'My Care at Home'

People's experiences of home care services in Suffolk (2023)

Cohort 1 (West)

healthwatch
Suffolk

Background and contents

The project aims to explore people's experiences of receiving and providing home care services in Suffolk. It will support Suffolk County Council to monitor the quality of home care services and provide an independent assessment as to whether care is meeting the needs of service users and carers.

In addition, HWS will share insight into the experiences of people delivering home care, to understand the issues and challenges they face. The findings will be used to inform workforce strategy or plans to support recruitment and retention within the care sector.

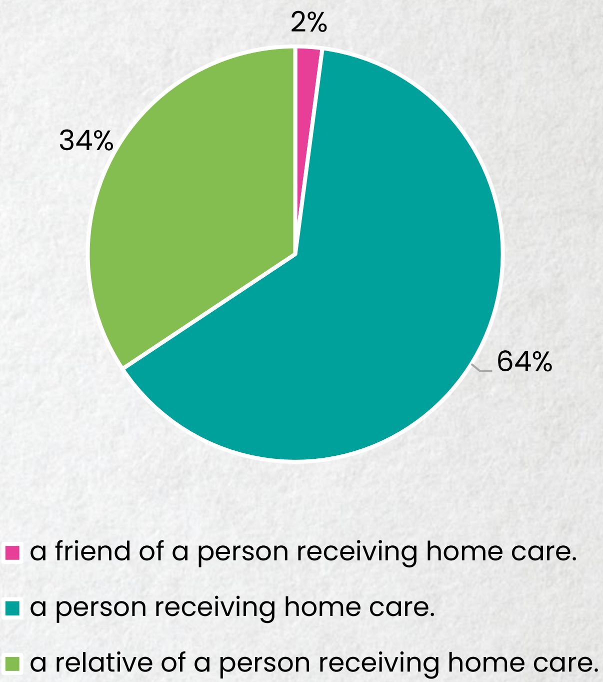
The survey will be issued to home care users in each of the three alliance areas covering Suffolk (Ipswich and East Suffolk, West Suffolk, and Waveney) at different points throughout the year.

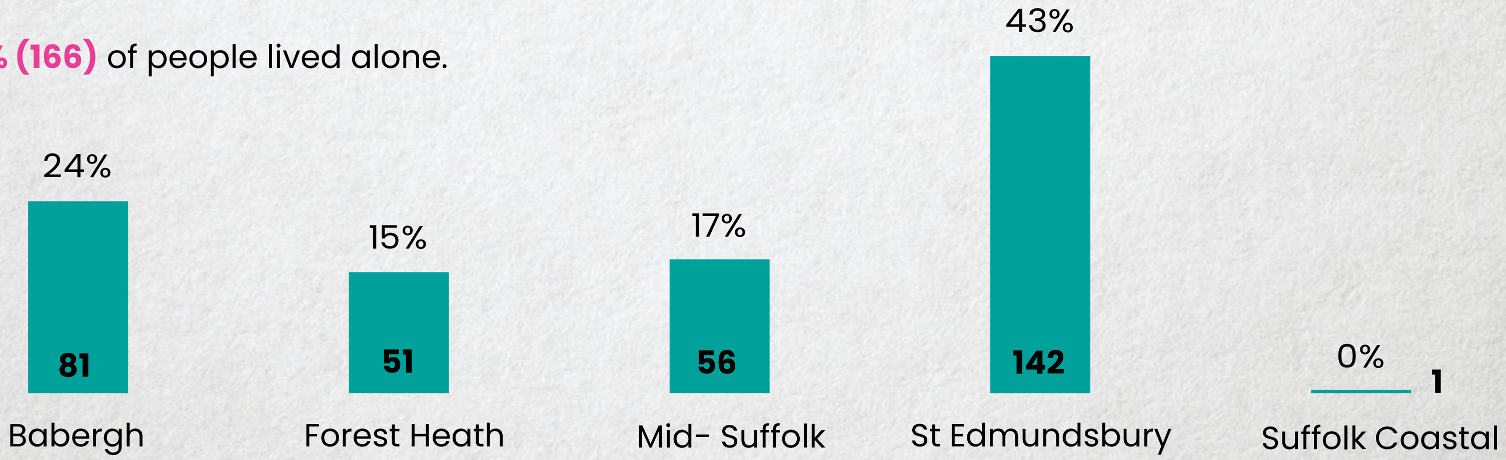
This report is based on responses from the **West.**

Contents	Slide number
Demographics summary	pg. 3-4
Results	pg. 5
Information about home care	pg. 5
Care plans	pg. 6
Carers	pg. 7-14
Complaints	pg. 16-18
Time keeping	pg. 20-24
Missed visits	pg. 26
Improvements	pg. 28-30

Demographics Summary

- A total of **1,311** surveys were sent out and **359** responses were recorded.
- Most responses were from a person receiving home care **(64%/ 213)** or a relative of a person receiving home care **(34%/ 115)**.
- **59% (188)** identified as female and **40% (129)** as male.
- **93% (299)** were White – English/Welsh/Scottish/Northern Irish/British - followed by any other white background **(3%/ 9).**
- **92% (271)** identified as heterosexual/straight.
- The largest proportion of responses were from people living in St Edmundsbury **(43%/ 142)** and Babergh **(24%/ 781).**
- **47% (166)** of people lived alone.



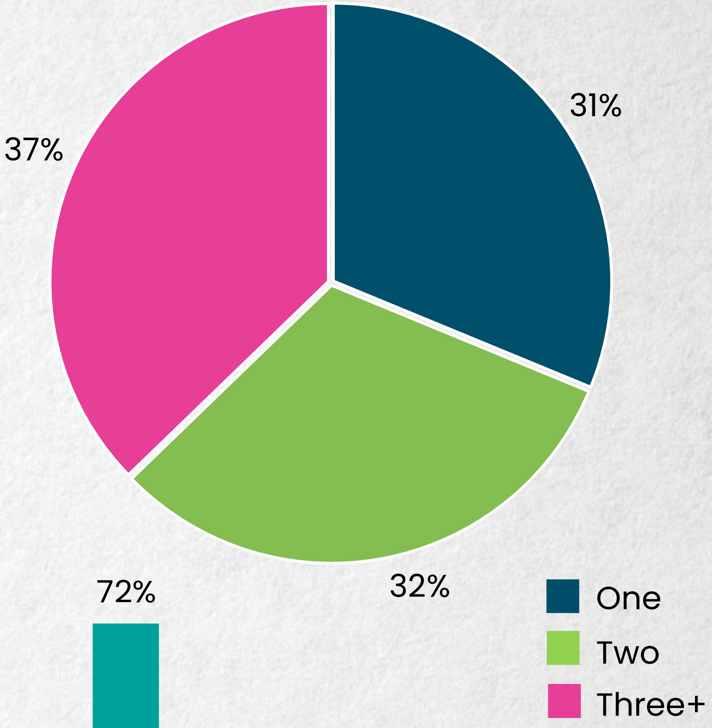


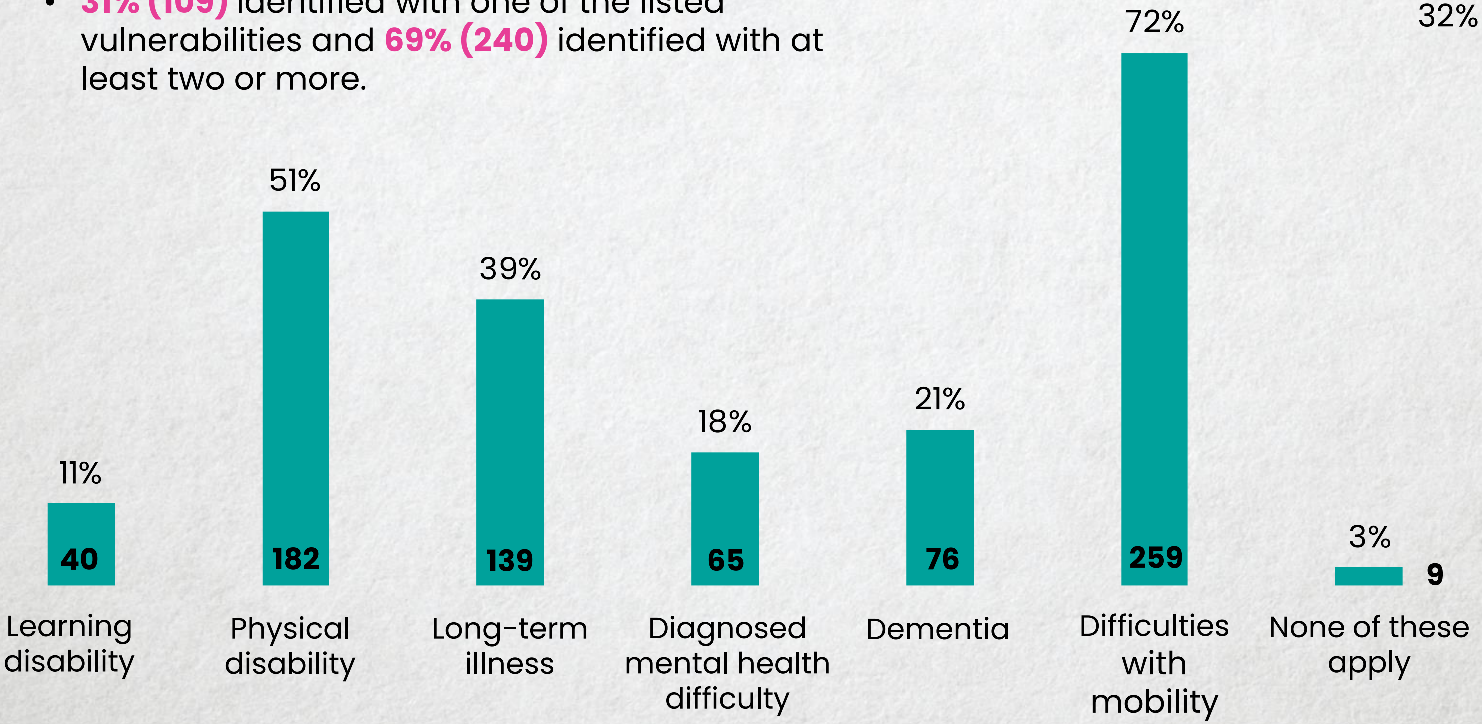
Vulnerabilities

We asked home care users to tick all statements that applied to them.

Of those who responded:

- The largest proportion of people **(72%/259)** reported difficulties with their mobility. This was followed by **51% (182)** who said they had a physical disability and **39% (139)** with a long-term illness.
- **31% (109)** identified with one of the listed vulnerabilities and **69% (240)** identified with at least two or more.





Care arrangements

We asked, 'How long have you been with your current care provider?'

- **355** people answered.
- Most people had been with their care provider for over a year **(51%/ 182).**
- This was followed by those who had been with their provider for two to six months **(19%/67)** and six months to a year **(18%/ 65)**.

Length of time with provider	Count	%
Less than 2 months	27	8%
2 to 6 months	67	19%
6 months to a year	65	18%
Over a year	182	51%
Can't recall	14	4%

We also asked, 'How many care visits do you receive a day?'

- **355** people answered, and of these:
    - **A quarter (25%/90)** received four or more care visits a day (the highest proportion).
    - **24% (84)** had two visits per day.
    - **22% (79)** had one visit per day.

Number of care visits a day	Count	%
Less than 1 a day	36	10%
1 a day	79	22%
2 a day	84	24%
3 a day	66	19%
4 or more	90	25%

Care plans

We asked, 'Has your care agency talked to you, and made a record (care plan) of, the care and support that you need?'. We also asked, 'Is the record (care plan) of your care and support accurate and up to date?'.

- Most respondents said their service had talked to them about the care they needed, and there was a record of it **(83%/278).**

- However, data inconsistencies suggest people are not necessarily clear about what care plans are, and their purpose. For example, **six** people who initially said their care agency had spoken to them and recorded their care needs went on to report that they did not have a care plan. Similarly, **13** people who had said there was no record of their care later reported that their care plan was up to date and accurate.

	Yes, it's up to date and accurate	No, it's not up to date or accurate	I don't have a care pan
Yes, they have talked to me and there is a record.	244	20	6
Yes, they have talked to me but there is no record.	13	5	18
No, they have not talked to me.	0	2	15

- Whilst supporting respondents to complete the survey over the telephone, Healthwatch staff reflected that people often expressed lack of clarity about what a care plan is.

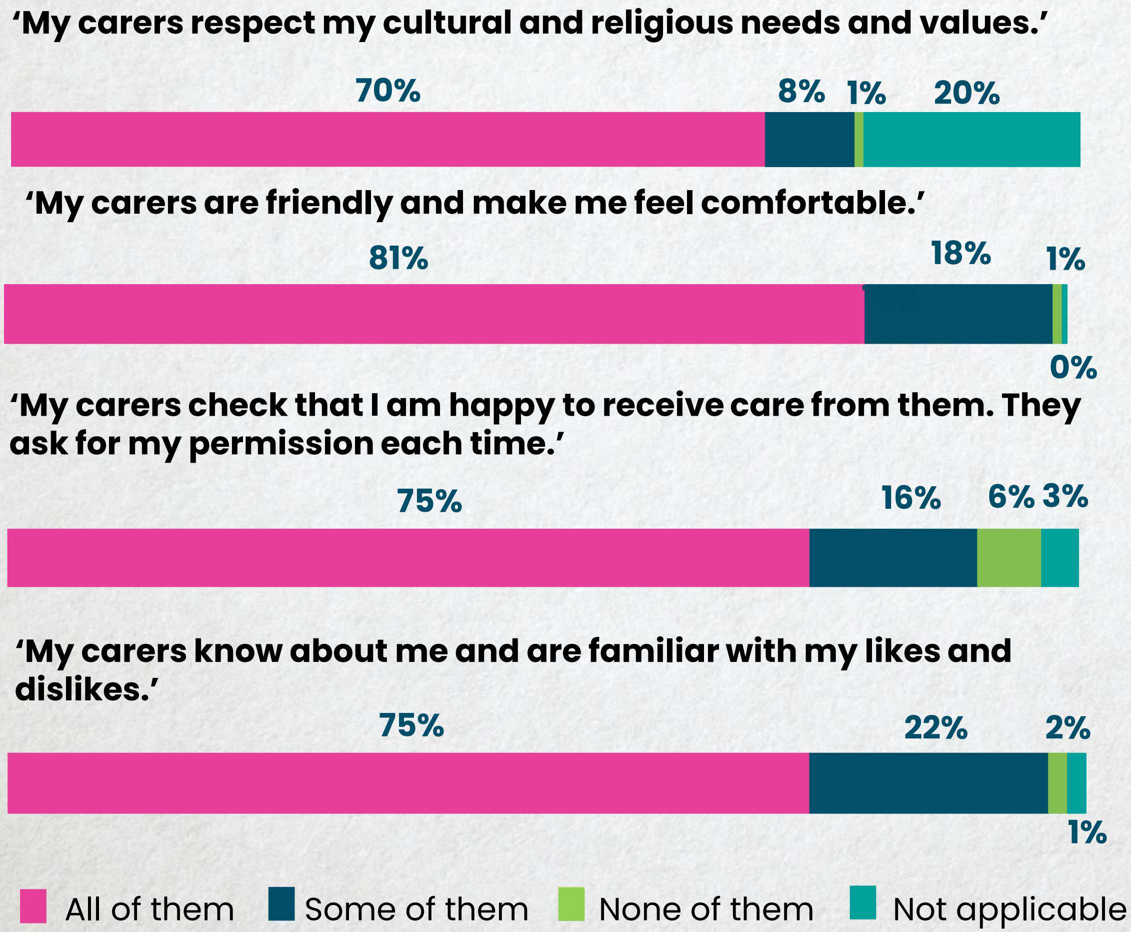
- It may also account for why up to **32** respondents did not answer either of the questions.

- Finally, one comment reflected the lack of understanding home care users and carers have about the role of care plans: ***"one carer states it's not just my care plan its hers as well".***

Your carers

We asked, 'For each of the following statements, please tell us whether they apply to all of your carers, some of your carers, or none of your carers.'

Some people did not provide a response for every statement, therefore total response numbers varied (between 325 and 338) across the different statements



'My carers respect my cultural and religious needs and values.'

'My carers are friendly and make me feel comfortable.'

'My carers check that I am happy to receive care from them. They ask for my permission each time.'

'My carers know about me and are familiar with my likes and dislikes.'

Our statements were based on aspects of care identified by regulators in England as being indicators of good home care provision.

Positively, most respondents felt each statement applied to all of their carers.

Other key findings included (see more across the following slides):

- **Twenty** people felt their carers did not check they were happy to receive care from them each time.
- **18%** felt not all of their carers were friendly or made them feel comfortable.

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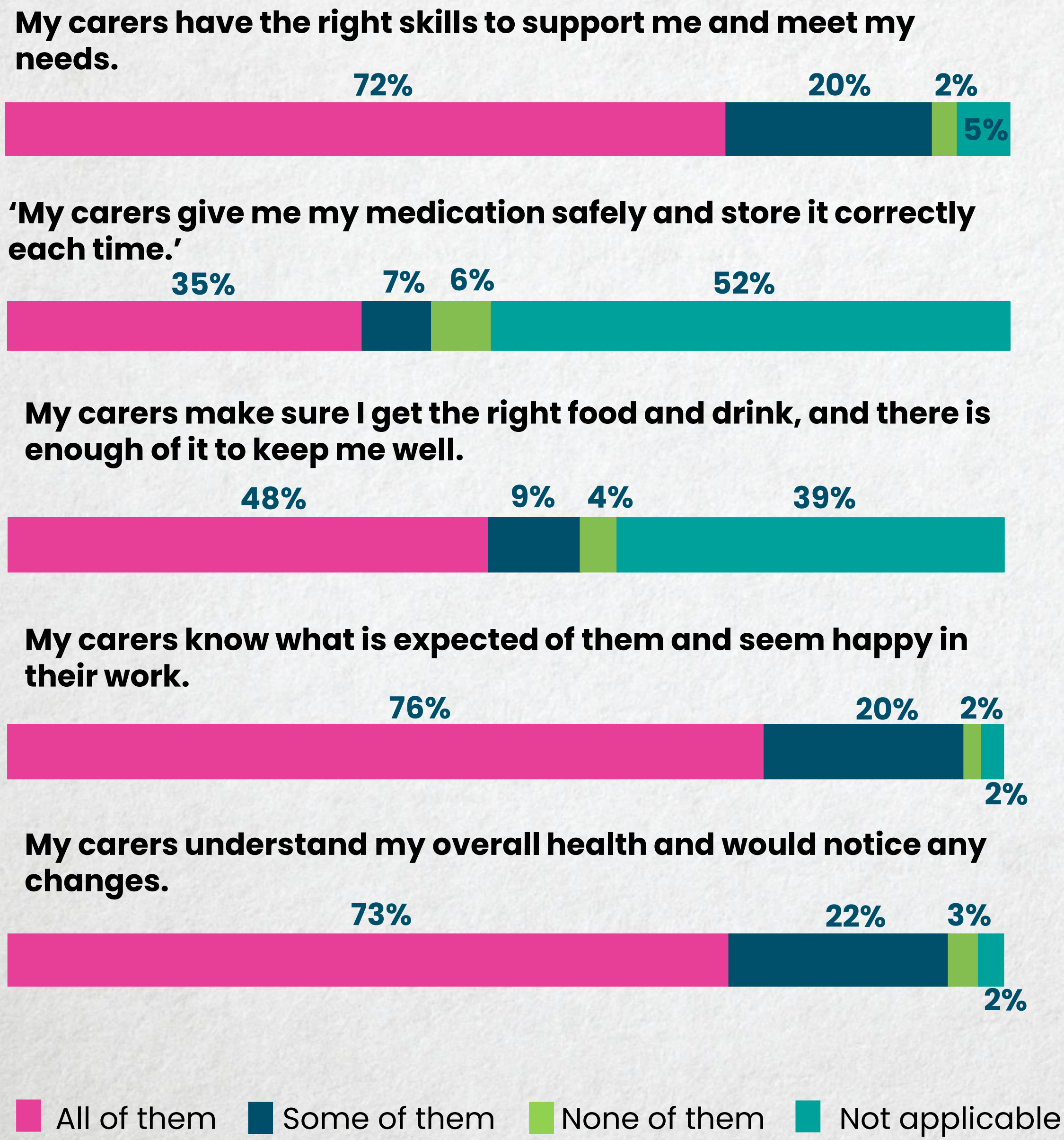
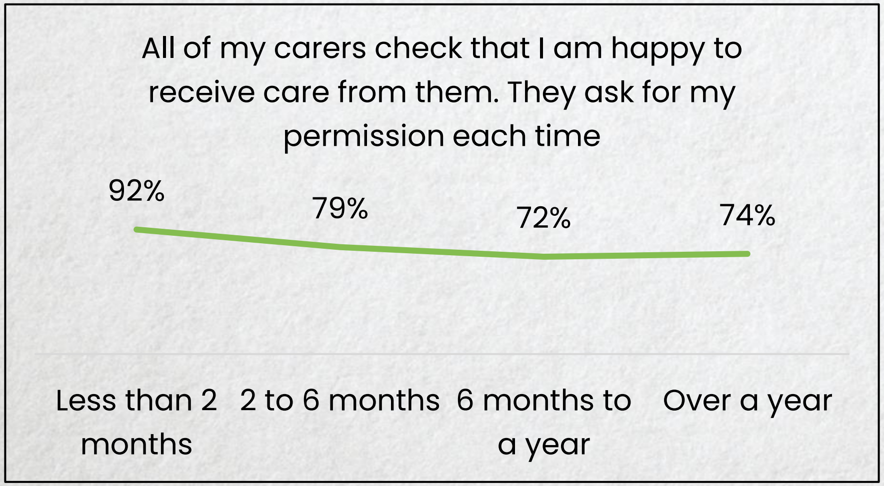


More key findings:

- **More than three quarters (76%/ 254)** said all of their carers know what is expected of them and seem happy in their work.
- **1 in 5 (20%/ 67)** said some of their carers have the right skills to support them and meet their needs.
- Some respondents **(6%/20)** said none of their carers know how to give them medication safely and store it correctly.

Statements about carers continued…

We looked at how people responded to our statements about carers differently according to the length of time they had received home care from their provider.



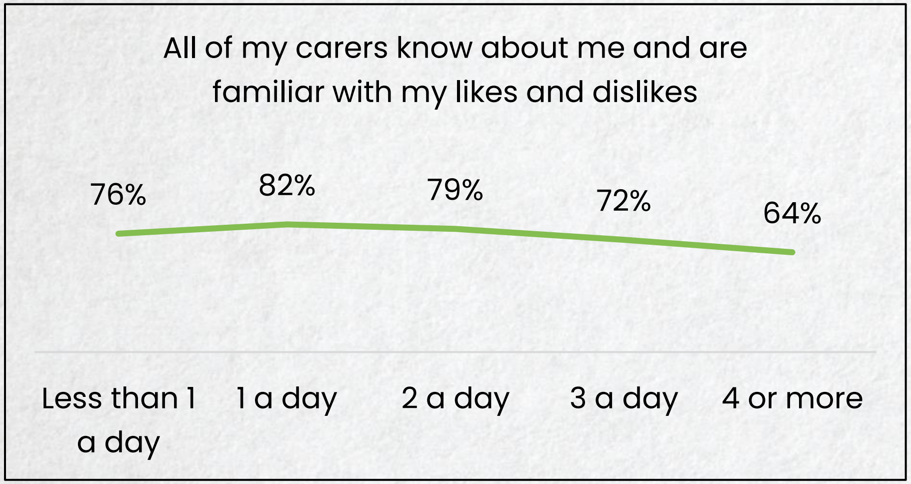
Please note: *Due to small sample sizes, caution should be exercised when generalising these results.*

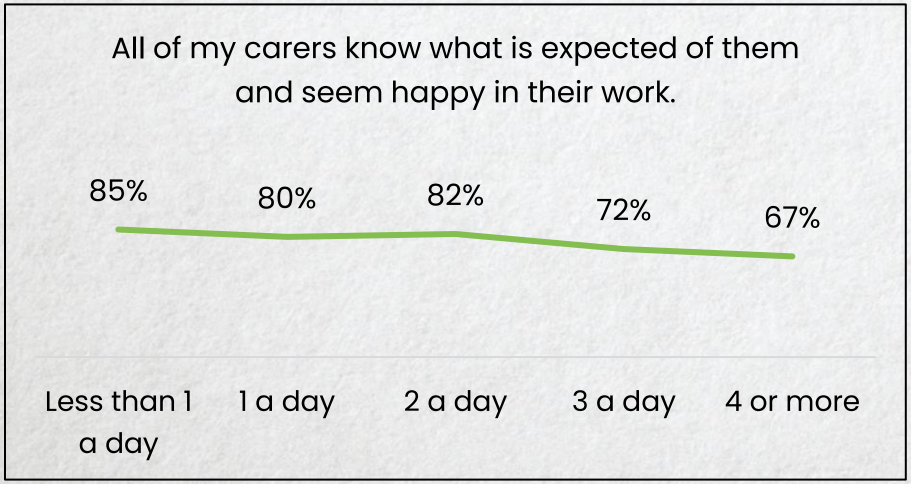
Broadly:

- Those who have been with their care agency less than two months were slightly more positive in their responses than those who had been with their provider for longer (**96%** of those receiving care for less than two months, compared to **79%** of those receiving care for over a year).
- A similar relationship is evident when considering people's experiences of consent/permission practices. In total, **92%** of respondents receiving care for less than two months said all of their carers check they are happy to receive care compared to **74%** of respondents receiving care for more than a year.

Statements about carers continued…

We looked at how people responded to our statements about carers differently according to the number of care visits they receive from providers.





Please note: *Due to small sample sizes, caution should be exercised when generalising these results.*

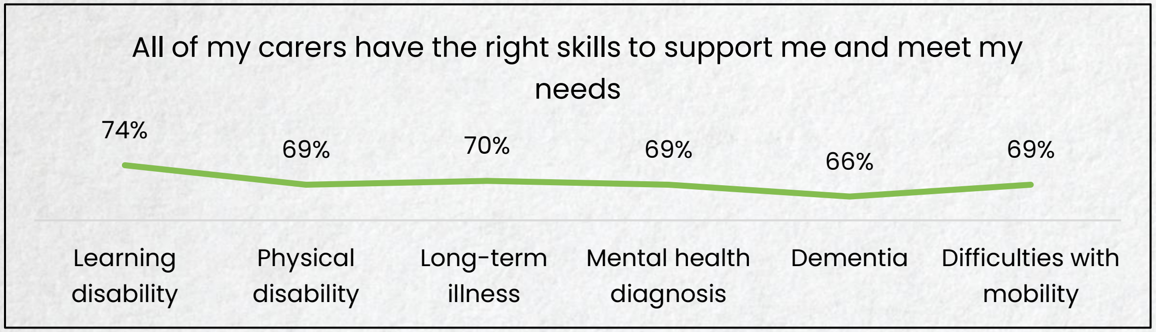
- Analysis reveals little in the way of noteworthy variation. However, responses across two of the statements indicates that people who receive more than four care visits per day are broadly less positive about their carers.

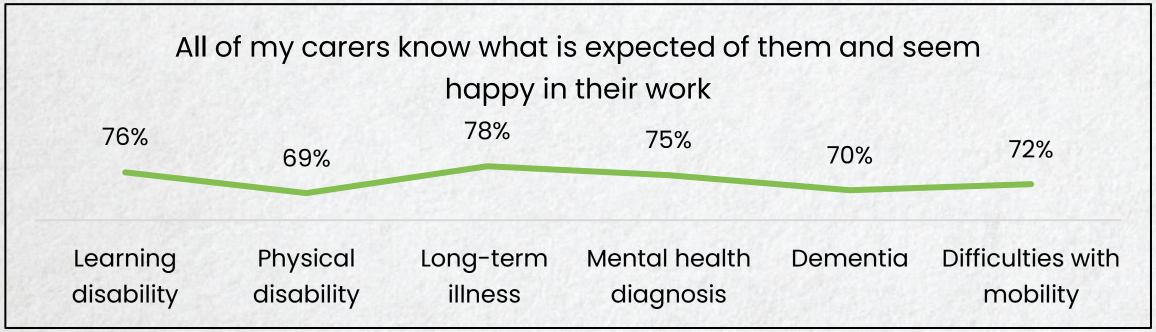
- For instance, **80%** of respondents who receive one visit per day said all of their carers know what is expected of them and seem happy in their work. This is compared to **67%** of respondents who receive four or more visits per day.

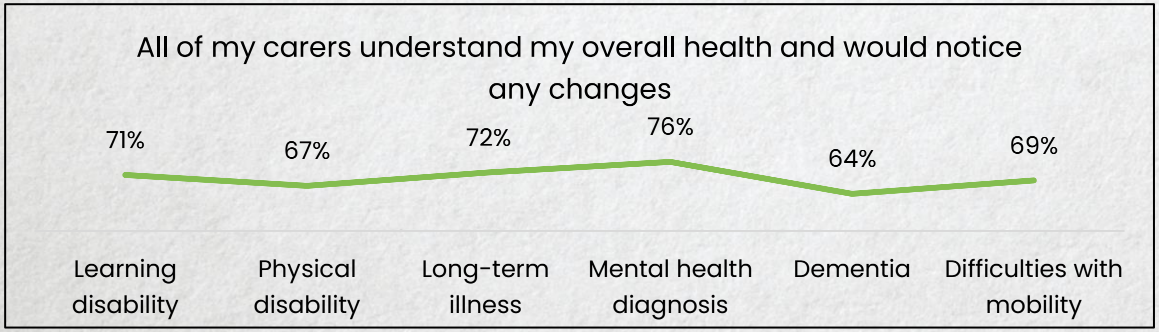
- Similarly, **82%** of respondents who receive one visit per day said all of their carers know about them and are familiar with their likes and dislikes. This is compared to **64%** of respondents that received four or more visits per day.

Statements about carers continued…

We looked at how people responded to our statements about carers differently according to 'vulnerabilities' listed in the survey.







***Please note:** Due to small sample sizes, caution should be exercised when generalising these results.*

- These graphs show how respondents with different 'vulnerabilities' responded to the statements about carers.
- Overall, responses are very similar across the different subgroups, with minimal variation.
- People with dementia were least likely to say all of their carers have the right skills to support them. They were also the sub-group least likely to indicate that carers understand their overall health.

Qualitative insights

About... carers

We asked people to describe an experience of home care services. **187** comments mentioned carers. Most **(139)** were positive.

139
Positive comments

38
Mixed comments

10
Negative comments

- Many described carers as ‘friendly’, ‘well-humoured’, ‘caring’, ‘supportive’, and ‘professional’. Some mentioned that they felt ‘respected’, ‘safe’, and ‘happy’. It was also common for people to describe carers as ‘friends’, and many looked forward to visits.

- Respondents often stated that carers had gone above and beyond for them and always offered to provide extra support when needed. The care provided was described as ‘excellent’ and ‘satisfactory’ and meant that many people were able to safely stay in their own homes.

> *“I’m treated well by the carers that come to my house and they give 100%. I can tell them my mental issues, depression, and anxiety problems at home or with my health and they will help me deal with it. I’m glad I have this care team. I don’t know how I would cope without them.”* – **Over a year.**
>
> *“Most of the carers are very helpful and chat to my mother about her family life, make her up in the mornings and always explain what they are doing when washing her.”* – **6 months to a year.**
>
> *“I feel safe with my carers. I am blind and paralysed. My carers treat me with dignity and respect.”* – **Over a year.**
>
> *“I am very pleased with all my care services and look forward to them coming as most days they are the only people I see. They treated me like real friends and are interested in what I do.”* ***– Over a year.***
>
> *“My carers are experts in caring for my acute needs. I am grateful, as I feel my dignity is preserved. They are, without fail, kind, generous and good humoured”* **– Over a year.**

Continued…

38 comments about carers were mixed and 10 comments were negative.
Some common themes emerged from these responses, and these are illustrated by the following quotes from our respondents.

1. Communication/ language

Communication was frequently highlighted as a problem due to language barriers and strong accents. This was particularly a problem for respondents with specific communication needs such as hearing loss and learning disabilities.

> *"It was very hard to understand them. I am autistic and have communication issues and a processing disorder, so the heavy accents made things extremely hard."* **– 2 to 6 months**
>
> *"Some of the carers English is limited, so understanding and hearing them is sometimes difficult."* **– 6 months to a year**

2. Attitudes

A few people felt carers had a negative attitude and were often not 'caring'. Instead, some described carers as 'bossy', 'impatient', 'abusive', or suggested they did not acknowledge others within their home.

> *"Most are nice and treat me properly. Some get impatient because I am deaf and cannot hear the first time".* – **Over a year.**
>
> *"Only a few carers take the time to speak to us properly. Two carers don't even acknowledge me and only tend to my husband".* – **Over a year.**

Continued...

3. Quality & consistency

★★☆

A small number of respondents suggested the quality of care was lacking and often varied between carers. This was particularly the case where carers appeared ‘rushed’, or where regular carers had been unavailable.

Specific areas where the quality and consistency of care were questioned included cleaning tasks, food and drink preparation, personal care, administration of medication, and knowledge of the customer.

Example comments included:

> *“Most provide the care as requested but sometimes 'rush' making the bed, cleaning commode etc.”* **– Over a year.**
>
> *“Not all carers ask what I have eaten at lunch visit and drink.”* **– Over a year.**
>
> *“Some medications in the evening have been missed.”* **– Less than 2 months.**
>
> *“It becomes difficult when another carer has to step in due to staff sickness and they have not been before. I would prefer they ask me how thing are done rather than struggle through.”* **– Over a year.**
>
> *“Mum had 3 baths in a year with many excuses being used, so she rarely had a hair wash. Mum’s hands had poo on them every time I visited.”* **– Over a year.**

“I have received some good care and some really poor care. I have been shouted at and watched a carer throw my pad from the bathroom to the hall. My meals are served in the containers they are cooked in. Some staff have been nice, and some have been abusive. I do have trouble understanding some of them. Sometimes they leave without saying they were going”.

Has received care for over a year

Complaints

We asked respondents 'If you had any concerns or complaints about your care, would you know how to raise them?'

- **344** people answered the question.
- **86% (296)** said **'yes**'. However, this means that **14% (48)** do not know how to raise a complaint.

We also asked, 'Is there anything that would stop you from making a complaint?'

- **32** people answered.
- The most common reason someone wouldn't complain is being concerned they would lose their care.

> *"Losing care package as carers are good with dad"* **– 6 months to a year.**
>
> *"The carers will walk out…"* **– Over a year.**
>
> *"In case it did affect the care given. Being alone with no one else around at caregiving times can be quite intimidating and you are literally at the mercy of those giving you care. It can be an uncomfortable experience"* **– Over a year.**
>
> *"There is no other care company to look after me and I don't want to go into a care home".* – **Over a year.**

Themes	Count
Losing care	7
Family would raise concern on their behalf	5
Previously complained & nothing was done	5
Upsetting someone	3
Being treated differently	3
Trouble explaining	3
Don't know how to complain	2
Not listened to or acted on	2
Confidentiality of complaint	2

Qualitative insights... about complaints

1. Family members raise complaints

Some comments highlighted a difference between friends, relatives and recipients of care. Some friends and relatives indicated they would raise complaints, even if the person receiving care would not.

> *"My mum wouldn't raise a complaint, but we would".* **– 2 to 6 months.**

2. Previously raised a complaint

Some respondents had previously raised a complaint, but felt it had been ignored, not acted upon, or they had been told nothing could be done about their concerns.

> *"You don't get listened to. For instance, there was one carer who was absolutely dreadful. I requested to take them off the rota, and they flatly said that wouldn't be possible".* **– Over a year.**

3. Not listened to or acted on

Some people suggested they would not raise a complaint because they did not think they would be listened to, or any action would come of the complaint.

> *"Only the knowledge that I don't think anything would come of it".* **– Over a year.**

4. Treated differently

A couple of people were concerned they would be treated differently by the carers and care provider if they complained, or raised concerns.

> *"Worried about them treating her badly afterwards. Upsetting them and being more aggressive in their ways".* **– 2 to 6 months.**

6. Concerned about upsetting someone

Respondents suggested that they would not raise a complaint about their care because they did not want to upset or offend any of their carers.

> *"Difficult in present circumstances re. gender, race. Not wishing to offend."* **– 6 months to a year.**

7. Hard to articulate

Some people said they would find it difficult to explain their concerns or said they would have trouble speaking to people on the phone to raise their concern.

> *"My wife would make the complaint on my behalf. I would tell her what I didn't like as I myself I can't put it into words, but my wife understands me and what I'm trying to say."* **– 2 to 6 months.**

8. Don't know how to complain

Some people indicated they did not know how to make a complaint or did not know who to talk to if they had a concern about their care.

> *"Don't know how or who I would speak to."* – **2 to 6 months.**

9. Confidentiality

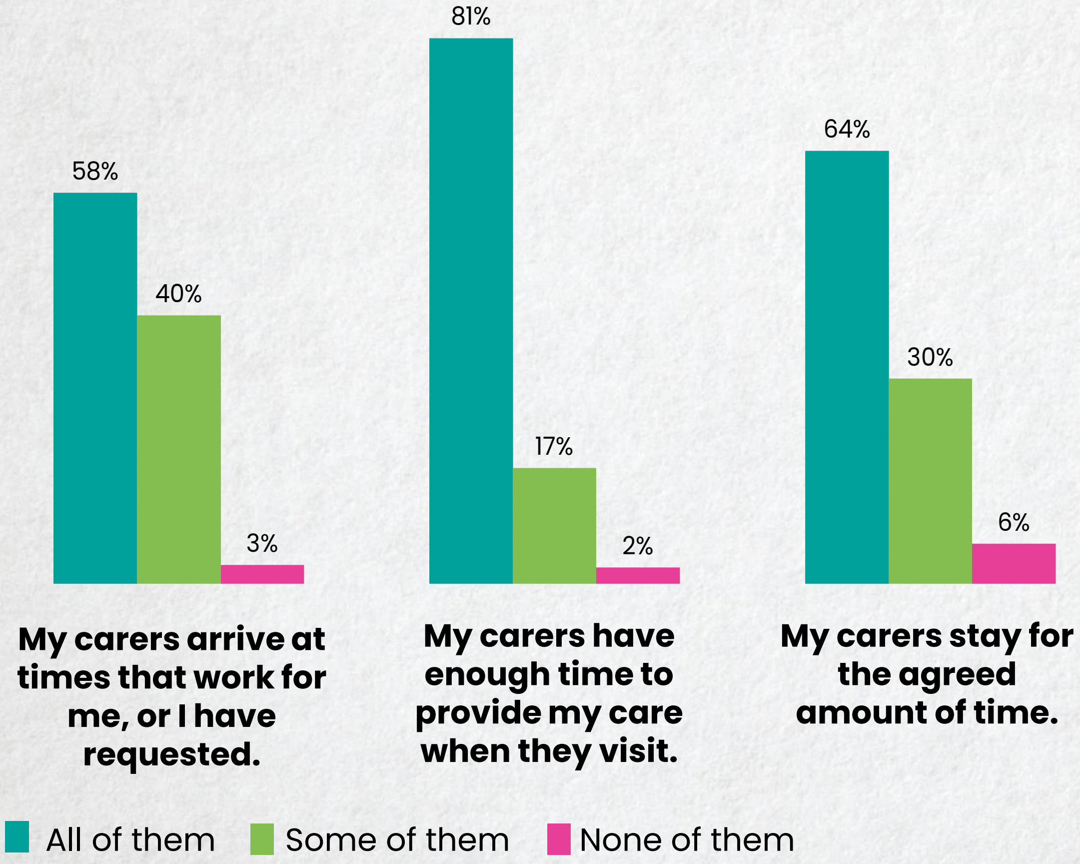
A few respondents raised concern about the confidentiality of the complaint, fearing that their carer(s) would find out who had made it.

> *"I complained about one of my carers and they found out and confronted me about it. They refuse to come here anymore."* **– Over a year.**

“I have the same small group of carers and I'm always notified if there's a new carer coming to visit. They all have given me excellent care and they help me to be more independent in my home.”

Has received care for less than 2 months

Time keeping



We asked, "For each of the following statements please tick the option that best applies."

Total response numbers varied between 324 and 334 for each statement.

- Most respondents felt each statement applied to all of their carers, including **81% (269)** that indicated all of their carers have enough time to provide care when they visit.
- **2 in 5 (40%/ 131)** indicated that not all of their carers arrived at times that worked for them, or that they have requested.

More than a third (36%) felt their carers did not consistent stay for the agreed time. 6% (19 people) indicated that none of their carers stay for the agreed amount of time.

Qualitative insights

About… timekeeping

We asked people to describe an experience of home care services. There were **48** comments that related to timekeeping and missed visits.

Negative themes	**Count**
Carers don't have enough time to provide care.	10
Carers don't arrive at suitable times	9
Carers don't stay for the allocated amount of time.	7
Carers don't arrive at allocated times.	6

Our quantitative data reveals high levels of positivity about timekeeping. However, **32** comments highlighted some specific concerns (e.g., that carers were rushed or did not stay for long enough).

Care times aren't suitable

Nine comments highlighted that carers would arrive at times that weren't suitable for the client. This resulted in medication being administered too closely together, being put to bed early or getting up early, and missing out on social activities.

> *"They don't come at sensible times and medication is offered too close together and mealtimes are also affected."* ***– Over a year***

Not arriving at allocated times

Six comments highlighted that carers would arrive outside of times agreed on people's care plans.

> *"The carers don't usually come at the times stated on the rota we are given. However, we have adapted to this situation".* **– 6 months to a year.**

> *"There is no fixed visit time, they usually carry out their duties, fill out their report then leave".* **– 6 months to a year.**

“I am young and the time they turn up is not suitable for me as I am unable to go out and meet friends due to bus timetables.”

Has received care for over a year

Continued…

Carers don’t have enough time

Ten comments suggested carers are often rushed and do not have enough time to provide agreed care. Therefore, if additional support is needed (such as making the bed, cleaning the commode, showering, or a chat), carers do not always have time to accommodate this. As a result, some peoples support needs are not being met, and others are relying on family to provide them with care.

> *“They have times to stick by, so no giving when problem e.g., I had a fall, bruised, needed help to shower. Carer told me no she couldn't stay and help me. I wasn't cared for, and she wasn't allowed to be a carer.”* **– Over a year.**
>
> *“Most of my carers don't have enough time for what is required of them.”* **- Over a year.**
>
> *“Sometimes it's rushed, and I'm not given enough time to do what I need to do (such as toileting). This then results in either having to wait for the next visit to be changed or asking my daughter if she can change me/take me.”* **- Over a year.**

Leaving early

Seven comments mentioned that carers were leaving earlier than their planned amount of time.

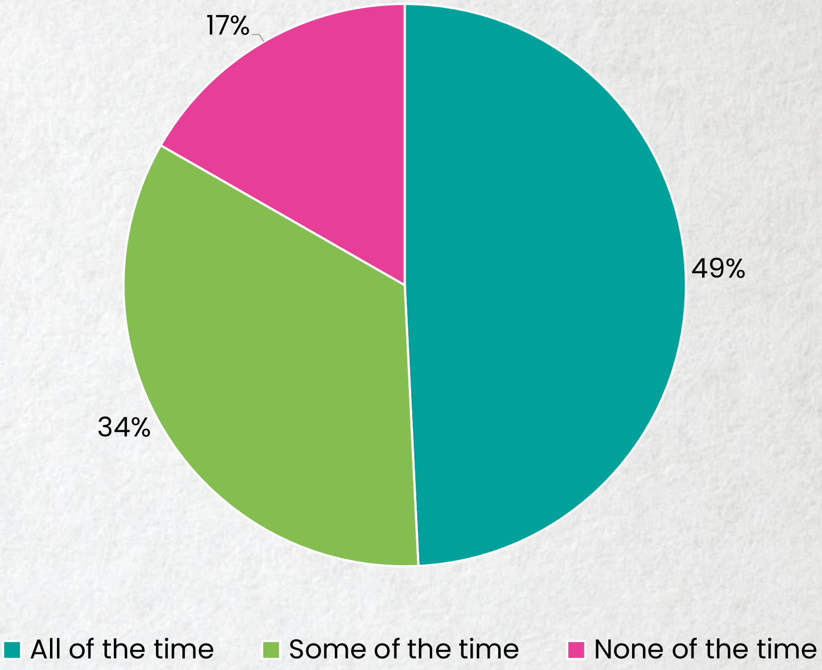
> *“The only concern is they never stay for any length of time because they are too busy rushing to the next person. Sometimes 5 minutes. Is just nice to talk. Mental health is a big part of care in my book and although my Dad doesn't live alone, others do”.* **- Over a year.**
>
> *“Carers are late most days and leave early. Most of the time they are here they are on their phones.”* **-Over a year.**
>
> *“Timekeeping is dreadful. It seems the carers have a list to get through. We are planned for 30 minutes but on some visits, carers are often in and out in 5 minutes or less”.* **– 2 to 6 months.**

Changes to your care

We asked, 'Are you kept informed about changes to how your care is delivered?'

323 people answered.

- Almost half **(49%/159)** said they were kept informed about changes to how their care would be delivered 'all of the time'.
- **17% (54)** of respondents were kept up to date about changes to their care 'none of the time'.



Impact unknown changes to the rota

Eleven people mentioned the impact of unknown changes to their rota, including carers arriving late and changes to regular carers. This included relying on others for care, missing medication, missing personal care, increased stress, strict care needs not being known, and the impact on family carers.

> *"One was so late that by the time they turned up my husband had done my care, and the care company apologized".* **– Over a year.**
>
> *"I am not always contacted about changes to my visits, and this sometimes causes me stress and it is not good for my mental health or change to normal routine for me".* **– Over a year.**

“Although a rota with named carers has been issued, different carers appear. When our regular carers were on holiday, we had different carers each day… unfamiliar with my wife’s needs. Most carers did not appear for the morning call… This meant my wife was left in her night clothes and unwashed, affecting her emotional and mental state. In this situation, the carers are often rushing and cutting corners to get in and out as quickly as possible. Occasionally, leaving the commode and contents to their next visit before being emptied…

“One such visit resulted in an overdose of medication. Her Parkinson’s medication must be taken three times a day at six-hour intervals. As the carers are never here for her first dose at 8am, I administer and always informed the duty carers I have done so. On this occasion, my notification was ignored, resulting in an overdose. On realising their mistake, they informed their office who phoned 111 for advice… No other help was offered or provided by the carers”.

Has received care for 6 months to a year

Missed visits

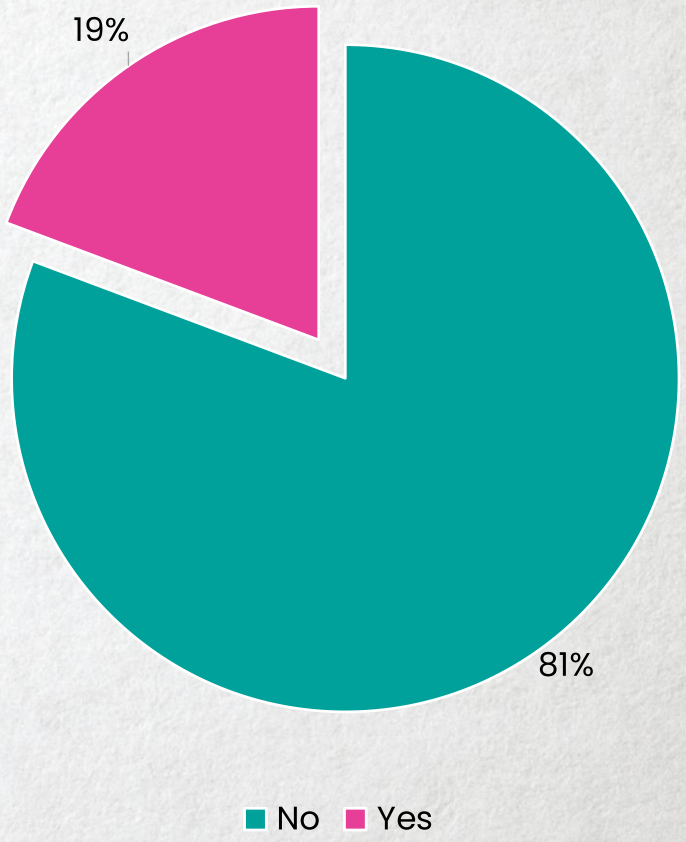
We asked, ‘In the last year, has there been an occasion when carers have not turned up at all to provide care (missed visit)?’

337 people answered.

19% (65) had experienced a missed visit in the last year.

A few respondents highlighted the impact of missed visits. This included how it had affected their evening routines, sleeping arrangements, and medication administration. People also said missed visits had increased stress and caused people to miss out on personal plans.

> *“Missed calls mean had to sleep in the chair”.* **– 2 to 6 months.**
>
> *“When returning home from a stay in the hospital in the evening the transport ladies had to put me to bed as the carers didn't come out”.* **– Over a year.**
>
> *“If they fail to turn up and I miss my medication it causes a lot of pain and is hopeless to do what is necessary to me getting my proper rest”.* **– Over a year.**
>
> *“Mum was missed off the rota last week. Lunch visit was missed. Mum's anxiety was sky high, I was out and situation was only saved by an out of the blue visit by a friend”.* **– 2 to 6 months.**



"All my carers are very friendly and always help me. They are above anything I would expect from carers. The staff are fantastic. I have never had a bad word with them. All the staff treat me with respect. They chat and laugh with me. I have never had missed calls. I cannot thank them enough for their help".

Has received care over a year

Qualitative insights

About… suggested improvements

There were **100** comments about things that could improve local home care services in West Suffolk.

1. Increased, and longer, visits

Twenty-one people said they wanted longer care visits, or more care visits in the day. Often, people wanted longer care visits so additional support could be provided to benefit their wellbeing (such as personal care, preparing food, and exercise).

> *"I would like to walk more but cannot do this alone, and obviously 30mins is not really long enough to do this as well as sort my food, get me dressed etc."* **– Over a year.**

> *"I would like a lunch time call to help me with my dinner. I forgot to eat or eat too late for my diabetes."* **– Over a year.**

> *"If I could have a little longer visit on one of the two times during the day (weather permitting) to be taken for a walk around the street to keep my legs strong and to do a meal on stove/oven instead of microwave meals, when my family are unable to bring/cook on their visit."* **– Over a year.**

Themes	Count
Longer visits or more visits	21
Regular carers	13
Abiding by care plan (arriving times & length of time)	12
Kept up to date with changes to rota	11
Better communication	10
Staff training	10
More carers & carers given more time to travel	7
Understanding of client & needs	6
Different care times available	5
Different gender of care	4

Continued...

2. Abiding by the care plan

Twelve people wanted carers to arrive at allocated times and stay for the time arranged in their care plan.

"Same time for visits each day would be helpful as my mother has vascular dementia, anxiety and depression and working to a routine helps her." **– 6 months to a year**

"Stick to times given so same every day. I can't cope with change and need a routine. I appreciate things happen but it's no longer an as and when occurrence it's now quite regular." **– Over a year**

"I would like the times that were arranged for my morning visits. They said they would be 9.00 or 9.30 but just lately they have been changed on a Friday, Saturday, Sunday to 10.30 when it's too late for me. Sometimes its 11am." **– Over a year**

3. Regular carers

Thirteen people felt having the same carers every day would improve consistency and ensure carers understand the person and their needs.

"Consistency of day carers. I need people who know my care routine." **– Over a year**

4. Being kept updated

Eleven people wanted to be kept updated about changes to their care rota, including when carers will be late, change of carers, and times. They suggested this would help to mitigate stress and anxiety caused by late or missed visits.

"Being notified more of a carer change... as I am not always informed of such changes, this would allow me to expect the change more easier knowing of a routine due to my mental health needs." **– Over a year**

Continued…

5. Knowledge of clients

Six people mentioned that carers need to have a better understanding of their needs, conditions, and individual care plans to ensure care needs are met.

"Carers that know me well and my needs and where things are in my house. Because of my dementia, it is hard for me to remember where things are". **– Over a year.**

6. Choice of carer

Four people mentioned they would prefer female carers, particularly when receiving personal care. One respondents suggested they felt uncomfortable receiving personal care from a male carers so would go without showering instead.

"More female staff alternated with males so that personal cleanliness can be maintained". **– 6 months to a year.**

5. Choice of care times

Five people wanted the choice of different care times because agreed times were often not suitable for them, particularly when evening visits were too early.

"Our evening carers are very early so we have to get ourselves into bed. We can just about manage to do it ourselves, but it isn't always easy". **– Over a year.**

5. Other improvements

Other suggestions included carers wearing name badges, access to a 24-hour emergency contact number, a review of care needs, and a copy of their care plan.

"Would like a 24-hour contact emergency number. I have no contact number between 22:00-08:00". ***– Over a year.***

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