nursing support and no home from hospital support. The client fell within two hours of returning home. When client's son called the GP he was told that they had not received the discharge form and he scanned this across to the GP who has arranged the further medication required. The client's son has been unable to return to his family for the past two weeks because his mother is still weak and dizzy and because of her husband's dementia she is unfit to care for him". 120138 May 2020 Woking CAB*

48. *"Client contacted Local Citizen's Advice to ask about her husband's care. Her husband went into hospital start of February. He stayed there for 5 weeks. After these weeks they moved him to [hospital]. There he stayed for two weeks. In early April they discharged him from Hospital. His wife received some equipment in the afternoon and in the evening he came home. Client has the feeling that there was no guidance what to do next, no clear care plan. The hospital organised carers for her husband to help him wash and help with daily care. Her husband also needs physiotherapy and there someone did come but the client would not call that proper physio. Client got a phone call last week that they have used the six weeks care and need to move on to private support. But client does not know how to organise that and who she needs to contact. Client is looking for someone to coordinate the care her husband's needs."*

49. *"Client has the feeling that her husband was better when he went to the hospital than when he came back. Because he is paralysed, he cannot use his legs. Last Friday [date] May he collapsed, and client needed to ask a neighbour to help her to get him up. Client is worried about her husband's condition and the level of care he needs". 120139 May 2020 Woking CAB*

Discharge to care home during pandemic with no follow-up plan for rehabilitation

50. We have also heard about people being discharged from hospital to a care home.

51. *"The care home is comfortable, staff are largely nice and attentive, but he feels he is missing out on rehabilitation treatment (after being discharged from hospital to a*

care home after a stroke - due to the hospital being used for Covid patients) and is left not knowing what is going to happen in the future” 124862, August, Reigate & Banstead CAB

52. This chimes with an example from Age UK Surrey: *“Clients are being discharged too quickly from hospital and no formal assessment is being done before they go home, resulting in re-admission to hospital”.*

Impact on Carers

53. The impact on carers of day centres and other activities being shut down has been considerable.

a. *“I am a carer for my disabled sister, who before the lockdown was receiving social care activities 5 days a week, and respite was being organised for me (I have my own severe health issues). When lockdown was announced this activity stopped...me and my husband are exhausted and unsupported, we struggle to find activities for my sister to do and have no idea what support we can get.” 122103 June 2020 Woking CAB*

b. *“ALL DAY CENTRES were told to close. I do understand and want to keep people safe...my daughter is mid 20’s...has Cerebral Palsy, epilepsy, severe learning disabilities, blindness, and moderate deafness... This very much concerns my husband and I, as she is having more fits, due to lots of stress, and this is not good for her. She needs routines as also has autistic traits in her behaviour, and so change is not something she copes very well with, at all... Please we do NEED help with this.”119878 May 2020 Engagement Event*

54. Additional insight from Age UK Surrey

Age UK Surrey have heard about

- Issues in assuming family will be carers:
“one chap with dementia needed care. The care assessment was done on the one day his very ill brother visited him and took some shopping and tidied up a bit. Care was refused as his brother was said to be his carer. He isn’t. He is ill and lives in another county. He is completely incapable of acting as his carer and has no wish to”.
- Delays in carrying out care assessments
- Carers feeling isolated and unsupported - lack of help for carers with dementia, no day services etc.
- Lack of clarity in visiting care homes
“A lady in her eighties was visiting her husband who is in his nineties, in a care home - trying to talk to him through the window, whilst mowing /strimming in the background.”

- Some care homes are being dictatorial, one gentleman feels his human rights to have a married life are being challenged by the care home, - he wants to get his wife out of the care home.

What we learned

