
What we're hearing about Adult Social Care

February 2025



"My husband when into hospital and was diagnosed with an incurable disease. Everything was put in place at home, stairlift etc. The OT was amazing, the equipment was delivered promptly. He was in the Royal Surrey County Hospital for most of February. They have been good. We got the equipment from Millbrook. Guildford Borough Council fitted the stairlift, the GP at Send surgery had organised everything before we came out of hospital."

"My son lives in supported living and I have just received a letter about a review of his finances. I'm not sure where to start."



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Contents

Contents	2
Executive summary.....	4
Introduction and approach	4
Key themes	5
Positive experiences.....	5
Financial assessments and communication.....	5
Sudden annual reviews with short deadlines	5
Lack of social care assessment before or at discharge from hospital	5
Difficulty in finding PAs	6
Continuing Healthcare confusion	6
Inconsistent responses to Helpdesk from different social workers across different locality teams.....	6
Recommendations	7
Deep dive into financial assessments and communication	9
Vulnerable people not receiving support to complete forms.....	9
Financial assessments not being dealt with in a timely manner	11
Back payment requested following financial assessment	12
Out of the blue financial reviews with short deadlines	13
Domiciliary care –capital depletion.....	15
Positive experiences.....	16
Lack of social care assessment at discharge from hospital	17
Direct Payments and difficulty finding PAs.....	19
CHC funding stopped	19
CHC not offered	20
Safeguarding dispute	21
Care home finance issues.....	21

Appendix.....	24
Involvement of unpaid carers in care home residents' care.....	24
Giving Carers a Voice Quarterly report – main themes.....	25
Carers lack of involvement in care plans in care homes.....	25
Combating Drugs Partnership Board Public Involvement – quarterly report	26
Feedback on priority populations shared with Public Health	28
Thank you.....	28
About Healthwatch Surrey.....	29
Contact us.....	29

Executive summary

This report brings together experiences shared with us by people who have proactively contacted our Helpdesk, who we have spoken to at community engagement events, input from local Citizen's Advice, as well as drawing on reports and projects from within our Luminus team.

We have included some of the themes that people have told us about, such as: information about care and support not being offered before or at hospital discharge, difficulty in finding PAs, and confusion with Continuing Health Care.

It is worth noting that we do hear some positive experiences about social care. However, much of what we hear via our Helpdesk are examples where people have already been in touch with the right channels for information and advice and are still frustrated by the process and turn to Healthwatch as a last resort.

When we do community engagement, people often say that they don't have experience of social care. When the conversation progresses, they sometime tell us about hospital discharge and help they've had from the local or county council (without necessarily realising this is social care).

Introduction and approach

This report is designed to highlight the themes we have been hearing about and includes quotes from local people to provide context on these themes. Whilst this report accurately reflects what we hear from the individuals we speak to, we are aware that it may not be representative of everyone's views of a particular service.

Any urgent or concerning experiences within this report have been escalated to the appropriate teams. All appropriate information and signposting has already been given.

If you would like more information or examples of what people have shared, please get in touch.

Key themes

Positive experiences

We do hear some positive experiences about social care. However, much of what we hear via our Helpdesk are examples where people have already been in touch with the right channels for information and advice and are still frustrated by the process and turn to Healthwatch as a last resort. When we do community engagement, people often say that they don't have experience of social care. When the conversation progresses, they sometime tell us about hospital discharge and help they've had from the local or county council (without necessarily realising this is social care). Examples are included in the appendix.

Financial assessments and communication

We have heard about several experiences regarding financial issues. They are all linked by a lack of understanding/ poor communication. In all cases, a package of support was put in place without clear explanation or understanding of how much the service user would have to pay. Some people report they have had no financial assessment; others have had partial assessments, but still been issued with invoices. We have also heard about vulnerable people who are not offered assistance in liaising with ASC.

Sudden annual reviews with short deadlines

The Luminus GCAV team have recently told us about carers who report they are receiving letters out of the blue, with less than a month to complete the forms for new financial assessments. These carers tell us they have not had a financial assessment for many years.

Lack of social care assessment before or at discharge from hospital

Citizens advice have shared with us some cases where people are not being given the information and advice they require when in hospital or at discharge.

Difficulty in finding PAs

We heard from Action for Carers about an example where a person is struggling to find a Personal Assistant (PA) to cover the awarded hours as they are too short. They have been given mixed messages about whether Surrey County Council (SCC) can share a list of agencies where they can use their direct payments.

Action for Carers Surrey also raised the issue around care agencies and PAs being paid differently and the implications for people. Once travel time has been factored in for PAs, some PAs would not earn the minimum wage.

Continuing Healthcare confusion

We have also heard two specific experiences about Continuing Healthcare (CHC). One experience was where a family was told following a hospital stay, that CHC funding would be stopped due to their son turning 21, (which was deemed a change in circumstances) and that he would have to live in supported living, rather than in the family home.

We also heard via Citizen's Advice about an elderly person who was eligible for CHC but had not been told about this by either the health or social care sector. Her family had turned to Citizen's Advice for information.

Inconsistent responses to Helpdesk from different social workers across different locality teams

Our Helpdesk is often contacted by people who are struggling with social care. In November we heard from a man whose elderly wife has a serious medical condition, with numerous hospital visits. He initially called us as he was worried that his wife needed to be admitted to hospital and they had been waiting for 6.5 hours for an ambulance. He himself had been discharged from hospital 5 weeks ago with a care package.

"I have serious breathing difficulties and need medication and other help. I received a letter today from SCC Woking Locality team saying that they would have to engage a new care agency and establish a contract, and they would get back to me."

225285 November 2024

He gave Helpdesk permission to contact Woking Locality team on his behalf.

However, we have had no response from Woking locality team (also shared with SCC ASC customer care team).

In contrast, when we have share issues with other locality teams, (and other social workers) some have responded quickly and have given us the information we wanted, or agreed to follow up as requested.

For example, we were contacted by someone from Redhill, who needed support. They put us in touch with their probation officer. We spoke to a senior social care practitioner who contacted the probation officer, and helped the client to access social care, and made a referral to the local mental health services.

What we would like from Locality teams is an acknowledgement of our email – and then confirmation that the team are aware of the person and their situation and that the locality team can take it forward.

It would also be useful if the locality team could advise us on what more we can do.

The main thing we hear about via the Helpdesk is the difficulty people have in getting hold of their social worker.

Recommendations

Theme	Evidence	Recommendations
		We recommend that AHWP directorate considers the following:
Vulnerable people not receiving support to complete forms	<p>A visually impaired person was sent invoices from SCC for her care without a full financial assessment being completed.</p> <p>An elderly person was asked to complete forms that he didn't understand.</p>	<p>If SCC is signposting people to CA and Age UK,</p> <ul style="list-style-type: none"> • Check that they are adequately resourced? • Track how much social workers are referring/signposting to CA and how long it takes for clients to get support? • Use this as a source of intel?

		<ul style="list-style-type: none"> Have a feedback mechanism, so improvements can be made?
Incomplete financial assessments	A person was sent invoices for care which she could not afford.	Ensure that invoices are not issued until a full financial assessment has taken place.
Communication	A person has been asked to pay tens of thousands of pounds in back payment for support from Headway.	Ensure that when a person is signposted to support such as Headway, they are told that payment is required.
Unpaid care home fees	2 people have told us that they have been threatened with court for unpaid care home fees.	Evaluate/check how well people/their families understand the financial commitment before care starts.
Poor communication re self-funder's payments for care at home	Family have been told to sell the family home to fund care despite the person still living in the house.	Investigate where refresher training for staff is needed to ensure correct information is given.
CHC funding stopped	A young man's family was told that his CHC funding would stop and that he'd have to go to residential care.	Ensure that interactions with families are considered and that care is truly person centred.
CHC funding not offered	An elderly person was not offered CHC despite being eligible and having many interactions with health.	Ensure that health and social care teams are fully aware of the eligibility criteria for CHC.

Deep dive into financial assessments and communication

All of the experiences below are linked by a lack of understanding/ poor communication about finance. In all cases, support was put in place without clear explanation or understanding of how much the person would have to pay.

Some people told us that they have had no financial assessment, others told us they have had partial assessments but have still been issued with invoices.

Citizen's Advice Woking told us:

"The main theme that runs through the cases that are being seen across Surrey is the lack of information about help and support to clients and their carers from health and adult social care, and people turn to the voluntary sector for this information and support."

Vulnerable people not receiving support to complete forms

Healthwatch Surrey has an arrangement with Citizen's Advice Woking who collate relevant health and social care cases from across Surrey on a quarterly basis. In the experience below, a visually impaired person was sent invoices from Surrey County Council for her care without a full financial assessment being completed.

Case Study 1

A person contacted Citizen's Advice (CA) to apply for a Blue Badge. The adviser did a home visit and discovered she was in a hospital bed in a downstairs room after falling and badly breaking her knee which will have a frame around it for the next 6 months. She also has very low vision due to wet and dry macular degeneration and is registered partially sighted. She finds paperwork extremely difficult to manage. She also has COPD and emphysema, arthritis, and heart problems. She needs aids to help cook,

wash, dress, manage paperwork and finances. The leg frame will be in situ until December and she will need physiotherapy afterwards to regain some mobility. Her failing eyesight contributed to her fall in the bathroom leading to fractured tibia and ribs. Surrey County Council had not conducted a full financial assessment but had sent a bill for £92.76 a week for care which she was struggling to pay. The CA adviser called the Financial Assessment team who agreed to halt invoices until a proper assessment had been carried out. She then received a letter arranging a telephone appointment, asking her to have evidence of her financial situation available for the call. She contacted the CA adviser again to ask if they could attend at the time of the telephone appointment because she could not gather all the information given her current circumstances and would not be able to read it in any event. The CA adviser did attend to support and once the assessment had been done, the care costs were reduced to £14.35 a week.

Questions:

- Why was a bill of £92.76 sent before a full financial assessment was carried out. How long would that have gone on if Citizen's Advice had not been involved?
- Why did the Financial Assessment team not do a home visit when the person was so vulnerable?
- How would this person have managed without the help and support of CA?
- Should this person have been offered a Care Act advocate?

Case study 2

In another case from CAW:

"I am 78 as is my wife. My wife is in hospital and due out Tuesday and I have been asked to do a finance assessment for a care package. I have been emailed a form which I do not understand, can you help me urgently please, I can visit."

Both the client and his wife are in receipt of evening rate Attendance Allowance which indicates they both have poor health and are vulnerable. An adviser called the Financial Assessment & Income Collections at Surrey

County Council on behalf of the client and an extension of 2 weeks was granted, but there was no offer for ASC to do a home visit and complete the form. The adviser told the person they spoke to that a chasing email had already been sent and the client was very anxious.

The response was:

“the email is automated and cannot be stopped, just ignore it.”

But the anxiety has already been caused just by the email being sent. A home visit was arranged on the day the wife was discharged from hospital. The form was completed but the couple did not know how much things will cost such as creams etc. not covered on prescription and incontinence pads, so these figures had to be estimated. The wife also had an electric hospital bed which is switched on 24/7 for the pressure pads. The form was submitted but no financial assessment yet has been received by the client.

Financial assessments not being dealt with in a timely manner

Surrey County Council sent a referral on 1st October to the local Citizens Advice to ask whether a 77-year-old lady would be eligible for Carer's Allowance as she was looking after her husband, who is unable to walk. He sleeps downstairs in a hospital bed.

The husband was discharged from hospital in March 2024 and the client self-funded his care of £4,500 a month until their capital fell below the £23,250. At that point they had a visit from a social worker who did an assessment and decided that an Occupational Therapist Report should be conducted. The clients are incredibly pleased with the company that are providing the care but the rates for this company are above the amount the Local Authority (LA) will pay and therefore there will be a shortfall of £800 a month when the LA start to pay. The client thought the LA would start to pay from mid-September, but the client was told that she would need to continue to self-fund until the OT Report was available.

At the beginning of November, ASC told the client to start making the reduced payments of £800 to the care company but by the end of

November, the LA had not made any payments to the care company. This was worrying the client. When the client spoke to the social worker, she was told the LA were looking to reduce the number of care visits from 4 to 2 a day and to replace the current company with a cheaper one. The client was told she could retain the care company if she could pay the difference, which the client would struggle to do.

For the local Citizens Advice to help the client and her husband a request was sent to the ASC Financial Assessment team for a copy of the financial assessment and care package. Without this it was not possible to check whether the client and her husband were eligible for any additional benefits and to work out whether they could afford to pay any shortfall for care. The authorisation form signed by the client and her husband was sent to the ASC Financial Assessment team on 12th December. No response yet had been received.

The entire situation has left the client extremely distressed as she feels that she is not being supported and her husband is a risk of not being cared for properly.

Back payment requested following financial assessment

One person, who had experienced a traumatic brain injury and attended Headway for many years, was unaware that this would need to be paid for. A financial assessment was recently carried out and she has now been asked to pay for the previous 4 years of visits to Headway – this amounts to tens of thousands of pounds.

The financial assessment also stated that she had cleaners, which was incorrect.

The statement below from her daughter demonstrates the impact this has had on the person.

“The social worker called her up and told her all of this over the phone and it really upset my mum. She was hysterical and I had to leave work to calm her down.

She has now stopped going to the Headway group, so she is now completely isolated and won't accept any help because she is worried that she will be charged. The charity

have been fabulous, but social services are the ones who are upsetting her.”

222585 October 2024

Question: When a person is signposted to support such as Headway, are they told that payment is required?

Out of the blue financial reviews with short deadlines

The Luminus Giving Carers a Voice team share the following experiences with us which they were told at a carers group. It appears that they have sent out a block mail out and its really taken carers by surprise. It's caused a lot of worry too. Carers have enough to do without being sent reams of paperwork to fill out.

“My daughter (in her 30s) lives with me, as her complex needs make it difficult to find somewhere for her to live independently. I have tried to find a suitable placement, but they can't cope with her. She needs to be kept occupied constantly. I now have carers 3 times a week who take her out and she attends a day centre [post 19] too. At weekends I spend all my time taking her out to keep her occupied – it costs a fortune! If I don't, she self-harms and rips her clothing. That's an additional cost if I can't repair the damage. It's all so tiring and stressful.

[Carer was very agitated and tearful].

I then received this letter from SCC about an annual review of her charges. There are reams of paperwork for me to fill out. She has had funding for 10 years and never had a review. I'm worried that they'll look at what I'm spending her money on and take it away and then I don't know how I'll cope. I don't mind making a contribution to costs, but I'm so scared about a reduction, or it all being taken away. I just don't know how I will cope. I'm just about clinging on with the help I get now.

The letter is dated the 9th January and I've been worried since then [now 24 Jan] It needs to be completed by the 31

January. How do I start? I don't know where to begin. This has just thrown me into a total spin.

The last time anyone from the council talked to me about her finances was 10 years ago when she left Young Epilepsy. They talked about what money she had and then left. I haven't had any contact since then and so this came as a real shock.

I can't sleep for worry. Any reduction would be disastrous. If I am unable to pay carers to take her out, her behaviour will deteriorate, and the self-harm and clothes ripping will escalate. I'll have to fill the gap and I'm just exhausted as it is. I cope with the weekends as I know that she is out and about during the week. I really would like someone to sit down and help me with the forms on a one-to-one basis. [Action for carers support worker then helped the lady to fill out the form. This took over an hour.]

My GP referred her to the continence services, and she originally had pull ups. This was changed to pads; I assume because of money. She will use the pads occasionally but the pull ups are better and so I now buy these for her.

GCAV January 2025

My son [21] lives in supported living and I have just received a letter about a review of his finances. I'm not sure where to start. Do you need to provide receipts for everything? It's all overwhelming. They want so much information. What if I get it wrong? I did ring the finance department yesterday and they said that they are trying to estimate if he needs to make a contribution.

I'm going to have to set aside some time to go through all this paperwork and make sure I get everything correct. It's an additional stress, that I could do without.

GCAV January 2025

Domiciliary care –capital depletion

One family told us that, having self-funded 24/7 carers for 4 years, and now run out of funds, SCC adult social care team said that their mum only requires carers 4 times per day, (which the family don't agree with) and suggested that the family home is sold to pay for it.

“Mum is 95, has Alzheimer's and vascular dementia. She has had 24/7 care for 4 years since she broke her hip. Recently she has needed to be hoisted out of her bed, she is incontinent, she can't walk, she can't feed herself and her food needs to be pureed. The carers get her up, so an OT [Occupational Therapist] has given her a chair on wheels. We have been self-funding for the past 4 years, and we are now well below the threshold. There have been 3 assessments that have been conducted by adult social care. Adult social care has now said that she does not need full-time carers, and they want her to have carers 4 times a day, leaving her alone for the rest of the day. The social worker said that they can leave water for her, even though she can't lift a cup. I am concerned that she would have a mini stroke, while she is left. They have also said that we could sell the house to pay for her care, but I live with mum, so that would make me (and mum) homeless.”

222039 September 24

Question: Why have the family been told that they could sell the house to pay for the care – if SCC is suggesting paid for care workers 4 times per day?

Surrey County Council website states:

You will have to pay the full cost of your care if your capital is above £24,500. This is called the 'Capital Threshold'. We do not take into account the value of your main and only home whilst you continue to live there. If you own a property which you do not live in, the value will be taken into account in the financial assessment.

Positive experiences

When on engagement in Woking at the leisure centre we spoke to people who had attended the over 50s club with the aim of talking to them about social care experiences. Initially several people said they didn't have social care experiences but as the conversation progressed it became apparent that they did.

We also spoke to an exercise class teacher who told us about many people who are unpaid/unrecognized carers who are managing by themselves. In some cases they are afraid that their partner may be put in a care home.

"My husband when into hospital and was diagnosed with an incurable disease. Everything was put in place at home, stairlift etc. The OT was amazing, the equipment was delivered promptly. He was in the Royal Surrey County Hospital for most of February. He had 3 separate visits. They have been good. We got the equipment from Millbrook. Guildford Borough Council fitted the stairlift, the GP at Send surgery had organised everything before we came out of hospital."

226608 December 2024

"My father in law has carers 4 times per day. He has had enough (of life) he is 89. He can't see, he has a zimmer frame I go to see him twice per day, my sister in law goes to see him too. He's lonely, he doesn't want to go out to community centres etc. He is embarrassed, he has continence issues, and that is stopping him from going out. He does get pads from the GP. He is lonely at night, when everything is still and quiet. He has got a panic button, they call him occasionally to check he is ok. The other reason he won't go to day centres is because he speaks broken English, he worries that people wouldn't be able to understand him, because he also had a mini stroke 8/9 months ago which affected his speech. He is worried about being outside the home. After the stroke, he was discharged from St Peter's to Abbey

Chase, he was there for 2-3 months. He also went to a care home in West Byfleet after he had a fall and fractured his arm. He was there for a couple of months. He did enjoy being in the homes, he appreciated the fact that there was always someone there. He now asks the family to stay overnight with him, but we can't do it regularly. He has had a care needs assessment."

226603 December 2024

"I teach senior exercises my clients are aged 60-92. a lot of them have partners who have dementia. It's a huge problem, a lot of them are not getting the support they need. One lady's husband was in hospital, he bounced back, but they said he could only go home with a care package in place. But he didn't like the carers. She is in her 80s and she is trying to cope with him on her own. Their family live far away.

Another couple - the lady is 88 and the man is 90 have been left to their own devices, the lady has dementia, they are struggling but they say they can manage. She is terrified that he will take her away. He has osteoporosis - one of these days he's going to collapse."

226609 December 2024

Lack of social care assessment at discharge from hospital

From Citizens Advice Aug- Sept

There still seems to be a lack of information being provided to patients and their carers before or at the time of discharge from hospital about what care and services can be provided.

"Client is 79, blind and lives alone. She had a fall and broke her femur, cracked her hip, and dislocated her arm and was struggling with everyday tasks. She uses a walking stick, wheeled walker, uses a stair lift, medical alert button, a bath lift, handrails inside/outside the house, and has a frame over

her toilet. She wears hearing aids and a talking watch that tells the date and time. She has an easy reader that she can put letters under to scan which then reads them out to her. She has a guide dog. She relies heavily on family and friends for general care and assistance, and to take her to appointments etc. Even though the client is under the care of her GP and more than one hospital department, no one has suggested an ASC assessment. The client is fortunate that she has family and friends who will help but this is not sustainable for those friends and family. The client is already struggling financially to meet all her care costs, and the reason Citizens Advice was contacted was because one of her family members asked whether there was any other way her income could be increased so the client could buy in more help. With all the contact this client has with health, why is this information not readily available”

CAW Aug-September report

“Client’s parents are 88 and 92 and live in Leatherhead. His mother, who has been caring for his frail father at home, is now in hospital with terminal cancer. The hospital is talking about discharging her home. The client is concerned about both his parents and what help would be available, both from a care perspective and a financial aspect.

Before his mother was ill, ASC had not been involved as with some family support, the couple had remained independent. The client did not feel the hospital were giving them any information about what the next step should be, and although the family had been taking it in turns to care for the father, that was not a long-term solution.

The client was given (by CA) a lot of information about how to contact ASC for an assessment for both his parents, and what should happen before his mother was discharged from hospital. He was told about Lasting Power of Attorneys (although there is currently a 20 week back log in these being issued), as well as the potential entitlement for both his parents for Attendance Allowance.

The client had not been in this situation before and felt totally overwhelmed because he did not know what help and support was available and was finding it hard to find out from the hospital what was going to happen.”

CAW report June– July

Direct Payments and difficulty finding PAs

We heard from Action for Carers about a person who is struggling to find a PA to cover their awarded hours as they are too short.

They have been given mixed messages about whether SCC can share a list of agencies where they can use with their direct payments.

Action for Carers also raised the issue around care agencies and PAs being paid differently and the implications of this. Once travel time has been factored in for PAs, some PAs would not earn [the](#) minimum wage.

This person was struggling to find a PA to work the awarded daily 45-minute morning personal care visit and a 3 hour weekly social visit. They spoke to SILC who said it would be virtually impossible to hire a PA with those hours. The person then looked at a care agency but as they are more expensive, they asked about reducing the required hours, but this was refused by SCC. They then asked the local team for information about other agencies:

“The client has also been told that he could go to another care agency with their direct payments, but the social worker has said that they can not disclose this. However, the Action for Carers Surrey worker has contacted the duty team, and was told that they do disclose.”

223389 October 2024

CHC funding stopped

When a young man with complex needs was discharged from hospital, his family were told that his CHC funding (which he uses for PAs) would stop

as it had been downgraded, and that he would have to go into a supported living facility, which the family don't want. The young man has had bad experiences in care/nursing homes in the past. There was also some confusion regarding finances. The family had not been told how much their budget was, so they had been underspending.

"We received an internal document that said that we had £7,000 in a bank, but we were not aware of that, we always spend the minimum. It is causing so much stress for us and our family. We have looked after him since he was 2, and since he has turned 21 they want to put him in-to residential care.

There has been no changes in circumstances. They have said that it should be covered by PIP. I feel like they are trying to take away my son. They have said that it's been taken away from us due to a change in circumstances."

222782 October 2024

Question: How does this represent person centred care?

Why would ASC be willing to pay for him to live in a nursing home, but not for him to live at home with PA support?

CHC not offered

Citizens Advice Elmbridge West received the following email:

"My mother lives alone aged 89 and has been discharged from hospital with a dissected aorta, this happened 2 years ago and has had a recent further dissection and returned to her home. She is paying for carer's and is above the threshold in savings for help. **Question:** as this is a medical problem and her blood pressure critical to her life, although returned home for end of life, should there be help looking after her medical problem at home as opposed to using her limited savings?"

The mother was not offered any intermediate care as she already had care in place before she went into hospital. The son wanted to know if there

is any available help that is not means tested. The mother has savings of more than £24,000 but these are rapidly reducing as she is having to pay for the care. People can ask for an assessment for NHS continuing healthcare if a GP or other health professional arrange this. If the initial screening is positive, then the mother will be eligible for a full assessment of her needs. The son was going to contact the GP to try and arrange this. The person was also referred to Beacon who offer free independent advice about continuing healthcare. But this information was forthcoming from Citizens Advice and not the health and social care sector.

Safeguarding dispute

A safeguarding concern was raised against the parent carers of a young man with complex needs. They believe that it was due to them not spending the allocated funds, due to an ongoing dispute over the hourly rate of pay necessary to attract a suitable calibre of carer for their son. They said that this situation had persisted since their son turned 24 in March 2022, when CHC formally took over his care from SCC and despite the same arrangement they were seeking having been in place for the previous two years.

The parents wanted to have this safeguarding concern removed from their son's record.

Care home finance issues

Concerns about money running out

"My mother in law is in [named] care home. My father-in-law is in the family home still. Nobody at the home seems to be able to tell me what will happen when we can't afford to pay the fees anymore. The finance manager mentioned a financial assessment by Surrey County Council but nothing more. They are useless. What happens if their contribution doesn't match the fees, will we have to make up the difference? Are her nursing fees taken into account? Will we potentially have to look for a cheaper home? They couldn't answer any of these questions.

[Signposted Age UK and SOLLA, Action for carers, self-funders report on our website]

223926 November 2024

Unpaid care home fees

We have heard about 2 incidences where people have unpaid care home fees and are being threatened with being taken to court.

One person applied for admission to a care home via SCC (she has a named social worker and this care was funded by SCC). She moved to one care home but then had to move again as she said she needed ground floor accommodation. She found this herself as her social worker said she couldn't find anything suitable. She has now been issued with an eviction notice and court for unpaid fees.

She has been able to fund private healthcare and says she has had no formal financial assessment. The financial picture is confusing, as initially her residential care was funded by SCC, and then when she moved, she was accepted as a self-funder.

A separate issue is that social care assessors have now told her that she does not need to be in a care home.

"I have an eviction notice and a notice to say that they are going to take me to court for unpaid fees and be made bankrupt. I was told on 17th July that I would be evicted, but the care home manager has been very nice to me. Some Elmbridge Social Care assessors came today –they told me that I don't need to be in a care home because I can wash myself, dress myself and sit on the toilet. I have so many other things that I can't do. I can't put my arms above my head. I only wash under the cold tap because I can't do anything else.

They said that I don't qualify for a care home, and I need to find somewhere else to live. I should go to the Council and ask for sheltered housing, but I need much more care than

that. I have no funds for Sheltered Housing because I'd have to pay for food and electricity etc, and I can't do things for myself. I can't touch my knees, and I need a walker to get round as I can't walk properly. I have reconstructed legs with pins in them. I have had no formal financial assessment. I only have my pension and a higher rate disability pension. I have spent all my money on private healthcare because I can't get seen on the NHS."

221125 August 2024

Questions:

- How can she be eligible for funding by SCC at the first care home, and then accepted at the next care home as a self funder?
- How can she have been accepted into a care home without funds being in place/payment being set up?
- How can she be assessed as needing residential care initially, and now appears not to require it?

In the second experience, we heard from a care home daughter. She said that her mother was placed in a residential care home against her will (she'd rather be at home) during the pandemic under Discharge to Assess due to a stroke which left her with complex care needs. The regional care home manager says they cannot meet her needs. She has had a CHC assessment which found that her needs mean that she requires a nursing home although she doesn't meet the criteria for CHC funding. The daughter either wants her at home with 24/7 care or to be placed in a nursing home which can meet her needs.

ASC have said that she can leave at any time. Her mother has physical health needs and mental health needs.

ASC say because her primary needs are physical CHC should fund this. The mum has capacity and therefore does not qualify for advocacy.

Beacon are the provider for advocacy for CHC but this comes with a cost, after an initial phone call of 60-90 minutes which is funded by the NHS.

ASC now say the daughter needs legal advice regarding the unpaid care home fees, for which her mother is being taken to court.

The daughter has had legal advice from Citizen's Advice.

Question: What can be done to ensure that people are prevented from falling through the gaps in service between ASC and CHC?

Appendix

Involvement of unpaid carers in care home residents' care

The Luminus Giving Carers a Voice team have recently conducted a project which highlighted the importance of involving unpaid carers fully as a valued part of the caring team, particularly via regular communication.

Giving Carers a Voice Quarterly report – main themes

The Luminus Giving Carers a Voice team have heard the following main themes from carers (over 18) this quarter:

- Stress and wellbeing – the impact of caring
- Difficulty accessing information and support
- Struggles for parent carers
- Not acknowledging and understanding autism
- Difficulties for under 18s who are carers
- Coping when your caring role changes.

More detail can be found in the report:

[Giving-Carers-a-Voice-Insight-Report-July-September-2024.pdf](#)

Carers lack of involvement in care plans in care homes

The Giving Carers a Voice team have recently conducted a project which investigated to what extent care homes understand the role and importance of unpaid carers, including such aspects as involvement in care planning and recognising signs of deterioration. The way care home staff interact with unpaid carers is a key part of the Enhanced Health in Care Home framework. It is widely recognised that unpaid carers are often an invaluable source of support for people living in care homes, but the commissioner for this project expressed wanting to set out practically what that means for care home providers.

The intention is to produce a toolkit with steps providers can take to improve relationships with carers, involving them in care and support planning, and ultimately find a balance that helps to support good outcomes for both the resident and their carer long-term.

The findings and recommendations from this work will also shape the res/nursing specification and work being done with the market to improve personalised care approaches, particularly for people with behaviour that is challenging or distressing. The study concluded that the following are important to unpaid carers:

- Regular communication

- Feeling that they are part of the caring team
- Access to management when issues arise
- Involvement of the resident in a range of activities and outings
- Listening to wishes and preferences such as dietary choices
- Concerns are mainly about funding and withdrawal of Continuing Health Care (CHC).

This ties in with the findings of our “carers’ experiences of hospital discharge” project from 2021, which found that the more that carers were involved and consulted in the discharge process and post discharge plans, the better the outcome for the patient and the carer.

The recommendations from this project were:

1. **Carer identification and key contact identification.** Work to reveal patients’ unacknowledged carers Focus communication through a single point of contact where possible
2. **Review processes and practices relating to hospital-carer communications – how do wards/teams contact carers?** Consider codesign of communication pathways with patients and carers
3. **Explain the discharge process to carers: include job titles and named staff.** Consider codesign of a guide for inpatients/carers
4. **Think HANDOVER, not ‘discharge’.** Provide a professional, efficient HANDOVER of the patient to the carer.

Combating Drugs Partnership Board Public Involvement – quarterly report

The Luminus Combating Drugs Partnership Public Involvement team’s area of focus for Q2 was on generational shift in demand. They engaged with young carers, students, individuals that identify as LGBTQ+, and families who had lived or living experience with treatment and support.

Key themes:

Support networks

They found young people’s friendship groups have a huge impact on whether they are using substances and influence which substances they

are using. Young people told us they would choose not to be with certain people because they are using substances, they also told us they would avoid certain places or friendship groups because of drug association. Peer support and the power of a good friend plays a key role in young people seeking help. Some young people told us they were worried about friends, identifying that their friend has problematic, risky use and wanting to share information with them by picking up a leaflet 'for my friend'. Staff on the ground doing youth work, told us they require clear information and support for wider determinants of health for them to be able to support young people away from drugs and alcohol to make better choices.

Barriers to having inter-generational conversations

People told us about stigma when talking about smoking and problematic alcohol use. They told us because it's legal it's seen as someone's own lifestyle choice and therefore, is harder to broach. The barriers to having conversations about other people's lifestyle choices starts from early on with the young people we spoke to. Young carers, carers/family, told us how they have had to deal with a parent or sibling who have both mental health issues and substance use issues. These issues around substance use were very often normalised at home. They felt that they themselves were not able or equipped to have conversations about problematic use and wouldn't know how to signpost to support and treatment services. Some of the older people we spoke to found it hard to talk about their mental health with their older parents. Stigma, even in older people, was apparent, hiding their substance use and not speaking about it to family/friends.

Culture

We heard that dealing or using can for some, be just a way of life and part of living in a particular area. We heard some experiences about life revolving around drinking at the local social club being told 'it's what we did growing up'. We heard that for some, drugs were readily available at home or through friends. Seeing friends or a parents substance use normalised their own. We heard from many, that people were using substances to cope with poor mental health. Cannabis use was widely accepted across generations.

Feedback on priority populations shared with Public Health

We recently shared feedback looking at the priority populations with the public health team.

We found that some of the people within the priority populations intersect with other priority populations. The impact of living with multiple issues is enormous. Many of the people we heard from had experiences of social care.

[What-were-hearing-about-Surreys-priority-populations-prepared-for-Public-Health-October-2024.pdf](#)

Thank you

We would like to thank everyone who gave their time and shared their experiences with us.

We would also like to thank our volunteers who supported us on these visits/during our engagement session and to the staff team who welcomed us.

About Healthwatch Surrey

Healthwatch Surrey champions the voice of local people to shape, improve and get the best from NHS, health and social care services. As an independent statutory body, we have the power 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.

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We are proud to be commended in the National Healthwatch Impact Awards, recognising our work helping to improve local NHS and social care. You can view [our video](#) highlighting how feedback has enabled us to make positive changes to health and social care services.



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.

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