My Care at Home (2023/24)

Interviews with home care customers

Published May 2024

healthwatch Suffolk

Trusted Insights

Contents

Navigate this report.

1. About Healthwatch Suffolk C.I.C

Healthwatch Suffolk C.I.C is a social enterprise delivering insight to shape local NHS and social care. We passionately believe that listening and responding to people's lived experiences is vital to create health and care services that work for everyone.

We collect and share lived experience to improve standards of health and social care in Suffolk, regionally and nationally. Our independent role is enshrined in law, supported by trusted data and embedded in local integrated care systems by established relationships with partners.

Our service is founded on long-standing values of transparency, accountability and accessibility. We want everybody to feel equally valued, listened to, seen and heard.

Our core purpose is to...

Collect and share lived experience to influence better standards of health and social care.

We live and breathe...

Co-production in everything possible. We are inclusive, transparent, accessible, and accountable. We believe passionately that listening and responding to lived experience is vital to create health and care services that meet people's needs.

For more information about our role, and how we are inclusive, please visit our website.

2. About this report

This report summarises the insights from qualitative interviews with home care customers in Suffolk. It is a part of a series of reports published to help Suffolk County Council to explore the quality of local home care provision.

Specifically, the purpose of the research has been:

- to support Suffolk County Council (SCC) to monitor the quality of home care provision in Suffolk, and to provide an ongoing assessment about whether care is meeting the needs of service users and their carers.
- to obtain meaningful insights from people that can make services better.
- to obtain meaningful insight into the experiences of people delivering home care (Carers), to understand the issues and challenges they face, with a view to feeding this into any workforce strategy or plans around recruitment and retention within the care sector.
- to inform the development of home care workforce plans and strategies.

Other reports associated with this project can be found at https://healthwatchsuffolk.co.uk/homecare/.

3. Who took part?

Key information about who took part in our interviews and some context about their experiences.

Our interview participants

A total of ten interviews were conducted as part of the 'My Care at Home' (2023) project.

- Four respondents were people in receipt of homecare services, and six were family or informal carers of someone who received home care.
- Four interviews related to customers receiving care in the Ipswich and east area. Three were about customers living in Mid Suffolk and Babergh. Two interviews related to care being delivered in Waveney and one interview was about someone living in the west of the county.
- Customers had a variety of different support needs, ranging from those who were entirely bedridden as a result of their health condition (e.g., because of a stroke) to those who were still active members of their community. In addition, one customer had dementia, one required support for their mental health needs and one interview related to two young adults with significant neurological conditions.
- The size of customer's care packages reflected the complexity of people's needs and the amount of informal/ family support available. In four instances the customer lived alone.
- Interviews with family/informal carers tended to be about customers with more complex support needs, where the customer could not participate in the conversation themselves.
- All of the experiences related to different care agencies.
- Five respondents had experience of receiving care from more than one agency (excluding Home First). Changes in agency occurred when:
    - the family requested a change, (due to concerns regarding the quality of care being delivered).
    - the care agency was no longer able to deliver care (e.g., went bankrupt or no longer covered that area of Suffolk etc.).
- the customer had multiple 'one off' hospital inpatient stays from which they had recovered.
- Three respondents reported they or the customer had been receiving home care for less than a year, two customers had been receiving care for between one and three years, and three customers had been receiving home care for five or more years.
- Nine of the care packages were set up to support a hospital discharge. The remaining case involved two young adults who had transitioned from children's services.

We would like to acknowledge and thank each and every one of our interview participants for sharing their personal lived experiences of home care support.

Participant summary

Role	Locality	Main support needs	Visits per day
Customer	Ipswich	Fall or mobility	2
Family carer	West	Stroke (Bedridden)	4
Family carer	Ipswich	Dementia	2
Family carer	Waveney	Neurological degenerative condition, autism, learning disability and visual impairment	2
Customer	Ipswich	Mobility	3
Informal carer	Babergh	Stroke (Bedridden)	4
Customer	Waveney	Disability or mobility	2
Informal carer	Mid Suffolk	Bedridden	4
Family carer	East	Bedridden	2
Customer	Mid Suffolk	Mobility and mental health	2

“We didn’t know what they were going to do. My dad was discharged home with a PEG [tube] for feeding. We’d had some training, but we weren’t going to do that. We thought the carers would do all of that. [The carers] came in later that day, and they didn’t really have a clue. They didn’t know what they were there for either. They didn’t have very much information.”

4. Our findings

Explore key themes in what people told us about their experiences of home care services in Suffolk.

Key issues explored

Care plans – is there a plan?

Amongst interview participants, experiences of care plans varied considerably.

Three people said they had a care plan, that it was accurate and, importantly, that it was in a place that they could access (either a physical copy in their home or in an online app).

> *"The care plan is all on the app. The carers can add notes for each visit. My DNR is on there and next of kin details. Carers add notes from their visit. They record detailed notes each time they come."*

> *"There is a care plan, a written plan. It is in a folder in [my wife's] room."*

Two respondents said there was a care plan but that it did not accurately reflect the customers care and support needs.

> *"We spent three hours with someone from the agency and the IWP. And the care plan came back after three hours of meeting, and it's still wrong. But it's wrong with quite dangerous stuff, like it says the carers are giving him medication. Well, if somebody comes out and sees that, then goes 'Oh, we have to give all his meds'. Well, they don't. They've not done that for months."*

> *"It is not up to date, there is stuff in there that is no longer relevant… I've asked for it to be changed but it always comes back the same."*

One person said they had a plan, but it was not accessible to her now that it was stored online.

> *"I haven't got a copy of the latest care plan because it is all on computer now. I used to have a copy, because I had a folder and everything was in that folder, but of course everything has gone paperless now."*

One respondent reported that there had been a care plan, and they felt this accurately reflected the customers' assessed support needs. However, changes in the way the carers were delivering care made him question whether the plan had been altered without his (or the customers') knowledge. It was clear that he did not have sight of the plan, and he was unsure about how he could get access to it.

> *"They are supposed to have two carers for 45 minutes each per visit, but we only seem to get 45 minutes for the two. Also only receiving one carer in the morning instead of two. We've tried to get some information from the council, and they have 'gone to ground'. It's not right because either someone is getting overpaid or someone has changed the hours and not informed us."*

One customer was awaiting a new care plan, following a review. At the time of interview, she had been waiting several weeks.

> *"There is a blue folder somewhere, but it is old. They came and did a review, and I phoned them after two weeks and asked what was happening with it, and they said they hadn't got around to doing that, so I don't know where in the pipeline that is now. That was a few weeks ago now. If the carers are going by the old care plan and they don't know how things have moved on, then they are just going to say 'no' to different tasks."*

One respondent did not know whether there was a care plan or not. Despite being actively involved in supporting her neighbour, she had not been included in any discussions about his care and support needs.

> *"I don't know if there is a care plan. I have asked to be involved but I was told that as I am not next of kin or power of attorney, they won't speak with me."*

One person said they did not have a care plan, though he was clear about the amount of care to be delivered, what the care tasks were and that the aim of the care was to support him in his caring role by providing respite.

Care plans – are they actively used?

Having a care plan is important because it ensures that customers and carers are clear about what support will be provided.

This includes the amount of care (time and tasks) and the purpose for which care is being delivered (e.g., to support a family carer, to support rehabilitation and reablement, to enable someone to live independently at home). It is also a place for recording information about people's individual preferences and wishes. It helps to ensure that the same care is delivered regardless of which care worker is on duty.

Simply having a care plan, therefore, is not enough. Carers need to be aware of, and follow, what is written in the plan. This is particularly important when delivering care to new customers or when the customer is unable to 'speak up' or advocate for themselves.

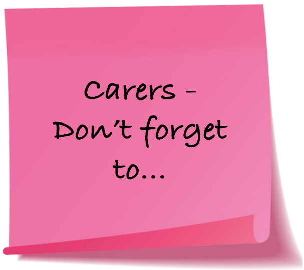
Most respondents (six) shared examples of the care plan not being actively used by their carers.

> *"We didn't know what they were going to do. My dad was discharged home with a PEG for feeding. We'd had some training, but we weren't going to do that. We thought the carers would do all of that. [The carers] came in later that day, and they didn't really have a clue. They didn't know what they were there for either. They didn't have very much information."*

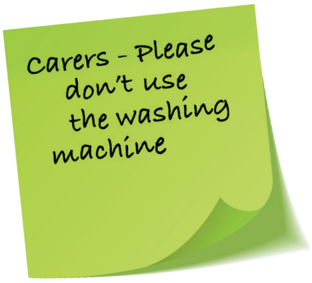
> *"I have a folder with my care plan in it, but the information in it is not up to date. There is stuff in there that is no longer relevant, but then, I can say so. When new carers come, sometimes you have to instruct them and tell them what needs doing."*

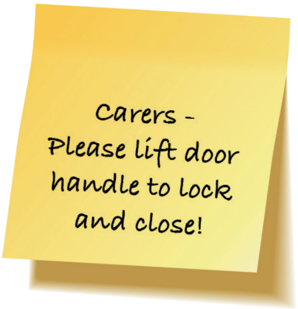
> *"Every day we would have to say you need to do this, do this, do this and then the next day someone else would come and it would be 'do this, do this, do this, all over again. Why bother? By the time we have told you what to do, shown you what to do, we may as well do it ourselves,"*

> *"The social worker put on the care plan [that I] need help in the kitchen to do my exercises but that didn't happen because I would end up in the kitchen doing my*



"We were getting a different person every day and it is a pain because you have to show them where everything is.





"I have to put stickers everywhere - 'Carers: Please don't use washing machine', 'Carers: Please lift door handle when closing the door'...

"There are stickers all over the place, it is ridiculous."

> *exercises on my own and they would be in here on their mobile phone, I could hear them talking on their phone. So that's not working. [Because of my disability] standing and doing things is difficult for me and it varies day to day what I feel I can do."*

> *"The two usual carers are fine. But then two days a week we get someone else and they are just 'doing a job'. There is no looking at the folder and looking at the procedures of anything like that. My wife is not meant to have wet wipes all over her body because she comes out in a rash. When the normal carers come it is fine, but when it is the other carers that come, I have to hide up the wet wipes because that is all they ever use. Everything is written down but they do not read that."*

> *"There is a care plan and it does reflect their assessed needs, but they are not sticking to it. They are supposed to shave my son but they don't do that, so now we do it for him. This is what we are trying to find out from the council, should they be shaving [my son]? If yes, then why are they not doing it and, if not, why haven't we been told?"*

> *"They throw the carers in at the deep end at the last minute and they don't know what they are coming in to and they don't know what they need to do. But none of them come in and look at that folder."*

In contrast to the comments above, one respondent, had a very positive experience of how his care plan was being used by carers.

> *"The agency uses an online app. It is so good. The care plan is all on the app. The carers can add notes for each visit. My DNR is on there and next of kin details. The carers are recording detailed notes each time they come."*

Care plans – time and tasks

All respondents were aware of how much time they had been allocated for care tasks. However, they did not always feel they were consistently getting the amount of care they were 'entitled' to. Some respondents took a pragmatic approach – that as long as all care tasks were completed it didn't matter, others were concerned that they were being overcharged for their care.

> *"They do all I want them to do. I wouldn't want them waiting here for ten minutes just so they give me the full half an hour."*

> *"[My mother] has been paying for an hour of care but only getting 10 minutes. We complained to Suffolk County Council to say 'This is fraud' but nothing came of that."*

While one respondent said carers would sometimes extend the length of her visits depending on her daily needs, it was more common for respondents to share examples of care visits that had been shortened. A couple of respondents mentioned lack of travel time as a reason for shortened visits.

> *"Mostly stay the agreed amount of time. Sometimes they seem in a hurry to go somewhere else. They don't get a lot of time between their calls. Sometimes they are one side of town, then they have to come all the way over to the other side and then go all the way back. Depending on the time of day they are doing that, it can be absolute madness. The traffic can be terrible."*

> *"One minute, [the carer] is in Hadleigh. Next minute, she is here [Ipswich] and she doesn't drive, she relies on the buses."*

> *"They haven't got time to stop to have a conversation. It's all about the time. I feel they are always in a rush. 'I said to one of them, 'Did you leave your engine running?' That didn't go down too well. But I got so annoyed with it."*

"Bolus feeds should be given slowly. Dad was also on numerous medication which also had to be delivered in a similar way. The tubes all needed flushing out each time. However, the carers were managing to deliver 800ml of feed, medication and change him all in 10 minutes, and were then leaving.

"This was despite the fact that he should have been receiving an hour of care per visit."

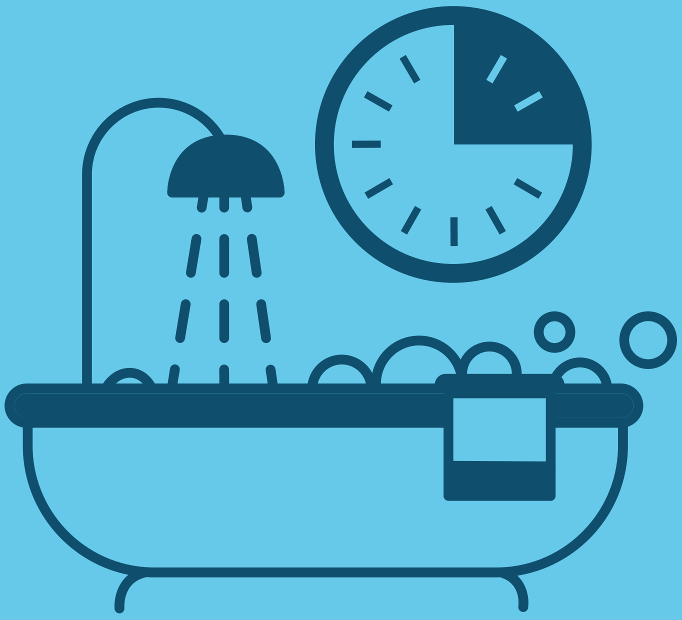
> *"The cover carers rarely stay for the correct amount of time, they always seem in a rush to get off."*
>
> *"I used to have a carer who would come in and say what are we doing tonight, and I might say well can I have a cup of coffee, so she would make that and then say well I'll be on my way then – three minutes she was here. This was just one carer. I don't have them often."*
>
> *"In the evening two carers come. Again, they should be there for 45 minutes each but they are usually gone within half an hour. They manage to get [the children] out of their chair, into the bath, washed and changed all in 15 minutes. That's not proper."*

Rotas

While care plans establish the amount and type of care and support being delivered, rotas are important for informing customers who will deliver care and when they can be expected. Most respondents received a rota each week. However, it was generally reported that these were not accurate.

Examples of quotes about rotas include:

> *"They give me a rota on my mobile."*
>
> *"I get an email every week to say who is coming."*
>
> *"I have a rota but doesn't always mean it will be at those times."*
>
> *"It's not always consistent that a rota is sent out. I got a rota last week, but nothing has been sent out yet this week. When I get one, the rota's usually accurate, the person it says will be coming is always the person who turns up and apart from if there are accidents etc., the carers usually turn up on time."*
>
> *"The agency uses the thing on the phone. It doesn't always work out that the person on the app is the person who turns up."*
>
> *"[The agency] uses an online app which tells me what time they are coming and what they should be doing. I can see for the whole week and for the following week too. I can see who has visited me and what they did at that visit."*
>
> *"They send out an email rota, that rota is different every day and then the carers do something different. The rota is a waste of time; we don't even look at it any more."*
>
> *"When they come in the morning, we ask who is coming in the evening. They don't volunteer the info and they don't usually say who the second carer will be in the evening. The evening carers don't usually know who will be coming in the morning."*



“In the evening two carers come. Again, they should be there for 45 minutes each but they are usually gone within half an hour. They manage to get [the children] out of their chair, into the bath, washed and changed all in 15 minutes. That’s not proper.”

"I don't want to be going to bed at 8.15pm and that seems to be most of the time now. We are not elderly, we are not tired like they are and want to go to bed straight after dinner. My friends can't come in the evening because they don't know what time the carers are coming.

"Care companies need to realise that lots of their people may still be very active and they can't treat everyone as if they are 'dead and in bed', but they do I am afraid. They don't see it very much like that, but they should do."

Changes in timing and delayed visits

Several respondents reported that changes to the times of care visits were a source of significant frustration.

While they acknowledged and accepted that changes were often unavoidable, they were keen to highlight the impact this had on them, particularly around mealtimes, the provision of medication, and their ability to participate in social activities. Some respondents reflected that a phone call could resolve some of the anxiety they experienced around delayed or changes in times of visits.

> *"I didn't know who was coming or what was happening, or when they were going to turn up. Lunchtimes you are waiting around and you don't know what to do, so I will go in the kitchen and do what I can, but because of my disability, I am putting myself at risk because I am doing these things to get some food. I understand the buses do not always run to time, so the carers are late, but someone could let me know. I didn't know what to do, whether to start getting my meal ready or not because I didn't know whether they were going to be 10 minutes late or an hour late."*

> *"I don't want to be going to bed at 8.15 and that seems to be most of the time now. We are not elderly, we are not tired like they are and want to go to bed straight after dinner. My friends can't come in the evening because they don't know what time the carers are coming. Care companies need to realise that lots of their people may still be very active and they can't treat everyone as if they are 'dead and in bed', but they do I am afraid. They don't see it very much like that, but they should do."*

> *"I have had it that the 9am visit, the carer hasn't turned up until 11.30am. And it is important because the first [visit of the day] is for tablets, and the last one is for tablets. The two in between are not so important. It is meant to be every four hours, but sometimes it is every two hours."*

> *"In the evening they should come at 4.45pm. They used to come at 5pm. The agency called and asked if we would be happy for it to be 4.45pm and we said yes, provided it was no earlier, because we like to feed the children before, and then the carers can clean them up and get them washed. There are some carers who will come early. My daughter likes to have her meals on time, she can get very awkward if her mealtimes are messed about. If the carer arrives early and we have to take the meal away, then she doesn't want it back afterwards."*

> *"Times are erratic and I never get a phone call to say they will be late. It can be difficult with meals. It means I only ever gets microwave meals."*

One carer reflected that scheduling care visits at inconvenient times was negatively impacting his wellbeing and, therefore, his ability to effectively care for his wife. Since the care package was initially arranged to provide him with some respite, the plan's outcomes were clearly not being achieved.

> *"My life is not my own. I get up at 6.30am. Put the heating on at 7am and then I've got to wait. It used to work well. I would get up at 7am, heating comes on at 7am. I'd have a quick wash, get [my wife] up and give her breakfast. The carers come at 7.55am and get [my wife] washed and dressed and then it's back downstairs by 8.30am and everything is lovely… We go to a dementia café on a Tuesday. We love it. We go singing and dancing. We sit on the same table with the same people, and we have a good laugh. You get entertainment and something to eat all for £5 each….. I phoned [the agency] the other day. I said 'You've got me down for 10.20am to 11am. That is no good for me. I've got the dementia café at 10am."*

> *"I don't like to leave [my wife] too long on her own. I used to go to [the supermarket] each week and time it so I left when the carer was with [my wife] and then get back half hour after the carer had left. But now I can't do that because I don't know when the carers are turning up."*

> *"I like to turn the telly off at 8pm, and I say, 'Right, time for bed' because I need some peace and quiet. I need my peace and quiet; I know [my wife] can't help it, but she keeps asking the same things over and over, and she doesn't know she is doing it. But sometimes I shout, and I need that break. It brings me down, and if it brings me down, it means I can't look after her."*

Carers

Feedback about carers was varied. Most respondents distinguished between their 'regular carers' with whom they had developed strong, trusted and positive relationships, and 'other carers' who were often described as 'just doing a job'.

Positive comments about carers included:

> *"When it first started, it was lovely. The same carer would come Monday to Saturday. She took to [my wife] and [my wife] took to her. And then we had another carer in the evenings. [My wife] liked it because she knew who was coming."*

> *"In the past we have had some really good carers, who have taken an interest."*

> *"[Do you see a point when you won't need the carers]. That is what I am working towards, and that is what I want to happen. I feel confident that it will happen because I am making progress, especially when I have the two to three carers who help and make me feel confident and help me to move forward."*

> *"There are some really kind caring ones and then there are the other ones."*

> *"They are all good carers, I like the carers."*

> *"Have a good relationship with some of the carers because I have known them for many years."*

Other comments about carers included:

> *"The two usual carers are fine. But then two days a week we get someone else and they are just 'doing a job'… The normal carers are usually quite chatty but the replacement ones hardly say anything… If they were all as good as the ones that come regularly that would be fine."*

> *"I normally have the same carer in the mornings but get a mixture of people in the evenings. But tend to have the same ones. As the company has grown, I have started to see more carers. I used to get the same person seven days a week, but then there were only a couple of carers recruited at that time."*

> *"We generally have the same couple of carers come. I feel confident that they know what they are expected to do. They are very knowledgeable and skilled. They generally keep to the same timings for visits, and they stay for the required amount of time. Difficulties arise, however, when the regular carers are on holiday or unavailable. The cover carers have been arriving at 5.50am for the morning visit, which means I have been getting up at 5.10am to get my father-in-law up, see to his catheter bag and get him ready for them. I feel I need to check what they are doing too, for example, that they have sorted his catheter properly at bedtime so that it doesn't leak during the night."*

> *"We had a regular two carers, which were fine, and then the agency decided to swap everybody."*

> *"Initially, we [got the same carers] and then we got loads of different ones and now we get the same one most of the time. She is probably the most regular, but it varies as she gets sent off to different places, and then we'll get somebody completely new, and they don't know what they are doing, and mum has to go through the same thing every time."*

> *"It is just a job to them – that's their attitude. You feel they are trying to see what they can get away with."*

> *"They come, do the minimum and then go."*

> *"The carer came the other day at 8.35am. All of the jobs had been done by 8.50am, and she asked if there was anything else she could do. I asked if she could help sort some clothes out, and she said, 'No, I can't do that because it is not written down'. I can understand if it was a big job but it was just sorting some clothes out, so my room was a bit tidier but she said 'No, it's not on my list' and that was it.*

Two respondents reflected on the Impact of good relationships with the carers on their mental wellbeing and recovery from illness.

> *"I get on well with the carers. I have a good relationship with them. It helps with my mental health."*

> *"I do have a good relationship with some of the carers, and that is great; it's brilliant; that just makes you feel calmer. But when they come and they are looking down on you and they are really brusque, you just feel worse than you did before they arrived. I feel they look down on me in a patronising way; sometimes I just want to cry."*

It was common for people feel confident in the care received from carers who knew them well. However, many experienced successive changes in staff visiting their home, which in turn led to loss of trust or other issues with their care.

“[Getting to a point where carers are not required] is what I am working towards, and that is what I want to happen. I feel confident that it will happen because I am making progress, especially when I have the two or three carers who help and make me feel confident and help me to move forward.”

“They throw the carers in at the deep end at the last minute, and they don’t know what they are coming in to and they don’t know what they need to do.”

Frustrations about changes to carers were often related to a feeling that ‘new’ carers lacked knowledge, experience, and understanding of the customer needs. Introductory meetings, shadowing visits and good practices around care planning can assist in making the transition between different carers more satisfactory for everyone.

> *“Sometimes, new carers come with a more senior carer and they are shown what to do and how to help people. Some of them just appear, but most of them [get an induction].”*

> *“They throw the carers in at the deep end at the last minute, and they don’t know what they are coming in to and they don’t know what they need to do.”*

> *“Half the time, I don’t know who the carers are. In the last couple of weeks, people have just been turning up because my regular carers are away at the moment. New carers are never introduced.”*

Some respondents viewed the ‘loss’ of a regular carer as a form of ‘punishment’. This was particularly true if they did not understand or could not see the ‘reasoning’ behind the changes. Good communication is key to establishing expectations and maintaining trust between customer and agency.

> *“Then all of a sudden things started changing. They gave me a rota on my mobile. 9 o’clock, 9.20. That’s no good to me. I keep telling [the lady in the office], who does the rota. Then, the next minute, I am losing [name of morning carer] for no reason at all. I get Tom, Dick and Harry coming. I messaged them and said can you tell me why I am not getting [name of morning carer] and I’m not getting [name of evening carer], and she never answered me. Both the carers still work for the agency. I get [name of morning carer] maybe three times a week now, but [name of evening carer] I have lost altogether and I don’t know why.”*

> *“We were getting what we thought were experienced carers, now we have been ‘downgraded’ to the younger ones, or the ones who are not so qualified or not so interested in the job.”*

> *“It was only because we complained so much that we got our regular carers back again because I threatened to get rid of them with our social care worker. When we had our six-monthly review, I said I was very unhappy with them, and he tried to get this all resolved, and that was when they gave us back our normal carers. I worry that they will disappear again and then we will be back to square one.”*

> *“[Name of office manager] is in charge of the rota, and she just changes it when she wants to. The excuse is that somebody’s ill, but when you talk to the carers, they say ‘No one’s ill; who’s ill?”*

Issues and complaints

Seven respondents had contacted their care agency to discuss issues about a carer or how their care was delivered. Agencies’ responses to complaints are crucial to building trust with customers and their families. The overwhelming feeling amongst those who had complained was that it made no difference, as their concerns were not always listened to.

Five respondents had raised complaints about the attitudes and behaviours of individual carers. Despite expressing a clear preference that the same carer not be sent again, this request was often overlooked by the agency, without any prior consultation with the customer.

> *“When I have asked them not to send a particular carer because they were really rude, they say we will see what we can do, and then the carer has turned up the next day. It makes me feel so low. You should be able to feel comfortable in your own home.”*

> *“The carer told me he had actually been when I know for a fact that he hadn’t because I had been here all day, and he was basically lying. I caught him out and I said to him that he was lying because I had been here all day. I knew he hadn’t [been round], and he argued and argued, and in the end, I told him to get out. I emailed the office and said I don’t ever want that carer coming to my house again. This was about six weeks ago, and then two weeks ago, they sent me the thing that says who is coming, and his name was on the list to come around, and I emailed them and said, ‘This is not going to happen; he is not welcome in my house’. So basically, what he now has to do is he has to drive another carer round, and he sits outside in the car.”*

> *“I have thrown one lady out one day because her language was so appalling that I wasn’t going to put up with it in my own home. She came again, but she was much quieter, so I was OK to have her back in my home.”*

> *“Only complained about one carer – felt listened to. When I do have her now, we have a good old catch up – so it is more on a personal level, so it is much better, instead of just ‘boom, boom boom’, ticking the jobs off.”*

> *“We made a complaint to the agency, copied in social care, and never got anything back. Social care got a response from the care agency, but we didn’t. Basically, I phoned the care agency, and the woman who answered the phone said, ‘I’ll get somebody to call you back’. I phoned them again. I said, ‘[those carers] had better not be back in the morning; we want somebody else in the morning’. And they sent the same two carers. I phoned the agency again and the woman I spoke to last thought it was hilarious that they’d made a mistake.”*

Three respondents said that despite raising issues with their agency, this had made no difference to the care provision. Respondents often felt a lack of communication between office staff and the carers.

> *“I phoned the other day. I said, ‘You’ve got me down for 10.20am to 11am. That is not good for me. I’ve got the dementia café at 10am. She texted me later and said ‘I’ve put you down for 8.45am’. The carer turned up at 10.20am. I said, ‘You’re too late, I’m going out in a minute’. She said, ‘It’s the only time I’ve got on here,’ so the office had never told the carer.”*

Where respondents had stated a clear preference that a carer not attend their home because of a concern, this had been overlooked by providers in some instances. This meant people could feel vulnerable or that their concerns were not being taken seriously.

> *"When I phone to say something isn't right, they say, 'I will pass it on to the manager', and then you don't hear anything else. You don't know whether the message has been passed on, and you don't see a change in what the carers are doing. I lose confidence. Sometimes it does make a difference, but you don't feel confident consistently that the messages have got through."*

> *"I phoned the office, and they said they were going to get back in touch with me, and they never bothered."*

Two respondents feared the consequences that would arise if they made a complaint, while a further respondent felt the agency had changed their attitude toward him since he had made a complaint.

> *"I am nervous that if [I complain], I would still get carers, but at their times, like 10am or 11am or late at night, and they would love it because they are getting paid and I am doing the job. When I turn the carers away, the agency is being paid for that job, but I am doing the work."*

> *"If you argue with the manager, you will find that you are punished, and your carer will come in earlier. So, I don't bother now."*

> *"Since I complained about that care worker, the office has not contacted me at all, whereas before, they often used to phone. I think they think I am a troublemaker, so they don't want to have anything to do with me."*

In addition to raising complaints with their care agency, four respondents had also raised issues about their care provider with Suffolk County Council.

In two of these cases, the respondent felt positively supported by their social worker/ IWP in tackling the problems with their care provision. The remaining two respondents were still trying to resolve their issues with the Council.

Additional themes

Training

Four people identified that a perceived lack of training for home care staff had affected their care, or the care for their loved ones. Specifically, they felt carers would benefit from more training on manual handling, medication, using health equipment, and understanding of different health conditions.

Examples of feedback included:

> ***Manual handling***
>
> *"They didn't know how to use the WendyLett system. So, it was sliding around all over the place because they hadn't locked it, and we had them stand on the bed to pull him up the bed. We've had them roll him while he's sitting up away from them, so he was literally flopping off the edge of the bed."*
>
> *"My wife has to get out on her Sara Stedy as often as possible to keep her muscles moving and apart from our main carers, none of the other carers are trained to do that. They can't get her in and out on her Sara Stedy. And that is very important. It all comes down to a lack of training."*
>
> ***Medication training***
>
> *"None of them knew about the PEG [tube]. Even now, we get them come in, and they don't know how to turn the machine off, or they are asking, 'Do I have to disconnect him when we roll him?'."*
>
> ***Condition specific training***
>
> *"The other thing I'd like is that they actually understand what his condition Is because none of them understand stroke at all. They don't understand why they can't just grab his arm to move it. They don't understand why he has this, what we call a carrot, in his hand to keep it open. None of it. They just haven't got a clue. I just*

assumed that stroke is something quite common and they would know."

"I don't feel the carers have an understanding of [my children's] condition."

"I am disabled. I'm not just elderly. I keep trying to explain to them that the two things are very different. I can't seem to get them to understand that. I try and explain it to the carers as well, having been a carer myself. I don't like being talked to like a four-year-old. I think sometimes, when they do their training, they are not taught about disability, and I think that is wrong because many people who I know are getting older and are disabled, and they don't want to be treated like four-year-olds. They don't want to be told, 'Well, I've come to put you to bed,' and you think, 'Well, thank you very much'."

Financial assessments and advice

All of the interview respondents who said they were paying for, or contributing towards, the cost of their homecare service (three), felt they would have benefited from more advice and support around financial processes. This included having:

- better access to the finance department to raise any questions or queries about their financial assessment or monthly invoices.
- clearer information about the rules and regulations for the use of direct payments.

"I have had three different amounts in the last year. It is paid through the bank, and yet I still get bills saying I own them money. You ring them up, and they won't speak to you. You get to eight in the queue, and then you get cut off regularly. Once I got through to them, the man was very rude to me, and I did report that. They say that under a certain amount you have to pay so much a week, and they are supposed to ask for your bank details every year – that hasn't happened. My bank balance is going down, and I am still paying the same amount. I think it is totally wrong. This all needs sorting out. I have written to them, and my friend who is power of attorney wrote to them as well and had a word with them, and he didn't get anywhere. He said it was a complete mess, and they didn't seem to know what they were doing."

"We're still sorting the finance. They just keep saying, 'Well, send statements when you can,' but nobody will give us an idea.... We've never had a personal budget until just before Christmas, and that's only £120, they're saying at the moment. But mum's under the threshold with my dad's money now, so we're a bit..... there's no advice with that, so she's sort of panicking and anxious. (Interviewer: You have had a financial assessment?} Yes, it was just a phone call, I think. And then my mum asked for somebody if they could come out and see her face-to-face because, she said 'I can't do this all on my own'."

"We were getting a direct payment, but we were paying any expenses. Then we got a call from the direct payments team asking for receipts for expenses. We said there were none, as we had been paying for those ourselves. The person said we could claim the expenses from the direct payment. So, we put in an expenses claim and then got a call from direct payments saying, 'No, you can't claim expenses, and you might have to pay back what you have been paid'. We can't win; there is no consistency in what they say."

Key learning

Explore our key learning from interviews with people receiving home care in Suffolk, and their family or informal carers.

The following is a summary of the key themes that emerged from the qualitative interviews with homecare customers and their families.

There is a lack of consistency in the provision and use of care plans.

Experiences from respondents indicates that there is a lack of consistency in the provision, use, and review of care plans.

A care plan is important because it ensures that customers and carers know what support will be provided. It is a place to record information about people's preferences and wishes. It helps to ensure that the same care is delivered regardless of which care worker is on duty.

Having a care plan, however, is not enough. Carers need to be aware of and follow what is written in the plan. This is particularly important when delivering care to new customers or when the customer cannot 'speak up' or advocate for themselves.

It is important that the plan is reviewed regularly to ensure it reflects the customer's current needs. It should also be kept in a place and in a format that is accessible to everyone who needs to see it (customers, carers, and social care staff).

Customers found changes to the times of their care visits frustrating.

While customers acknowledged and accepted that changes to the times of care visits were often unavoidable, they were keen to highlight the impact this had on them, particularly around mealtimes, provision of medication, their ability to participate in social activities or opportunities and support them as family carers. Often, a phone call could help minimise the anxiety people felt about delayed visits.

Trust and rapport between customers and carers was key to creating positive experiences of homecare.

Customers often distinguished between their 'regular' carers, who they trusted and felt confident with, and 'other carers' who were often seen as 'just doing a job'.

Providing opportunities for carers to develop positive relationships with customers and their families through introductory meetings, shadowing visits, and good practices around care planning can help make the transition between different carers more satisfactory for everyone.

Some respondents viewed the 'loss' of a regular carer as a form of 'punishment'. This was particularly true if they did not understand or could not see the 'reasoning' behind the changes. Good communication is key to establishing expectations and maintaining trust between customer and agency.

Carers often seem rushed, and care visits were shortened.

Respondents reported that care visits were often cut short. For some, this created a perception that the carers were trying to cut corners or simply did not want to be there. Lack of travel time was highlighted as a key issue impacting carers ability to stay for the 'allocated' time. Ensuring carers have adequate time to complete visits would assist in building trust with customers and their families.

Customers need to feel listened to when raising issues with their care provider.

The overwhelming feeling from customers who had raised issues with their care providers was that it 'made no difference' because nothing had changed. The way in which agencies respond to complaints is crucial to building trust with customers and their families. Respondents felt there was often a lack of communication between office staff and the carers.

Customers would like more clarity and support around financial assessments and direct payments.

Customers found processes around financial assessment, invoicing, and direct payments confusing. They highlighted inconsistencies in the advice they had been given and difficulties in contacting the finance department for advice and support.

Customers feel that care staff should have more awareness of how to meet people's specific needs through training.

It was clear that people expected their carers to have knowledge of how to assist people with specific needs (such as catering for particular health needs or assisting with personal aids).

Customers felt the quality and efficiency of care could be improved through the provision of specific training for their carers. This included training in manual handling, medical equipment use, or improving understanding of specific conditions (e.g., stroke training).

Providers should promote continued and specific staff training (in additional to mandatory qualifications and training) to improve the personalisation of care and help address issues of trust and confidence between care staff and those they care for. It would also help to reduce dependency on family carers for specific types of support.

> “They didn’t know how to use the WendyLett system. So, it was sliding around all over the place because they hadn’t locked it, and we had them stand on the bed to pull him up the bed. We’ve had them roll him while he’s sitting up away from them, so he was literally flopping off the edge of the bed.”

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