healthwatch Suffolk

"What's it like?"

People's experiences of residential and nursing homes in Suffolk

Created October 2020

Contents

1. The sample

Methodology

Healthwatch Suffolk (HWS) worked with 165 care homes across Suffolk. These were all homes registered with the Care Quality Commission (CQC) as providing care for older people. Fifty-nine of the homes were registered with CQC to provide nursing care.

Care homes were asked to promote the surveys amongst their residents and relatives. Hard copies of surveys were made available to homes on request. Homes were also able to request facilitators to visit the home to assist residents with completing the questionnaires.

Healthwatch Suffolk promoted the survey to the public through contacts at Suffolk Community Healthcare, while also promoting the survey to the target professionals through our links with GP surgeries, social media, and connections throughout the local community.

Case studies

Four anonymous case studies are also included, initially interviewed as part of the "What's it Like" survey of residents living in care homes and carried out before the COVID-19 lockdown.

These have been written by our research team and updated to include their unique experience of life during the lockdown, highlight the difficult issues faced by residents in care homes (as well as their relatives and friends), and the emotional and physical effects on all of them.

Responses

Six hundred responses were received in total – 290 from residents, 310 from relatives or friends (23 of which were from friends).

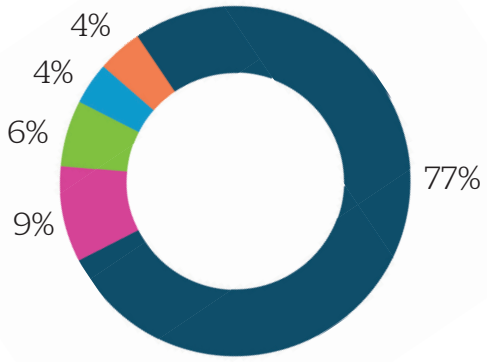
Responses related to 108 different care homes – this represents 65% of the total care homes written to.

Forty-six (1%) people chose not to disclose which home they were responding about.

Geographically, responses were received from about 70% of the care homes in East Suffolk, 63% of the care homes in the North Suffolk and 58% of the care homes in the West Suffolk.

	Total no. of homes in area	No. of relative responses received	No. of resident responses received	No. of homes received responses about	% of homes received responses about
East	88	181	126	62	70%
North	32	30	82	20	63%
West	45	66	66	26	58%
Not disclosed	-	33	16	-	-
Total	**165**	**310**	**290**	**108**	**65%**

***Graph**: "Did you have help to complete the survey?", featuring answers of "**help from a HWS facilitator**", "no response", "help from a carer", "help from a friend or relative", or stating that they "didn't need any help".*



Facilitators

Facilitators visited 43 (26%) homes to assist residents who would otherwise have difficulty completing the questionnaires on their own.

Over three-quarters (77%) of the residents we heard from received help from a facilitator to complete the questionnaire.

To ensure impartiality care homes were asked not to assist residents, however, 17 people (6%) said they had received help from a carer. Only 4% (11) of residents completed the survey on their own. These figures highlight the importance of providing assistance to enable residents to fully engage with any feedback process.

	Suffolk homes	HWS sample
Outstanding	16%	13%
Good	74%	77%
Requires Improvement	8%	9%
Inadequate or undisclosed	2%	1%

CQC ratings

The table below shows the profile of CQC ratings for all of the care homes contacted as part of this project, compared to the profile of the homes we received responses about. Overall, the CQC ratings of the homes in the sample broadly reflect the overall Suffolk profile, with the majority of homes falling within the "good" category.

Funding of care home placement

Five hundred and eighty-six people answered the question asking how their or their friend or relative's care home placement was funded.

Overall, 49% (286) of respondents said that the care home placement was 100% funded by the resident and their family. For comparison, data provided by the Insight and Intelligence Team at Suffolk County Council, based on a survey conducted in 2016, indicated that around 51% of care home residents are self-funders.

Twelve per cent of relatives or friends responded about someone who was in an NHS-funded placement (either

Continuing Healthcare or NHS-funded nursing care) compared with just 2% of residents. This is not entirely unexpected, as residents funded through the NHS are likely to have complex needs that may have prevented them from being able to complete a questionnaire themselves.

Thirty per cent of residents responded saying that they did not know how their care was funded.

Length of stay in care home

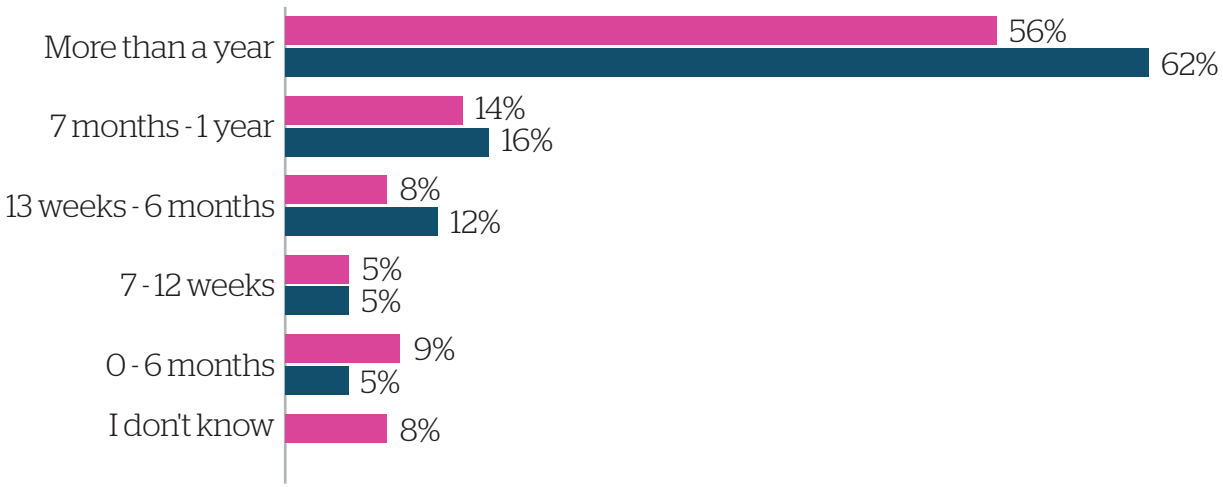
Overall, three in five responses to the surveys were about a long-term placement. Fifty-six per cent (161) of residents said they had lived in a care home for more than a year, and 62% (187) of relatives said they were responding about someone who had lived in a home for more than a year.

The high percentage of long-term placements within the sample is an important consideration when analysing the questions relating to the "journey into care" and the choices people made at the time of moving into a care home. (See section 2 of this report).

Eight per cent (23) of residents said they didn't know how long they had lived in a care home.

Length of stay in the care home	Resident response	Relatives and friends response
More than a year	56%	62%
Seven months to one year	14%	16%
Thirteen weeks to six months	8%	12%
Seven to 12 weeks	5%	5%
Zero to six weeks	9%	5%
I don't know	0%	8%

***Graph**: Length of stay, featuring answers from **residents**, or **relatives and friends**.*



Health needs

Five hundred and eighty-five people answered the question about health needs.

Care home managers were advised that "residents who lack capacity to consent should not be included in the survey, however, we would encourage their relatives to take part". It is therefore not surprising that 63% of relatives said they were responding about someone who had a form of dementia compared to only 6% of residents.

Resident mobility and the need for assistance to move around were the most commonly reported health needs. Residents were also more likely to report "other health needs" - 41% compared to only 7% of relatives. The most commonly mentioned other health needs mentioned by residents were heart conditions or issues with blood pressure (12%, 34), arthritis or musculoskeletal conditions (9%, 26), issues with balance or legs leading to falls (7%, 20), and diabetes (6%, 18).

Appendix 1

We have also included a brief report summarising conversations that Healthwatch Suffolk research staff had with care home managers across Suffolk. They were not the result of a structured interview.

The information requested was expected to be inputted and added to a report resulting from the HWS online survey about COVID-19 experience - however, given the nature of this report, Healthwatch Suffolk decided the brief report - given the subject matter - should be included.

A thank you

Healthwatch Suffolk would like to take this opportunity to thank Care UK staff, along with all others involved, in helping us to co-produce the surveys used for residents, relatives and friends.

Health need	Resident reported	Relative reported
Form of dementia	6%	63%
Trouble with memory	38%	47%
Need help to move around	56%	48%
Hearing impaired	37%	21%
Visual impairment	18%	15%
Support post-stroke or TIA	17%	11%
Mental health difficulty	8%	10%
Parkinson's	6%	9%
Learning disability	7%	4%
No significant healthcare needs	10%	3%
Other	41%	7%

2. Moving into a care home

Involved in choosing a care home

Eighty-six per cent of relatives said they were involved in choosing the care home for their family member. In comparison, only 49% of residents said that they had been involved in the decision.

Reasons for moving into a care home

Respondents were asked why they, their friend, or relative had moved to a care home and what other options (such as home care or sheltered housing) they had considered at the time.

Home care or sheltered accommodation not suitable

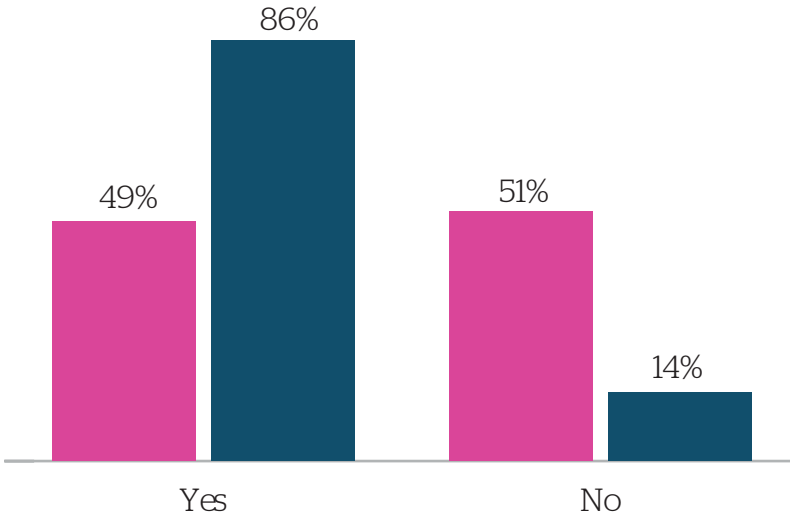
One hundred and sixty-eight people said that they, or their relative had moved into a care home because alternatives weren't suitable.

Seventy-six people said 24-hour or night-time care was needed.

Main theme	%
Home care/sheltered not suitable	53%
Safety/independence	42%
Partner/family unable to help	27%
Hospital	22%
Complex health needs	13%
Loneliness	12%
Dementia or Alzheimer's	10%
Had link to care home	9%
Moved from another care home	7%
Unsuitable home	5%
Finance	3%
Mental health	3%

Fifty-seven people said that their health and medical needs were too complex to be met by domiciliary care. Other reasons respondents felt home care or sheltered accommodation was not suitable for their

***Graph**: "Were you involved in choosing your, your friend or relatives care home?", featuring answers from **residents** and **relatives and friends**.*



needs included having to wait too long between home care visits (8), feeling that the home care was too intrusive (6), and carers being unreliable (9).

> *"My son sorted it out. I fell a few times and I don't think I was managing my house. The children decided that having people come into my home wasn't good enough. I feel safe here, it feels like a real home."*
>
> *- Resident, East, doesn't know how care is paid*

> *"Carers coming into the house three or four times a day wouldn't have been enough to ensure she didn't fall or have an accident, especially at night."*
>
> *- Relative, North, part paid by the council*

Home care or sheltered accommodation

One hundred and thirty-three people said the move into care was triggered by a loss or reduction of personal safety or independence. The majority cited regular falls as a key reason for their move.

Sixty-two people talked about having a fall, or multiple falls, before then moving into a care home.

Thirty-eight people talked about a general loss of capability to be independent, twenty-one relatives felt their family member was unsafe living at home, and seven residents said they felt unsafe at home.

> *"She felt safer moving into residential care as she had had several falls and was scared of falling again."*
>
> *- Relative, 100% paid by resident*

> *"I'd fallen at home a few times (pegging out washing and again in the kitchen during the heat wave) so I began to question my ability to be completely independent."*
>
> *- Resident, East, 100% paid by resident*

> *"Social services told me at a meeting that it would be too dangerous for him to return home."*
>
> *- Relative, East, NHS nursing care*

Partner or family unable to help

Eighty-five people linked the move into a care home with family and relatives being unable to provide the support needed.

Twenty-eight people had moved into a care home due to the deteriorating health or death of their partner, who had previously taken on the role of being their full-time carer at home.

> *"After my wife died, I couldn't look after myself, I got depressed... then move into a home."*
>
> *- Resident, East, 100% aid by local authority*

Eighteen people said that their partner or family were unable to fulfil the role of carer. This was for a variety of reasons, including the family needing respite or the resident's health and care becoming more complex.

> *"Wife unable to cope with providing 24-hour care at home as has her own health issues. This enabled them quality time together at this stage."*
>
> *- Relative, East, NHS Continuing Healthcare*

Sixteen people said there were either no relatives, or none that lived nearby, who could provide support.

> *"I was admitted to hospital and needed surgery for bowel and prostate cancer. Once that was done my doctor said that I couldn't go home. My bathroom was upstairs and as I needed to be on or very near to the toilet all the time I was sent here. I didn't have any choice or say, nobody asked.*
>
> *"I was sent here. The taxi brought me here straight from the hospital. I have no family, only friends that help me when they can."*
>
> *- Resident, West, 100% paid by resident*

Hospital

Seventy-one people linked hospital admissions or discharge to the move into a care home.

Forty-eight people said that they had been discharged directly from hospital into a care home. Typically, they were placed where a space was available, and had little or no choice. Often this happened because it was deemed unsafe for them to return home, due to a sudden change in their health or care needs.

A further 14 said they were discharged from hospital into a care home for respite, which became permanent.

"Hubbie and I were in hospital with chest infections. I struggled to look after him. Doctor sent me to hospital, on Xmas eve they moved us here and they used to take us to be with each other. We didn't have a choice, but we could be together. We were told we had to go into residential care. I couldn't cope."

- Resident, North, 100% paid by resident

Complex medical needs

Forty-one people mentioned complex medical needs as a reason for moving into a care home.

Nineteen people said that they (or their relative) had experienced a major stroke. The consequent loss of independence then led to them requiring residential care.

"Major stroke which left them paralysed down one side. Doubly incontinent and totally dependent on staff to dress, toilet, and shower or bathe. Cannot talk and is unable to voice her needs completely."

- Relative, East, part paid by council)

Sixteen people had experienced the sudden onset of another illness (such as cancer), or serious injury which led them to needing residential care. Serious injuries (such as a broken hip) were typically caused by a fall.

Loneliness

Thirty-nine people mentioned loneliness as a reason for moving into a care home.

Seventeen people talked generally about a sense of loneliness and living alone, a further 12 mentioned the death of a partner, and another eight people had moved to a care home in Suffolk to be nearer to family.

"My husband has dementia and we weren't coping very well at home. [He] moved in first. I would visit him once or twice a week, and the home said I could have lunch and tea with him when I visited and I found that I didn't want to go back home at the end of the day to be on my own.

"My husband and I were a team at home. So when he came in to the home I couldn't cope on my own. My family didn't live close enough to help. I like people around me so I felt lonely on my own. There is always someone around to help here."

- Resident, East, 100% paid for by resident

Dementia or Alzheimer's

Thirty-two people, mostly relatives, mentioned dementia or Alzheimer's as the reason for a move into residential care.

Twenty-one relatives said that it was unsafe for their family member to be living at home due to their dementia/ Alzheimer's. A further nine said that the elderly partner of the person living with dementia was struggling to cope.

Had link to care home

Twenty-one people had chosen to live in the care home they were in, as they already had a link to the home.

Thirteen people said they had moved in to be with their partner or sibling who already lived there, while eight people said they had chosen the care home as they had previously enjoyed respite care there.

"I had stayed in this home during recovery after previous hospital stays until being well enough to go home, so I did know the staff and environment and always thought that if I had to move into a home, I'd come here because I trusted them."

- Resident, East, 100% paid by resident

Moved from another care home

Twenty-one people said they had previously been living at a different care home before moving to their current residential care home.

Seven had moved because they were unhappy at their previous home, while five said that their previous home was unsuitable and couldn't meet their changing needs.

Four said their previous home had closed down, three people had been evicted due to aggressive behaviour (caused by dementia or poor mental health), and two people ran out of money so became council-funded, but were evicted as the home wouldn't keep them on the reduced council funding.

"After my wife died I couldn't look after myself, I got depressed. Then move into a home. The money ran out and I couldn't afford to stay there as the home wouldn't negotiate the fees so I was forced to find an alternative."

- Relative, East, 100% paid by local authority)

Unsuitable home

Fifteen people said they could not remain living at home as their health and care needs were incompatible with their house. This was typically due to having too many steps in the house, the toilet being upstairs, or the house being unable

to accommodate adaptations when needed.

Finance

Eleven people cited financial reasons as part of the reason they moved into a care home.

Eight said that they or social services had deemed home care to be too expensive, due to the amount of care they would need.

> *"It became too expensive to manage her care needs at home, due to needing both day and night supervision."*
>
> *- Relative, name of home not disclosed, 100% paid by resident*

Mental health

Nine people had moved into a care home because of poor mental health. Six people had been sectioned into a care home which provided specialist mental health support for elderly people.

Who prompted the move into a care home

Respondents were not asked who had prompted the move into a care home however in 80 cases it was possible to identify this from the answers people had written.

Most people said the initial idea or suggestion, was raised by a family member – such as a son, daughter or sibling.

Compared to relatives, residents were more likely to say that the idea to move came from themselves – however this may be due to selection bias (by design, we only spoke to the more independent residents).

Relatives were more likely than residents to say that a social worker raised the idea of a move – however this may also be due to selection bias (social workers recommend residential care for those with the highest needs).

> *"Dad was severely missing his late wife, and took an overdose (second attempt). After hospital care, Dad wasn't allowed to return home because the mental health doctor decided Dad couldn't live alone."*
>
> *- Relative, name of home not disclosed, part paid by council*

Case study 1 - "Mrs R"

Mr and Mrs R have been married for over 54 years. Mr R was diagnosed with vascular dementia 10 years ago, and for some years Mrs R looked after him at home but following her diagnosis of cancer this became more difficult and his behaviour changed for the worse. Initially, he was sent for respite, but was desperately unhappy as the home did not give sufficient or appropriate care for his condition at that time. He returned home after a week, and was home for a month with Mrs R caring for him 24 hours a day without any support from social workers or additional care.

Although Mrs R says he was not ready for full-time care, he was eventually sent to another "totally unsuitable" care home for respite, where he stayed for seven months. This home had insufficient carers, leaking toilets and only one working shower. There were several incidents when a resident entered Mr R's room inappropriately dressed. Despite being threatened with safeguarding if she tried to move him, with the help of her social worker he was moved into another home. The home he left then demanded one month's money because Mrs R had not given one month's notice.

The new care home was equally bad, with no activities or stimulation, insufficient carers, poor food and five changes of managers in two years. Despite Mrs R's efforts, her husband's condition deteriorated badly. He did not always recognise his daughter, walked with a shuffle and began to sleep all day and wander at night. Mrs R constantly enquired about what was wrong and one day, without explanation, the doctor ordered the home to stop all medication. Mrs R then discovered that he had been given a drug, without consulting her or her family, which was inappropriate for his conditions and age, and had resulted in his condition deteriorating - probably permanently. Following her complaints, the General Medical Council investigated, and the GP eventually apologised to her. Throughout this whole experience, Mrs R had little or no support from the home or social services but coped on her own, and despite visiting more frequently, nothing changed. Mrs R had to replace all his clothes and take them home to wash every day. She was left to look after patients, showed people around the home and helped do general work while the remaining carers looked after other patients. Despite increasing numbers of residents, no additional carers were employed. One carer actually became the chef. During this time, Mr R had several falls and concussions.

Mrs R complained one day because Mr R hadn't been showered, and pads and clothes had not been changed. "The smell was vile". She discovered that safeguarding was in place and social services were investigating. Council funding was removed and - just before Christmas - residents who received council support were informed they had to move within 21 days. Mr R had been there almost two years. They were told their first choice of care home was full and others were too far away, but following the intervention of her social worker, a place at their first choice was made available.

Throughout his diagnosis and treatment, until this final home, Mrs R felt completely alone, coping with a deteriorating

situation and with no support. This affected Mrs R's health and, as she explained, "the effect is like three-times grieving as there is the diagnosis, then moving into a care home, and then the knowledge that it will be followed inevitably by death".

Mrs R says there is no comparison between this and previous care homes. The staff are very helpful, she can talk to them at any time and they go through everything with her. Her financial position has improved, and she has now also received excellent advice from Work and Pensions about her entitlements. She said that "we are treated with respect by all the staff and I am hugely impressed. The care is incredible and they treat him like a granddad, and they talk to the residents all the time". Mr R is much happier and "still flirts". Mrs R derives great comfort from knowing that he is well-looked after and safe, and she is very happy to leave him now and does not worry.

Because Mrs R has confidence in the care her husband is receiving, she herself feels much better and her health has improved. She said that "it's like a family. I can go when I like, and they are wonderful with him".
However, Mr and Mrs R have been badly affected by COVID-19 and Mrs R is feeling desperately lonely and depressed. Not only for herself but because of what happened to her husband during the crisis.

Mr R had an accident in the home and was taken to hospital with concussion. He was due to be discharged, but the care home would not take him back as he had not been tested. He ended up in hospital for 10 days, during which time discussion took place between the hospital and care home as the care home was reluctant to take him back until special arrangements were made to pay for his care. He was then tested twice; both proved negative. During his hospital stay, he lost 13lbs and was skeletal. Mrs R believes that as he was not in a dementia ward he was not helped to eat or drink, was not moved or washed and his meals were just taken away from him uneaten. He was eventually sent back into isolation in the home where he was put onto end-of-life treatment. Mrs R and her daughter were allowed to see him wearing PPE as he appeared to be dying.

When he was discharged into the home, he was in agony and would scream if he was touched. Mrs R even contacted a funeral home as he was so close to death. However, the care home staff were incredible and took such good care of him that he began to get stronger, to eat pureed food and drink from a spoon. He eventually could use a wheelchair. Staff promise they will have him walking. When he was eventually moved back into the main care home these visits ceased and she relied on staff who used Facebook so that she maintained contact. She can now book a half-hour appointment and see Mr R in the garden while socially distancing and he continues to make progress. Mrs R cannot praise the care home staff highly enough, but has complained to the hospital about his treatment there.

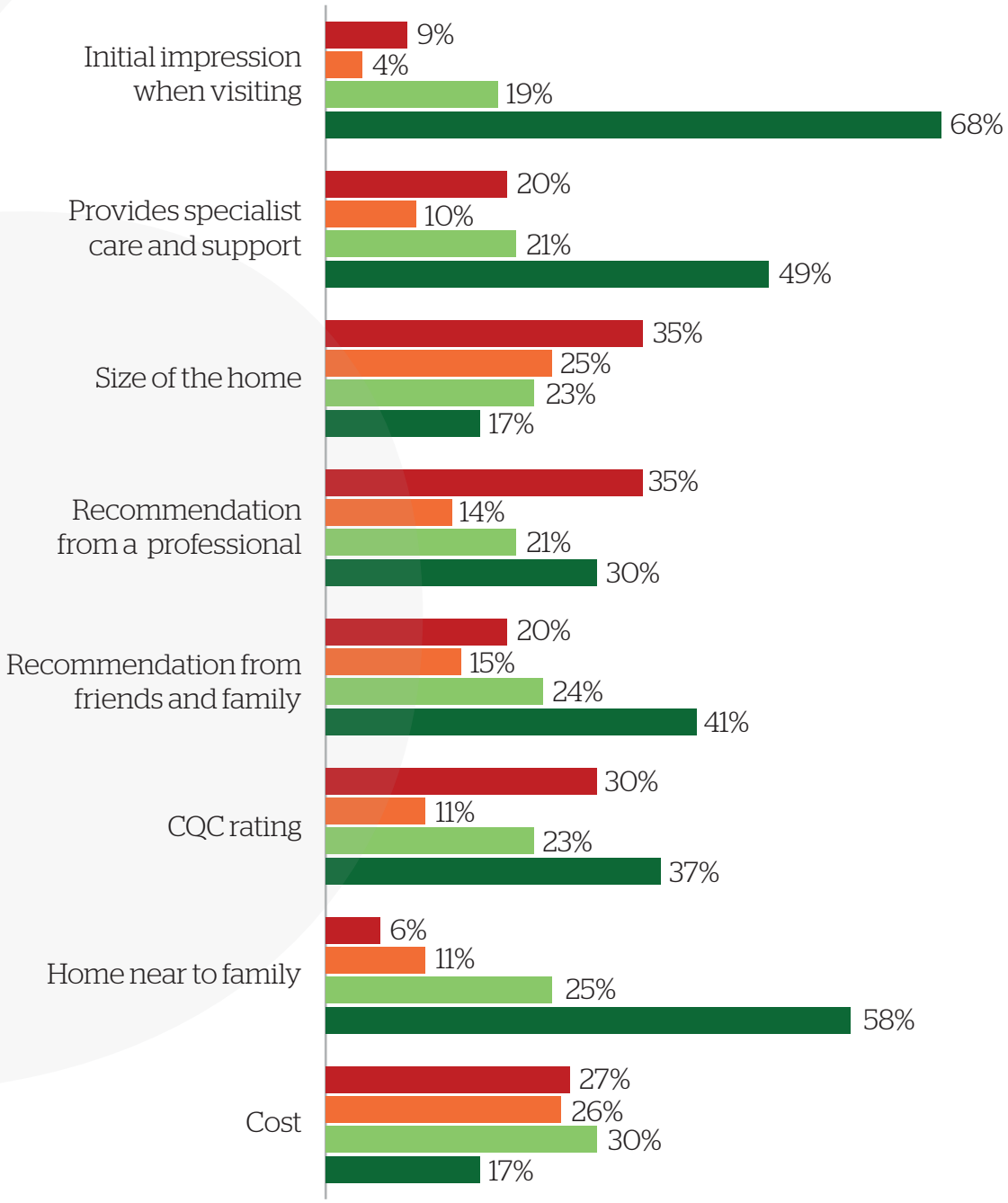
The whole experience has had a detrimental effect on Mrs R's physical and mental health, and although hugely comforted by Mr R's progress, she is still traumatised by the whole experience. She is now in a bubble with her daughter and has started shopping locally, so her situation is improving, but it was only the efforts of the staff in the care home that helped Mr R survive this awful experience.

3. Choosing a care home

Respondents were asked how important different factors were in choosing a care home or shortlisting care homes.

Across the whole sample (residents and relatives), first impressions when visiting the home were most important, followed by proximity of the home to family.

***Graph**: "How important are these factors when choosing or shortlisting a care home?", featuring answers of "**not at all important**", "**somewhat important**", "**important**", and "**very important**".*



4. Care planning

Care plans

The majority (87%) of relatives or friends were positive that a care plan was in place. However, residents were less positive in their response, with 56% saying they either did not have a care plan or they did not know if they had one.

Among the residents and relatives who said there was a care plan, 70% were confident that the care plan was being regularly updated. However, a fifth of relatives and almost a third of residents said they were not sure, and 5% of all respondents said the care plan was not regularly updated.

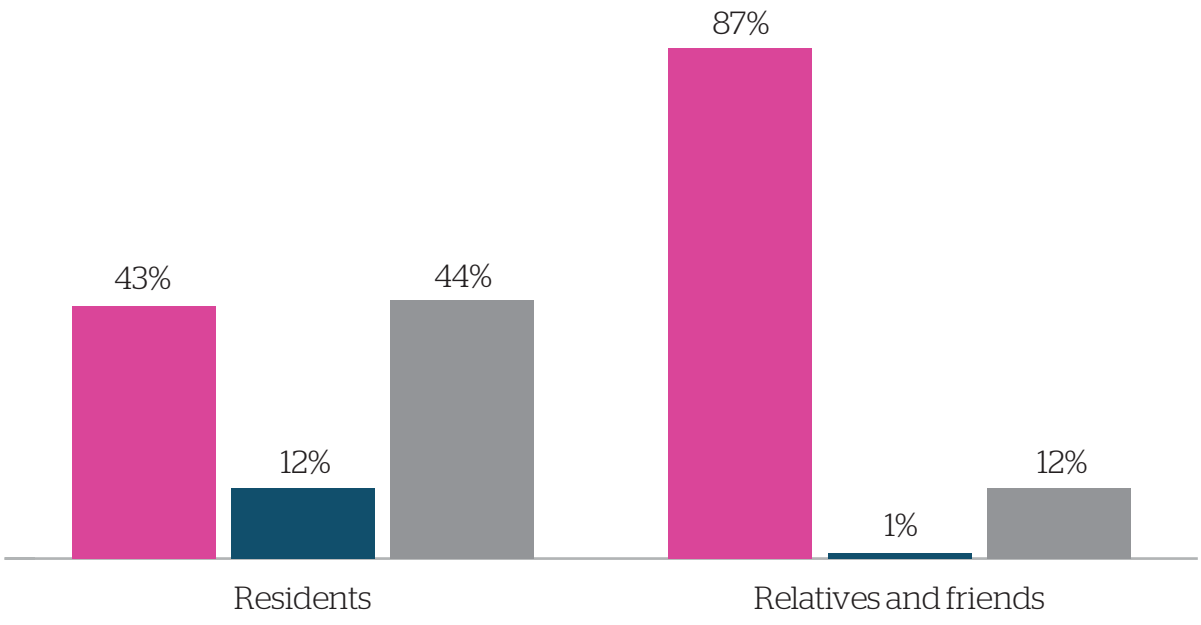
Feeling safe

Although both resident and relative surveys included a question about feeling safe in the care home, the questions were worded differently. Relatives were asked "do you fell your friend or relative is safe living within the care home?", while residents were asked to rate how much they agreed or disagreed with the statement "I feel safe living in this care home".

96%

of respondents said they felt that their resident, friend, or relative was safe

***Graph**: "Do you have a care plan in place?", featuring answers of "yes", "no", and "I don't know".*



For the purposes of comparison, resident responses have been converted to fit with the relative responses.

Five hundred and forty-six people answered the questions about feeling safe in the home. Overall, 96% of all respondents said they felt safe or that they felt their relative was safe. Residents were slightly more positive than relatives.

Twenty-two (4%) respondents either said they did not know, that they were not safe, or their relative was not safe.

The relative questionnaire asked respondents to explain why they felt their relative was not safe within the home. (After each quote shown in this section, we have specified the locality of the home and how long the resident has been living there).

Four relatives made specific mention of injuries their relatives had sustained while in the home.

> *"Had a fall (not witnessed by staff) in dining room - fracture neck of femur. Dining room not monitored at all times regardless of how many residents are in there. Shortage of staff seemed to be the cause. He does often have falls because he still thinks he can walk."*
>
> *- Relative, East, 13 weeks to six months*

Staffing and staff attitudes are the focus of concern for eight relatives.

> *"Low staffing, often left waiting a long time for care, staff are often obviously not interested in the job, special diet often not provided."*
>
> *- Relative, West, seven months to one year*

> *"The total lack of care by most of the carers, buzzer ignore or pulled out, clothes lost, relative's attending to personal care. Have had meetings with manager and social services, nothing has improved."*
>
> *- Relative, West, seven months to one year*

One respondent also felt that as their relative had not been living in the home long, it was too soon to make a judgement about safety.

Getting to know you

Respondents were asked how satisfied they were with the way the care home had got to know them, their relative or friend. Ninety-one per cent of relatives

were either "very satisfied" or "satisfied" that the home had made efforts to get to know their family member. Residents, by comparison, were slightly less satisfied.

Among those who were less satisfied with the way the home had got to know them or their relative, the main issues related to staffing included:

- There not being enough staff
- Infrequent staff changes
- Staff attitudes
- A lack of time for staff to get to know residents
- Staff knowledge

"Every resident, assisted by relatives, is encouraged to complete a "My Life" book with details of their life history, places they have visited, their work and hobbies, and other things important to them.

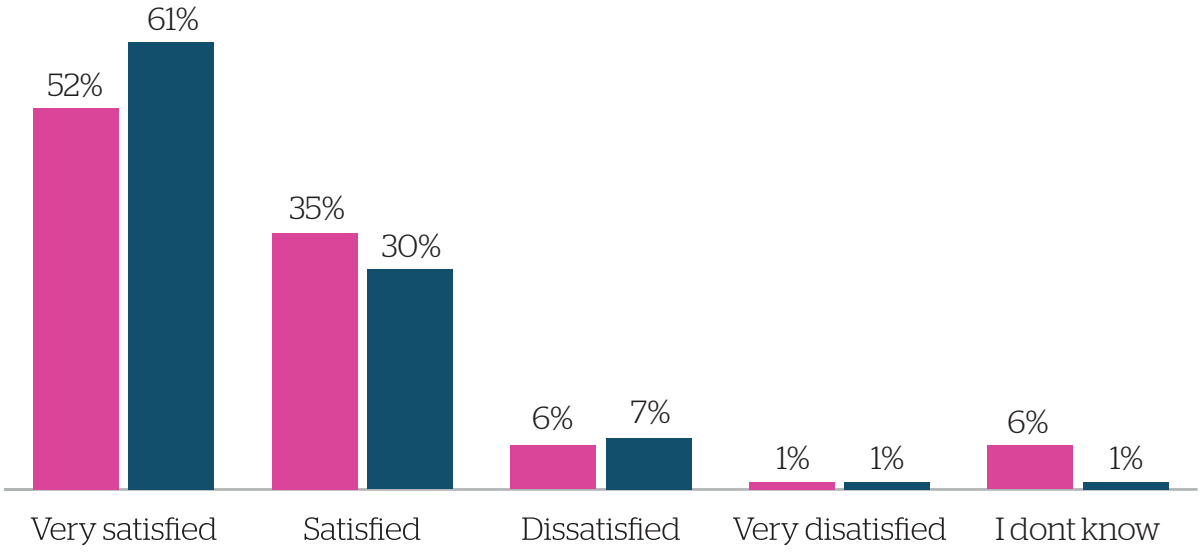
"This is used by staff to get to know them and to suggest activities e.g gardening that they might find interesting and engaging."

- Relative, East, seven to 12 weeks

"I was an airspace engineer and there's nobody in here who I can talk to, nobody to have a conversation with. They're not polite, they don't understand what I'm saying. The carers hardly speak to me."

- Resident, West, more than a year

***Graph**: "How satisfied are you with the way the care home had got to know you, your relative, or friend?", featuring answers from **residents**, or **relatives and friends**.*



5. Relative experience

Relatives were asked about their experiences of visiting care homes. Respondents were overwhelmingly positive in their responses, with over 85% of relatives agreeing with all of the statements and over 50% agreeing strongly.

Respondents whose relatives were in CHC-funded placements (24) were least positive, having the lowest proportion of respondents agreeing with five of the seven statements:

- "I feel involved in decisions" (77% versus 90% for total sample)
- "Staff are available to talk to me" (77% versus 88%)
- "The care home listens to me" (81% versus 87%)
- "The home informs me of any changes in my relative's health and care needs" (77% versus 87%)
- "I trust the carers" (86% versus 92%)

Respondents whose relative in the care home had dementia were slightly less positive on two of the statements than those whose relative did not have a dementia.

Forty-nine per cent of respondents whose relative had dementia strongly agreed with the statement that "the care home listens to me", compared to 58% of those whose relative did not have a dementia.

We also found that 58% of respondents whose relative had dementia strongly agreed that "staff are always available to talk", compared to 68% of those without a dementia.

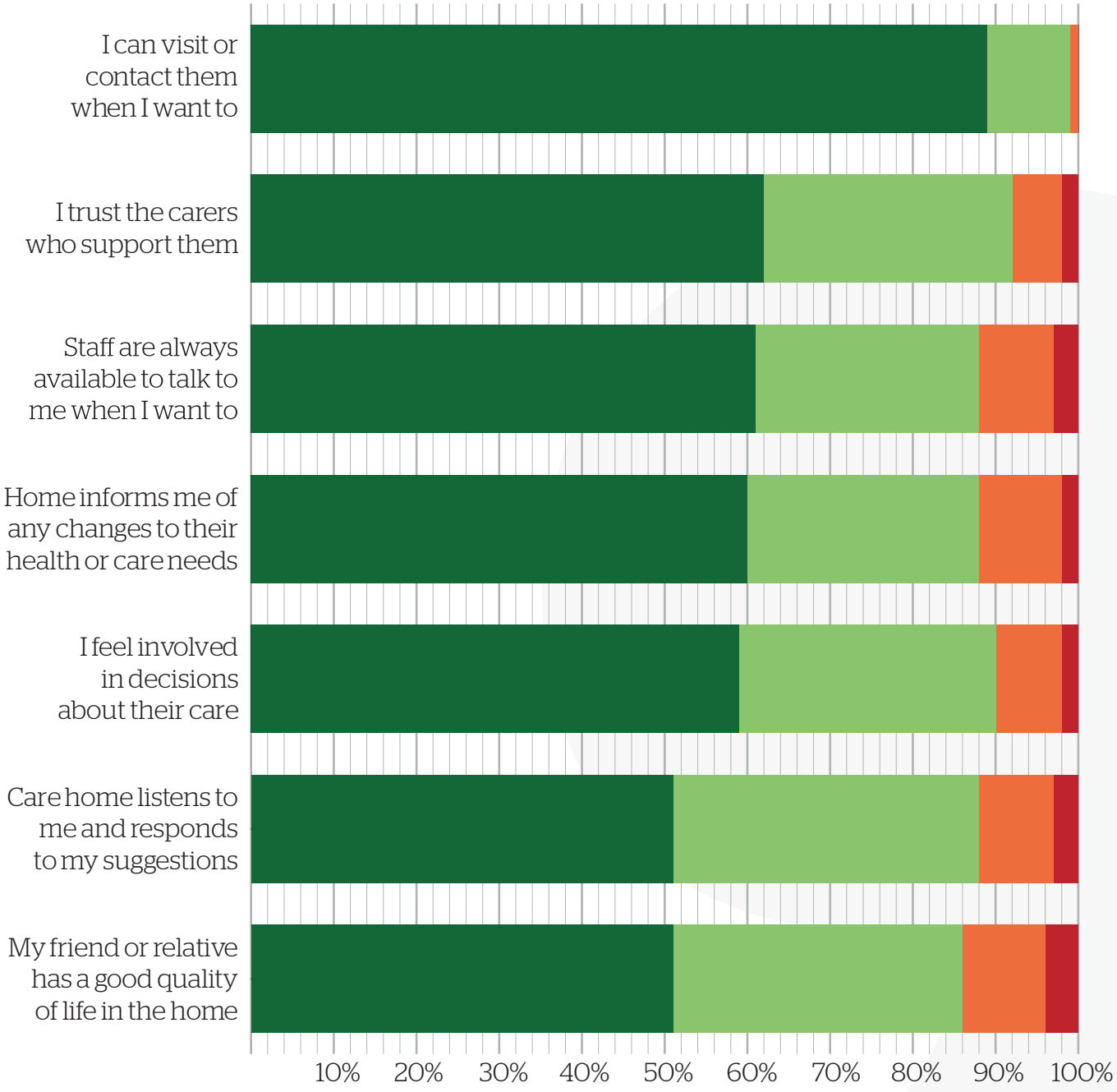
An evaluation of the overall rating that relatives gave care homes compared with how they rated homes on these specific statements reveals they were, on the whole, consistent in their assessments. For example, those who gave care homes an overall rating of four or five stars agreed strongly with all or most of the statements, and those who disagreed or disagreed strongly with several of the statements went on to give the home an overall star rating of one or two.

While there was no specific open-ended question for relatives to provide more detail about their experiences with care homes, some comments were left at the end of the survey. Communication was key to many of these comments – either because of a lack of communication or outlining how homes had gone out of their way to communicate with families and ensure they were involved in their relative's care. A couple of relatives mentioned the lack of response they had from a manager to specific complaints or issues.

"When we have made complaints to the manager, we have never had follow up communication."

- Relative, West, part paid by council

***Graph**: "How important are these factors when choosing or shortlisting a care home?", featuring answers of **"strongly disagree"**, "disagree", "agree", and **"strongly agree"**.*



Case study 2 - "Mr J and Mrs D"

J and D were living in sheltered accommodation and had carers coming in three times a day to help J with personal care, to prepare meals, and stay with him, which enabled D to go out on occasions. However, they could not provide night care and D was struggling to provide the 24-hour care he needed, so they decided they would move into an extra care home. Their social worker at the time helped arrange it and they were assured that the home could provide 24-hour care.

They moved into the home in May 2019, but from the first day, D realised that the home was totally unable to provide the 24-hour care J needed. Everything carers did for residents was timed, and J could only be changed twice a day rather than when he needed it. The only care provided was getting him up in the morning and putting him to bed at night, but as there was only one carer at night it could mean a very long wait and J got very agitated. The lack of 24-hour care for J meant that D had to provide even more of his care than when they had carers coming in to their home. J felt unsafe if D went shopping, as unsupervised residents living with dementia did walk into their flat, but she did not want to lock him in. This lack of care was detrimental to the health and well-being of both J and D. D believes it was all down to poor management practice.

D therefore tried to arrange a move for J into a more suitable care home, but when she approached the East Suffolk Council was informed that there was no social worker available. However, her son intervened, and they were eventually appointed a social worker. This social worker was brilliant and helped them secure a place for J in his present home and also helped them secure benefits to which they are entitled. J originally went for two weeks respite and after being re-assessed he moved in permanently. When searching for this home, D spoke to carers she knew about homes in the area and they told her about the "good homes" they knew. She said that "he is well looked after and most importantly people are kind. He hasn't lost his sense humour and the carers like that".

Her husband moved into his present home in September 2019 and D remained in their previous home. The move was made more difficult because when it was time for him to move, he was sitting in his wet clothes and waiting to be changed. This confirmed that the care provided was not what they were told to expect. Everything was time-orientated and management did not seem to be able to help.

Prior to COVID-19 lockdown and despite living in different homes, D saw her husband six days a week, travelling for an hour on the bus and walking to and from the bus stop each day. She did not visit on a Sunday because of the lack of a suitable bus service. She has some health problems which mean travelling could be embarrassing, and as she is rather wobbly, she used a light walker that she could lift on to the bus, hold it close to her, and then help her walk to the care home. Because she needed to use the walker, D had to make sure she picked the right time to travel. She avoided rush hours morning, lunchtime, evening, and busy times such the school drop-off and pick-up times. She said that "people were so very kind

and helped her even when she didn't need it". As the bus stops were draughty and could be very wet and small, her family bought her a brilliant coat to keep her warm and dry when travelling, as it sometimes took a lot longer than an hour each way depending on the buses. She couldn't afford taxis every day.

D loved the home that J moved to and found it was helping him enormously. His condition improved so that he could hold a conversation again. However, during the COVID-19 lockdown, D did not see her husband from 10 March until 1 August, as she was in sheltered accommodation and her husband in a different care home. D rang him every day, although J didn't seem to understand why she couldn't visit him. D was in isolation and had not seen anyone other than the carer who knocked to see if she was OK. It upset her that she was unable to visit J and she was "getting tetchy". When the care home rules changed from 1 August, relatives were allowed to make appointments to see a loved one, and she has now arranged to see her husband for half an hour each Monday.

During this period although she wanted to live nearer her husband, the situation was very complicated. She had put her name down for social housing so she could be closer to him, but then had an offer which facilitated a move closer to her son in a different area, which she really wanted to do as it gives her more independence. She moved to this new flat very recently and will continue to visit J once a week and see him for half an hour until a transfer to a care home closer to her can be arranged. She still calls him every day.

She travels by taxi to see him as she does not feel safe on public transport, and the travel is complicated. She has negotiated a good deal with a very helpful taxi company she has used for years. Her social worker is exceptional and is supporting her in trying to negotiate a move for J as, although she is very happy with the care J is receiving, she knows that a move close to her will be beneficial for both of them.

D says she "hasn't let it get her down. I just get on with it". She is comforted by the thought that J is still receiving excellent care and there is regular testing. The attitude in his present care home is "can I help you?". Although his condition has deteriorated during their period of separation, she hopes that a transfer to a home close to her will help and they will be able to see each other very regularly and can again enjoy being together.

6. Dementia care in the home

This section explores relative or friend experiences of a care home if their loved one has had a diagnosis or shows early signs of dementia.

People living with dementia should receive high quality support from staff with specialist training. They have a legal right to have this care regularly reviewed throughout their life. Relatives and friends were asked if they were satisfied with the support their relatives received and whether their relatives were assessed annually.

The survey was for residents with the capacity to consent to participate in the survey, and the Healthwatch facilitators were guided by care home staff to speak to appropriate residents.

Six per cent of residents stated that dementia was an issue affecting them, and 62% stated that loss of memory was a health issue.

In contrast, 257 relatives and friends responded to this question. Seventy-four per cent (191) confirmed that their relative or friend had a diagnosis of dementia or showed early signs, and 26% (66) said they did not.

This result was confirmed by responses to questions around health needs of a relative, as 63% (190) responded that dementia was a need to be addressed and 37% (111) said it was not.

As the number of residents stating that they had been diagnosed or had early signs of dementia was so low, this section will concentrate on the responses received from relative and friends.

74%

said their relative was diagnosed with or showed early signs of dementia

Satisfaction with dementia support in the home

Fifty-two per cent (97) of relatives and friends were very satisfied with the support their relatives received and 17 gave comments. Thirty-five per cent (66)

> *"Staff are patient and show they care and talk in a respectful way, I have never heard any staff be short or belittle any resident, they have fun together with the residents."*
>
> *- Relative, anonymous*

of relatives and friends said they were satisfied with the support their relatives received.

> *"There appears to be a lack of training and understanding in the junior staff of the final stages of dementia."*
>
> *- Relative, anonymous*

Twenty-five respondents also made comments about the support, most of which were very complimentary.

There were several who despite expressing satisfaction did have reservations. Eight per cent (16) of relatives and friends were dissatisfied and 2% (three) were very dissatisfied. Issues raised included staff shortages, lack of training, or lack of understanding of the needs of those living with dementia. Meanwhile, 3% (five) relatives and friends said they did not know if there was support for residents.

In conclusion, the majority (87%) of relatives and friends who responded are very satisfied or satisfied with the support residents receive for their dementia.

The issues raised echo some of those raised in other areas of the survey responses, including a lack of staff, lack of training, and lack of understanding of the specific needs of residents living with a dementia. These areas of concern need to be addressed as a matter of urgency, especially in the circumstances that are being experienced currently.

Knowledge on whether a relative or friend received an annual assessment from Social Services

Thirty-one per cent of relatives and friends who responded to this question confirmed that their relative or friend had had an annual assessment, 35% said they had not had one, and 34% didn't know if one had taken place.

Over two-thirds of relatives and friends could confirm a changing needs review had taken place

When broken down by category, those respondents expressing very satisfied or satisfied views about support for dementia were split almost equally, with 54 respondents saying that an assessment had taken place, 62 saying one had not, and 62 saying that they didn't know.

Only two of the dissatisfied respondents said a review had been undertaken. Seven of those respondents who expressed dissatisfaction and one of the very dissatisfied respondents said they didn't know if an annual review has been undertaken. Seven of the dissatisfied

respondents and two of the very dissatisfied respondents said no review had taken place.

This research indicates that over two-thirds of relatives and friends either did not know or said that their relative had not had a regular or annual review from social services to assess changing needs. With less than one-third of relatives and friends confirming that a review has taken place, more effort needs to be made to ensure that annual assessments are undertaken and that relatives or friends are included in discussions and informed of changes.

Activities organised to support residents living with dementia

The importance of specific activities to support residents living with dementia was commented on by relatives or friends. A wider reflection on the range of activities can be seen later in the next chapter, but comments were made expressing some satisfaction about activities specifically designed for those residents living with dementia.

This report highlights the need for a wide range of activities to be made available to residents living in care homes and especially for those living with dementia.

Being enabled to participate in activities they enjoy increases satisfaction ratings. Although not a specific question in the dementia section of the survey, the results of this analysis show that relatives and friends recognise the benefits to their relatives of activities designed to meet their individual needs, and complement the findings in the section about activities in the home.

"Every resident receives tailored care and attention and occasional pampering eg manicures, jigsaws for another resident, individual activities programmes plus a programme of home events.

"I like that the residents are helped and encouraged to make their own lunches.

"He always makes the same sandwich but I believe he has some satisfaction in doing this. He has also been involved in cooking - a great skill for someone who loves food."

- Relative, anonymous

"Adapted everything to suit Mum's needs and had her involved in everything possible."

- Relative, anonymous

7. Activities and interests

This section comprises of the five questions dealing with the residents' activities and interests, both inside and outside the care home. The residents and their relatives and friends were asked whether they found the activities interesting and stimulating, whether they received support to be involved and whether they were asked for ideas. Relatives and friends were asked if they were kept informed of the resident's involvement and interest in the activities available.

Offering a range of activities

Two hundred and sixty-five relatives or friends and 279 residents replied to the question asking whether the care home offered a range of activities.

A majority of both residents (83%) and relatives (89%) strongly agreed or agreed that the relevant care home offered a range of activities in which residents could participate.

Twenty-three (9%) of residents and 22 (8%) of friends and relatives disagreed or strongly disagreed that a range of activities was provided, and five of these residents did speak about attending activities.

Details of the activities available to the residents

The chart to the right shows the variety of activities available to residents in the care homes. Very few of the residents mentioned only one activity, and facilitators did not ask residents to give the activities in order of preference. Residents only knew of these activities

Available activities	Number
Art	26
Singing	26
Reading	24
Quizzes	23
Exercise	21
Music	19
Bingo	19
Crafts	18
TV	18
Church meetings or services	17
Knitting, seweing, or crochet	17
Garden or gardening	15
Baking, cooking, or food	11
Cinema, films, or slideshow	9
Board games	8
Flower arranging	7
Ball games	7
Scrabble	7
Word games	6
Jigsaws	4
Cards	3
Puzzles	3
General entertainment	3
Care home olympics	3
Tea and coffee mornings	2
Poetry	1
Theatre	1
Laptop curling	1
Men's club	1
Radio	1
Bridge	1
Sky Sports	1
History	1
Crosswords	1
Aromatherapy	1

taking place in their home - they may, or may not, participate in all of the activities they named.

The majority of the information about available activities (95%) came from those residents who strongly agreed (180) or agreed (130) that a range of activities were available.

The most popular activities were art and singing, with 26 residents speaking of each. The term "art" includes painting and colouring but does not include crafts which are detailed separately. Although some residents do refer to art and crafts, there were sufficient residents referring specifically to painting, drawing and art to detail this separately.

> *"I like arts and crafts, drawing and colouring, scrabble, question time - but hearing the questions can be hard. I like singing or telling stories, but sometimes that attracts too much attention. I get involved when I can but if I don't feel good there's no pressure to be involved."*
>
> *- Resident*

Gardening was one of the most popular outdoors-based activities among residents

Crafts were still among the most popular activities, with 18 residents speaking of the availability of crafts, 17 talking about knitting, sewing, and crochet specifically, and seven others of flower arranging. If these activities are added to crafts, this does become the most quoted activity (42) by residents.

There were 26 specific references to singing, which includes hymn singing, music therapy and musical entertainment.

Musical activities, in addition to singing, were varied but included playing music, listening to music and people performing for the residents.

Reading was also very popular, with 24 residents saying they enjoyed this. Reading is by its very nature normally a solitary activity and no one mentioned being part of a reading group, although poetry was mentioned by one resident.

Eighteen residents said how they preferred watching TV, often in their rooms so that they could enjoy the programmes they like.

Board, word, card games and things such as jigsaws were popular with 24 residents, and seven of whom spoke about Scrabble. Another very popular activity spoken about by 22 residents was exercise, which includes dancing.

Gardening was one of the commonly mentioned outside activities listed, and sitting in the garden or visiting garden centres was an activity enjoyed and looked forward to.

Cinema, film, or slides were combined as an option, and spoken of by nine residents while 17 residents spoke of church meetings and services. Seven residents mentioned bowls or ball games, and 11 residents included cooking or baking and references to food in their comments.

The less popular activities only mentioned once included theatre, laptop curling, men's club, radio time, Sky Sports, bridge, history, aromatherapy, and reflexology.

These may only be minority interests, but are still part of the activity in care homes and highlight how care homes often make great efforts to meet the needs of the individual resident.

Reasons for not participating in activities

Eleven residents, despite agreeing that there are a range of activities, did not get involved for various reasons. For example, they did not wish to be social, were not fit enough to join, or the activities do not suit them.

The two residents who strongly disagreed that a range of activities was available both said that they did not participate.

Eight of the residents who disagreed that there was a range of activities said they still participated in activities often on a limited basis, but others did not attend sometimes because of ill health or personal choice. Three of the "did not knows" mentioned participating in activities.

"I don't do singing, but I love quizzes and I do talks about holidays, history and animals. I have a high IQ and when I was told I was to be in a home it was a hard road to travel. The activities I organise stimulate me."

- Resident

"I don't mix - I do what I want as I get lumbered with the wrong people. I'm on the outside looking in - they help me with the horse racing. I have become a loner."

- Resident

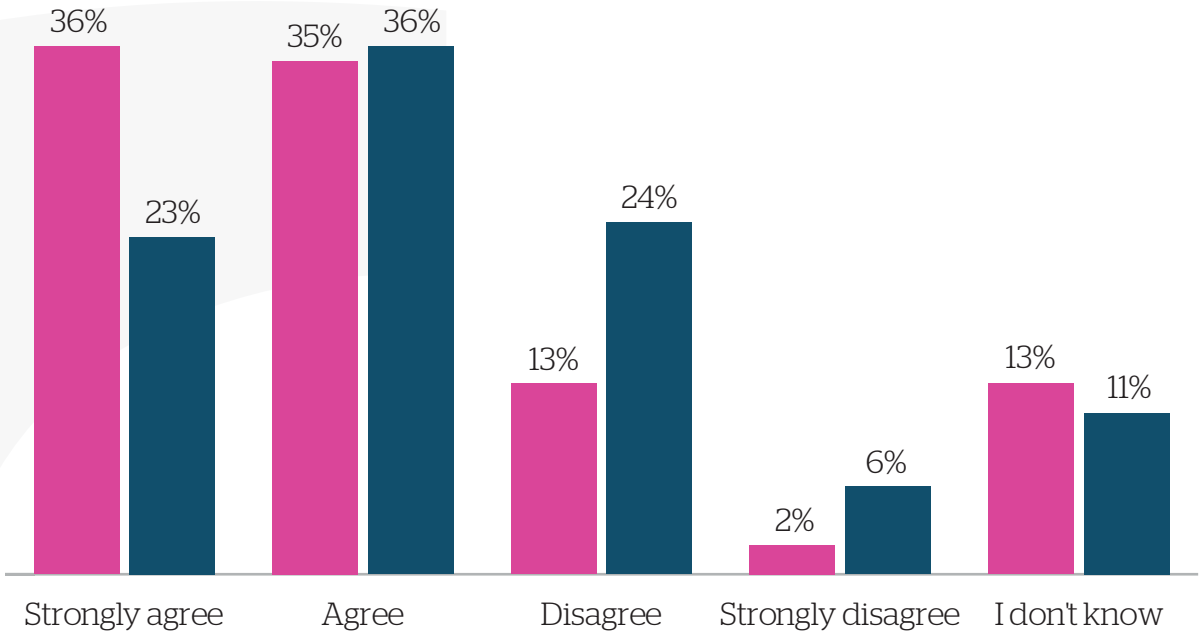
Interesting and stimulating activities

Two hundred and fifty-two relatives and friends replied to this question and 272 residents.

One hundred and ninety-three (71%) of residents strongly agreed or agreed that activities are stimulating compared with (149) 59% of relatives and friends.

Residents expressed a greater level of satisfaction with the available activities

***Graph**: "Are the activities interesting or stimulating?", featuring answers from **residents**, or **relatives and friends**.*



than their relatives and friends. The residents are also less harsh in their judgement of the available activities than their relatives and friends. Forty-two (15%) of residents disagreed or strongly disagreed, compared with 76 (30%) of relatives and friends.

Support with joining in with activities

One hundred and ninety-six (73%) of residents and 206 (80%) of relatives and friends agreed or strongly agreed that there was support in getting involved in activities.

Fifteen per cent of both groups disagreed or strongly disagreed. More residents said they didn't know if the support was available compared to friends and relatives (5%).

Although the majority of residents either strongly agreed or agreed that support was there if needed, a minority (15%) of both residents (40) and relatives or friends (38) stated that they disagreed or strongly disagreed that there was sufficient support.

Residents doing activities outside the home

Two hundred and forty-nine relatives or friends replied to the question about activities outside the home, with 68 (27%)

"This house has changed my life, it's turned me around and made my life so much calmer. The staff don't need prompting to help me, they're always there for me."

- Relative

"I'm the only man in here so I tend to avoid the activities, but I did enjoy going out to the cinema. We've been to the garden centre and seen the waterways development.

"It's a bit boring sometimes in the winter, I can't get out to walk about as much as I'd like, but in the summer I can be in the garden."

- Resident

strongly agreeing and 76 (31%) agreeing residents were able to participate in activities outside the home.

Eighty-seven (24%) disagreed or strongly disagreed that residents were able to do activities outside the home. However, residents were slightly more positive about opportunities outside the home, with 170 (64%) strongly agreeing or agreeing.

Relatives were more negative, with 87 (35%) disagreeing or strongly disagreeing that relatives are able to do activities outside the home.

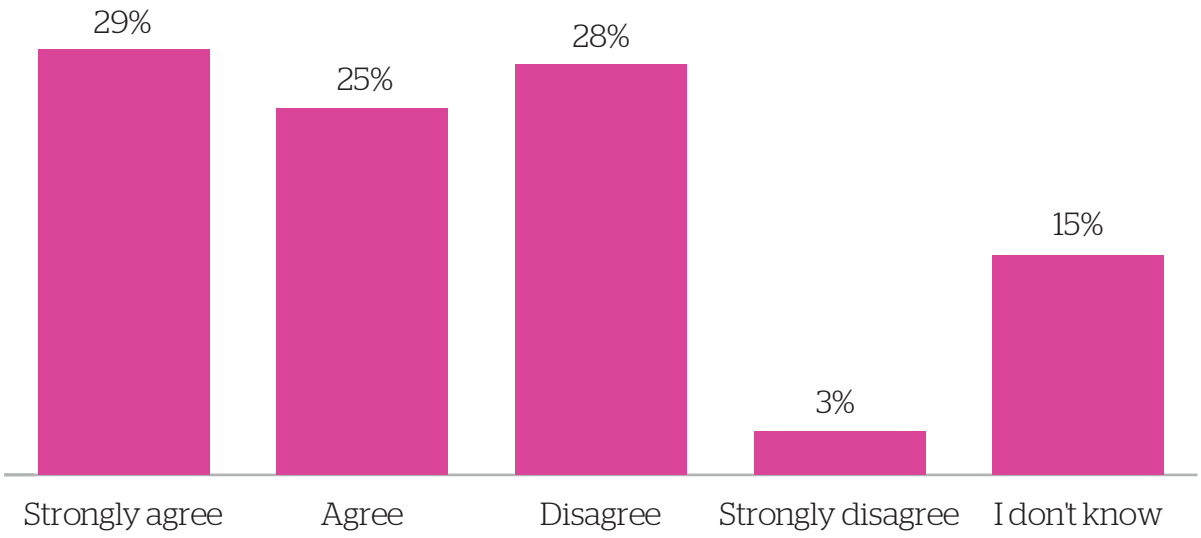
Fifty-seven (21%) of residents either disagreed or strongly disagreed that they were able to do activities outside the home.

The opportunities to join activities outside the home were very much affected by health, weather, and - in some cases - the limited number of wheelchairs that can be accommodated.

Asking for ideas and keeping relatives informed about activities in the home

Only residents were asked if they were consulted about suggestions for activities in the home, and 267 replied. These figures were less positive, with 77 (29%) strongly agreeing and 67 (25%) agreeing that they were asked for ideas, while 75

***Graph**: "I am asked about my ideas for activities", only featuring answers from **residents** in this instance.*



(28%) disagreed and eight (3%) strongly disagreed that they were asked for ideas.

These figures reflect doubt about whether residents are asked regularly for ideas for activities. Asking more regularly for suggestions or ideas may encourage participation, and even higher levels of satisfaction could be achieved.

Keeping relatives informed about activities their relative takes part in and whether they are stimulated

Two hundred and sixty-one relatives and friends responded to the query about whether they felt they had been kept informed about their relative's activities. Sixty-seven per cent (174) agreed strongly or agreed that they had been kept informed about their relatives. Twenty-eight per cent (73) disagreed or strongly disagreed with the statement that they had been kept informed, and 5% (14) didn't know.

Relatives and friends were not asked to add comments, but the figures reflect some negativity about being informed, as 67% responses are positive, but a third are negative or claimed they did not know.

Facilitators observations

When visiting care homes to support residents in completing the survey, the facilitators noted the different ways care homes informed residents of the activities arranged for them.

- Most care homes produced some form of paper copy or leaflet to inform their residents. This information could be distributed to each resident individually as part of a booklet, laminated sheet or ordinary sheet of paper. Information about activities was often placed on notice boards or pinned up in resident rooms.
- Thirteen residents responding to the survey spoke specifically about how they knew what was happening during the week, and many implied that they received information.
- Issues arose for those whose eyesight or other health issue did not enable them to see the details, and it was often carers who would ask if they wanted to attend.

8. Carers and staff

This section comprised of questions delving into the residents' relationship with carers and staff. Both relatives, friends, and residents were asked the same questions. There was only one comment section where relatives, friends and residents could add their opinions, where they provided details on many topics.

The number of friends, relatives and residents responding negatively and disagreeing or strongly disagreeing was often very small, where this is given in percentage form numbers may not sum to 100%, but all representations are accurate.

Negative quotations from both "disagree" and "strongly disagree" comments have been used to demonstrate the negative issues raised.

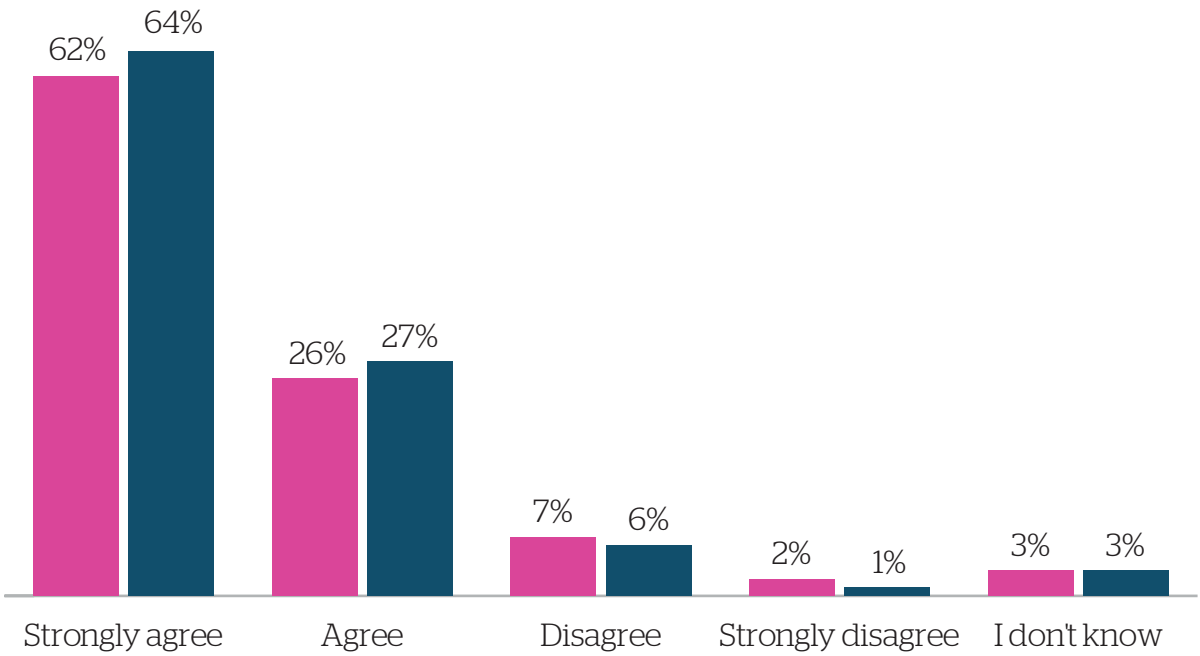
Two hundred and seventy-nine residents responded to this question and 269 relatives and friends. Over 90% of both residents (90%) and relatives and friends (91%) either strongly agreed or agreed that the staff were good at communicating with residents. Only 7% of both relatives and friends (21) and residents (19) disagree or strongly disagreed.

Communication

Positive results were reflected in the comments of both residents and relatives and friends.

However, 18 residents who responded positively regarding the communication with staff, did express reservations about whether the staff communicated well with them, and 16 residents disagreed or strongly disagreed.

***Graph**: "The staff are great at communicating with residents", featuring answers from **residents**, or **relatives and friends**.*



> "Staff are always kind and helpful. If I cannot sleep at night, the staff help to make me comfortable. Staff come into my room for a chat and cheer me up."
>
> - Resident

> "Some of them do and some don't [communicate]. Some say hurtful things without realising. Sometimes they help more strongly than I want."
>
> - Resident

A majority of the relatives and friends, 91% (244) also responded positively that staff communicated well with the residents Seven per cent (19) of the relatives and friends disagreed or strongly disagreed.

Relationships with carers

We found that 97% (268) said that they strongly agree or agree that they have a good relationship with carers and staff.

Relatives and friends also reflected a high regard for the relationship between residents and carers with 91% (242) strongly agreeing or agreeing.

The 2% (7) residents who disagreed or strongly disagreed made comments that included complimentary remarks about their carers.

> "The staff are too busy to really stop and chat. If you have a problem, you can talk to the Head of Carers but she's been so busy taking on the responsibilities of manager since he left. The previous manager was a very difficult person to talk to, the resident family meetings weren't always very positive.
>
> - Relative

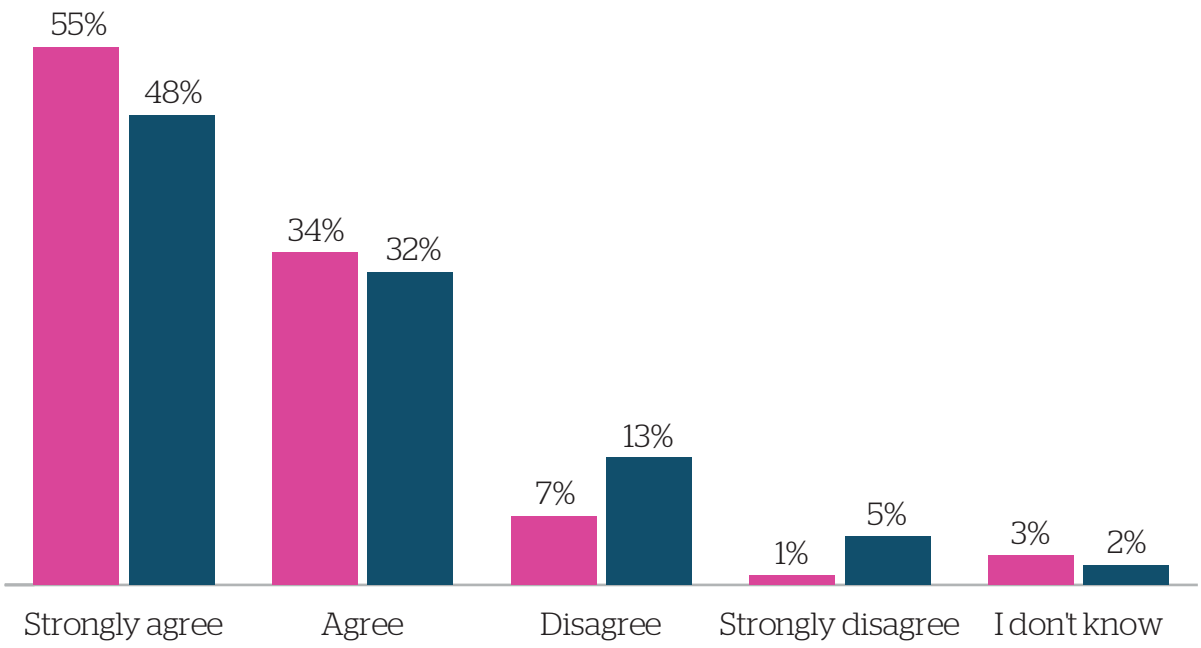
Taking time to meet personal needs

The responses of both relatives and friends (80%) and residents (89%) were very positive although 17% of relatives

97%

said they have a good relationship with both carers and staff

***Graph**: "Staff take time to meet resident's personal needs", featuring answers from residents, or relatives and friends.*



and friends and 8% of residents expressed some difficulties with carers having time to meet residents' needs.

More time needed

Although only a small minority of relatives and friends and residents disagreed or strongly disagreed that carers were given enough time to meet residents needs, some of those who agreed or strongly agreed qualified their judgements with positive comments. Eight per cent (21) residents disagreed or strongly disagreed.

Insufficient staff

A significant issue spoken about by relatives and friends was that there are often insufficient carers to look after the numbers of residents needing care.

Over 30 relatives and friends specifically mentioned a shortage of carers or the use of agency staff.

> *"On the whole they are very good, however due to apparent short staffing, Mum doesn't always get help to shower in the morning which she finds upsetting as her hygiene is important to her."*
>
> *- Relative*

Dignity and privacy of residents

Once again, the numbers of relatives and friends and residents stating that the staff and carers respected residents' privacy and treated them with respect were extremely high.

Ninety-four per cent (262) residents either

strongly agreed or agreed and made positive comments. And despite the high number of residents who strongly agreed or agreed, 3% (9) made negative comments about their lack of privacy or dignity.

Nine

residents made negative comments about their lack of privacy or dignity

Relatives and friends were also very positive about residents' privacy being protected and treated with respect.

Ninety-two per cent (246) of relatives strongly agreed or agreed, and only 5% (13) disagreed or strongly disagreed.

> *"They're not always available, sometimes I have to wait a bit too long to use the toilet. It is my biggest bugbear with this place, sometimes it too long and I end up wet."*
>
> *- Relative*

Staff available when needed

Eighty-five per cent (140) of relatives and friends strongly agreed or agreed that staff were available when they needed them.

Likewise, the percentage of residents (88%) saying that staff are available when they need them was almost the same as those of relatives and friends.

However, 10% (26) residents felt that staff and carers were not always available when they were needed to be. However, there were still complimentary remarks about carers and the care they receive.

> *"All I ever want is a cup of tea and they always bring one. Whatever time I ask."*
>
> *- Resident*

Case study 3 - "Mr K"

Mr K moved into his present care home to accompany his great friend, who could no longer afford to live in their original care home. Mr K had moved into residential care after he had collapsed with pneumonia and his daughter suggested that he moved into the same care home as his wife, who was living with dementia. Mr K continued to live there following the death of his wife, and it was here that he met the gentlemen who was to become his friend.

It was when his friend could no longer afford to stay in that home that Mr K considered his own situation and knowing that his funds 'weren't a bottomless pit' he said that if his friend was going to be "tipped out" he would leave too, so that they could continue with their friendship. A family member was involved with his present home and following a visit and discussions they decided to move in. His friend moved in just after Christmas, and Mr K moved in later, about the second week in January this year.

The two gentlemen came to visit the home first in a taxi that could take their wheelchairs and told the original home they were going shopping. When they returned and were asked where their shopping was, they said they had been "window shopping".

They spent about two hours looking round and the staff all seemed very friendly and they were quite impressed with it. They had a very good report of the home and were told it was a nursing home, and as both need nursing care (Mr K for medication and his friend because of mobility issues) it suited them very well. Although quite independent at the moment, Mr K knows he will need more care in the future. His daughter organised the move, but everything was discussed with them and it was understood they wished to stay together. Mr K said that the pair "have struck up a friendship and we have been three years together. We do crosswords and puzzles together. The home copies them and makes them bigger for us. We love gardening and are called Bill and Ben. We are having a greenhouse delivered tomorrow and we hope to find a good spot for it".

Mr K and his friend have planted seeds from last year's produce and Mr K's room was full of seedlings ready to be moved into the greenhouse when it is built. They grow tomatoes and vegetables, but this year is concentrated on sweet peas, geraniums and other flowers, which they hope will help the home to win the local garden in bloom prize.

Both friends have motorised scooters, so when the weather is better they hope to go to the supermarkets and to the town centre. And as they are close to the pier and beach they can go under their own steam. Mr K said that they "have pavement chairs. I keep mine charging in my room as we have tons of room in here and can take it down in the lift. I haven't done it yet, so I'll need 'L plates'. My friend is quite used to it as he's had his for a number of years". They feel compared with the original home they can get out and about more and in a safe manner without worrying about too much traffic.

Mr K is pleased with the home, which has met all his expectations and he is quite happy there. They were downsizing so

were a bit dubious when they moved as the other home was "top of the range". The contrast with the original home is the numbers of residents living with dementia in this home, and many stay in their rooms so there is less social life. Mr K says it is upsetting for the residents with dementia, but they are looked after and Mr K and his friend cope.

When our researcher rang to update Mr K with a progress report, we found he was in hospital and very ill with the virus. He felt "horrible". We wished him well and said we would call him in a couple of weeks to see how he was, as he was obviously struggling to breath and not able to talk much. When our researcher next rang him, he had been discharged from the hospital and was in isolation in his care home. He was still in a wheelchair and unable to walk.

Mr K explained that he had been admitted to hospital with suspected COVID-19, and spent 14 days there. He was sent back to the home as ready to be discharged, but after seven days was told by the doctor that he ought to be in hospital, so was readmitted. He was kept in hospital for a further three weeks. He can remember very little about it. When he was discharged back to the home, he remained in isolation with one-to-one care for 14 days, and was having physiotherapy to help him recover.

He was unable to walk and was in a wheelchair and unable to have visitors or to see his great friend. When we first rang him to see how he was getting on, he said he was still not able to walk (but since then has been improving gradually). He is now meeting up with his friend L and playing games with him again. His friend is in "great form". Mr K has weekly meetings by appointment with his daughter in the garden, and is hoping to be able to get out to the greenhouse as soon as he is fit enough. He says the staff have been brilliant, but during the period of isolation he felt very lonely despite telephone calls keeping him in touch with his family. He is very grateful for the care he received in the home.

9. Personal care and support

This section dealt with all aspects of residents' personal hygiene, appearance and support with everyday parts of their lives.

Residents, relatives and friends were asked if residents received sufficient support at mealtimes with access to other health services, and with looking after their teeth or dentures. They were also asked if they had freedom to get up and go to bed when they liked.

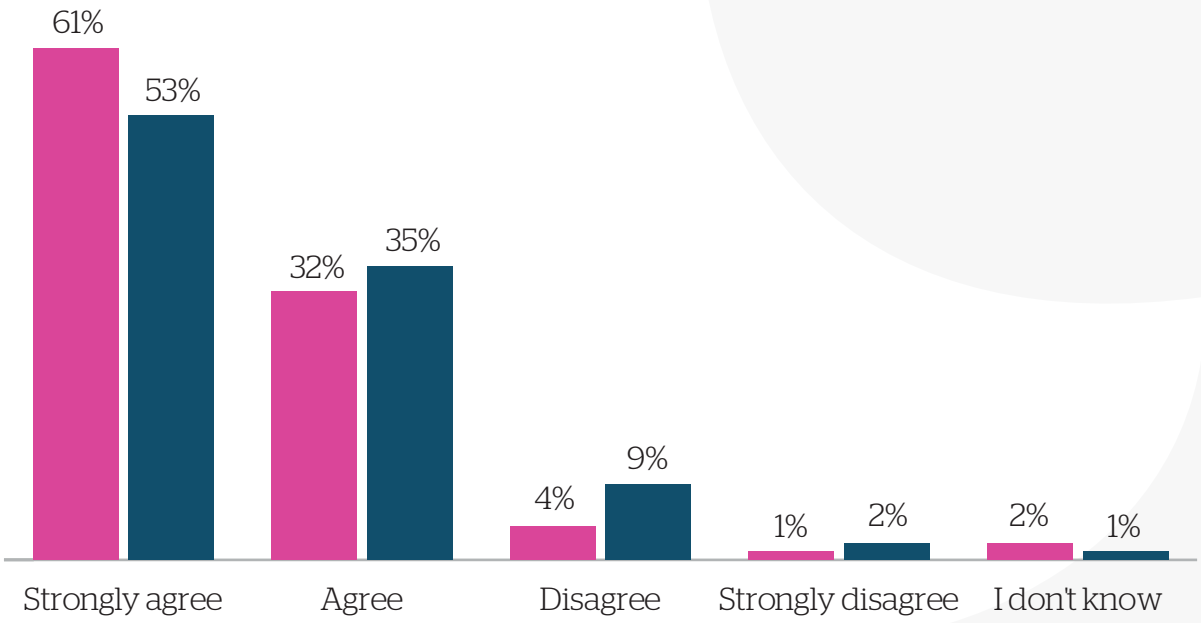
> *"They believe that it's important we are happy with how we look. On the whole, the care here is very thoughtful."*
>
> *- Resident*

Two hundred and seventy-four residents responded. Of these responses, it was found that 93% (255) were very positive and strongly agreed or agreed they received the support they needed.

Two hundred and sixty-seven relatives and friends also responded and again a large majority of 88% (236) strongly agreed or agreed that they felt their relatives were well-supported with their personal hygiene and appearance.

Only 11% (29) of relatives and friends and 5% (15) of residents disagreed or strongly disagreed that support was sufficient. Additionally, only 1% (2) of relatives and friends and 3% (7) of residents stated that they did not know.

***Graph**: "I feel well-supported with my personal hygiene and appearance", featuring answers from **residents**, or **relatives and friends**.*



This reflected a large measure of satisfaction from both relatives, friends and residents on the level of care delivered to ensure personal hygiene and a satisfactory appearance.

However, residents who agreed sometimes qualified their positive comments and only 11% (29) of residents disagreed or strongly disagreed that they were well-supported with their personal hygiene and appearance.

Eighty-eight per cent (236) of relatives and friends strongly agreed or agreed that their relatives were well-supported with personal hygiene and appearance.

Again though, of the 35% (94) of relatives and friends who agreed, several modified their positive comments.

"My relative is not checked on to see if she has a toiletry need as she is sometimes unable to ask."

- Relative

"I have had clothes go missing. The bathrooms are too cold to have a bath and a shower is out of action. It's been a good while since I have had either a bath or shower."

- Resident

Ten per cent (27) of relatives and friends disagreed or strongly disagreed that their relatives were well-supported with personal hygiene and appearance. Issues raised alluded to laundry problems, the lack of available showers and baths. One major issue was whether staff and carers were ensuring that residents received adequate toilet care.

"They help me and am washed well but I wouldn't say I have as many showers as I'd like, but they help me as much as they can."

- Resident

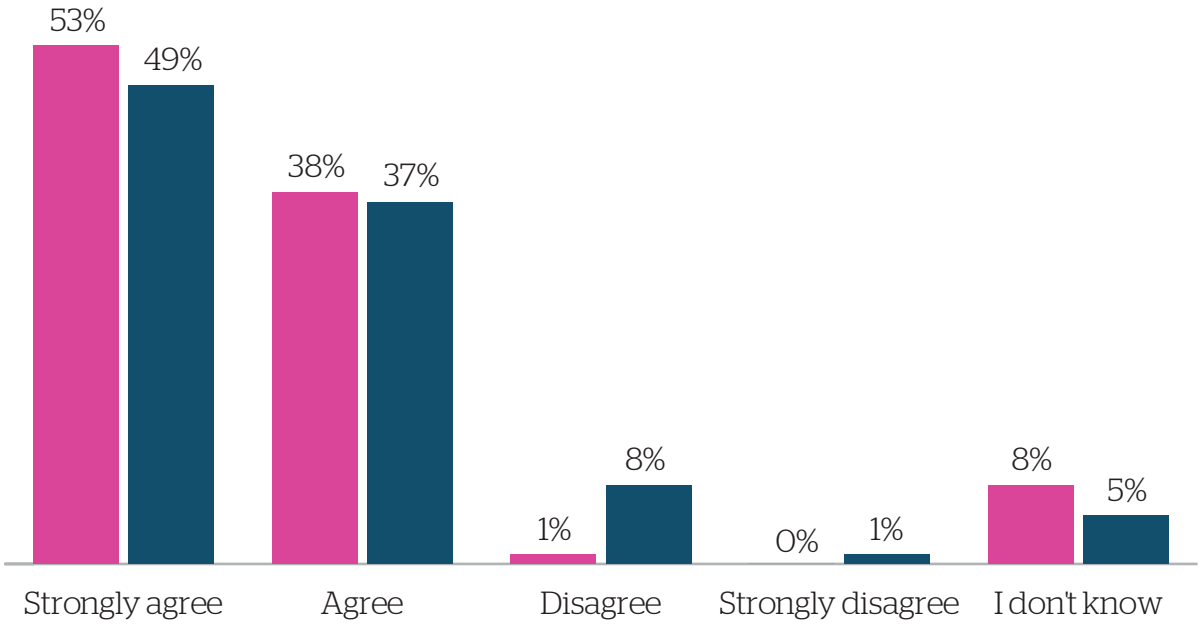
Support at mealtimes

Two hundred and sixty-six relatives and friends and 268 residents responded to this question.

Fifty-three per cent (141) of residents strongly agreed and 38% (101) agreed that they received the support they needed at mealtimes.

However, specific comments about support at mealtimes were quite rare when compared with other issues such as dental or denture care. One resident,

***Graph**: "Residents feel well-supported at mealtimes", featuring answers from **residents**, or **relatives and friends**.*



who despite agreeing there was support, did say that they had trouble chewing and that they did not receive support or assistance with their difficulty.

Only 1% (5) of residents disagreed or strongly disagreed that they received support at mealtimes and only two of these made a specific comment.

There were few specific comments from the 86% (229) of relatives and friends who strongly agreed or agreed about sufficient support at mealtimes.

"The dementia residents don't get help to eat, sometimes I see them look at their plates and they need help to eat and there are no staff to help them. I don't really get the help I need all the time, especially with eating peas. I've only been asked twice in two years if I need help."

- Resident

"Her biggest difficulties have been the morning shower and the quality and quantity of the food.in spite of repeated mentioning of these issues to the staff concerned."

- Resident

Nine per cent (25) of relatives and friends disagreed or strongly disagreed about sufficient support at mealtimes.

Getting up and going to bed

Two hundred and fifty-six relatives and friends responded to the query, and 266 residents. Residents were much more positive about whether they were able to get up and go to bed when they wanted to, and 94% (251) strongly agreed or agreed that they had choice compared with 76% (195) of relatives and friends.

This difference was confirmed when "disagree" and "strongly disagree" responses are examined, with only 5% (12) of negative responses from residents compared with 16% (39) of relatives and friends.

The difference was repeated with 9% (22) relative and friends stating they did not know compared with only (1%) 3 of resident selecting "don't know". Very few comments were made by relatives and friends about residents being able to choose when to get up and go to bed.

Sixteen per cent (39) relatives and friends disagreed or strongly disagreed.

> *"I have seen staff making people go to bed even if they do not wish to, I have seen my friend without her teeth and staff forgetting to put them in."*
>
> *- Resident*

More positive comments were made by the 94% (251) of residents who agreed or strongly agreed.

Twenty-seven per cent (73) residents agreed but with some reservations, and only two of the 12 (5%) of residents who disagree or strongly disagree made specific comments about choosing when to get up and go to bed.

> *"I don't get to choose when I go up and go to bed which upsets me."*
>
> *- Resident*

> *"Getting up and going to bed depends on staff availability."*
>
> *- Relative*

Accessing other health services

Two hundred and sixty-six relatives and friends responded to this question, and 268 residents.

An almost identical percentage of relatives and friends (237) and residents (232), with 89% and 87% respectively, strongly agreed or agreed that the home made sure to help residents in accessing

other health services when they were needed.

Residents could often rely on their families to take them or can go unaccompanied. Interestingly, around 7% of residents said they did not know (20), which was greater than the proportion of relatives and friends at 5% (13). But there was only one comment specific to outside health agencies.

Looking after teeth and dentures

Two hundred and sixty-three residents, and 264 relatives and friends responded to the query about support for their teeth or dentures.

Seventy-two per cent (190) of residents and 66% (174) of relatives and friends strongly agreed or agreed that residents received or did not need support.

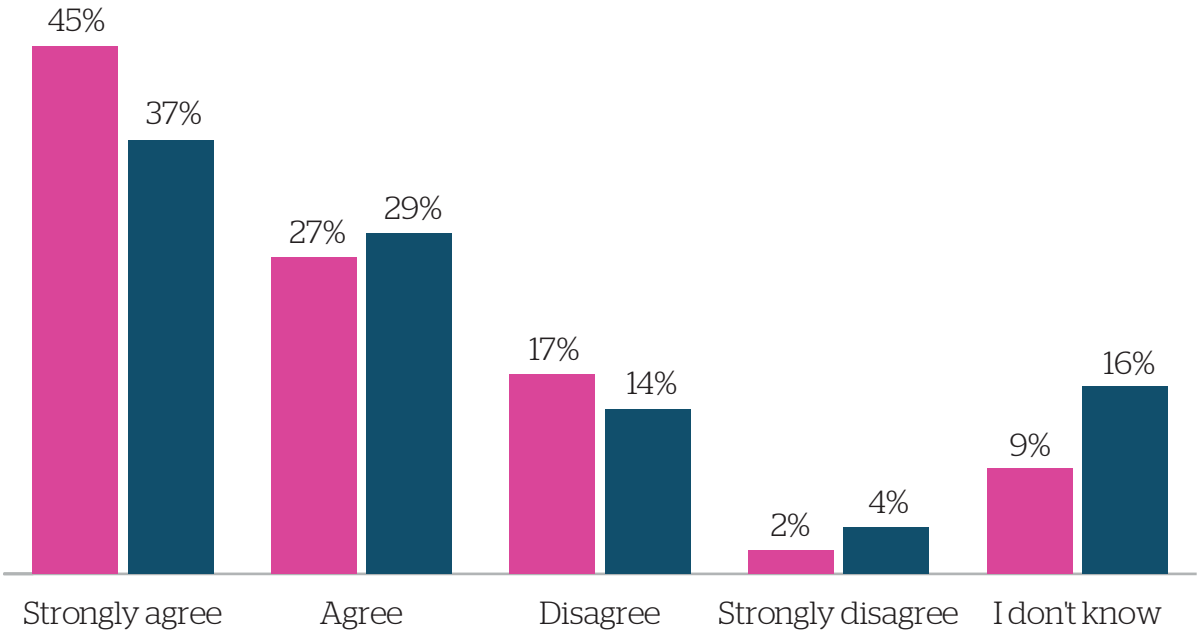
Nineteen per cent (50) of residents and 18% (49) of relatives and friends disagreed or strongly disagreed that sufficient support was received.

Only 66%

of relatives and friends expressed satisfaction with dental and oral care support

These figures show that both relatives and friends, and residents expressed more dissatisfaction with dental and oral care than any other aspect of personal care and support.

***Graph**: "I am encouraged and have support to look after my teeth/dentures", featuring answers from **residents**, or **relatives and friends**.*



"The dentist is my biggest downfall - the home made a date for them to come and they cancelled the appointment. The nurses chase them up. My feelings are a 'large black cloud'."

- Resident

There were 66 specific comments from residents about their teeth or dentures. Twenty-seven of these stated that they did not need help, 26 commented on internal care from the home, and 13 spoke about access to dentists outside the home.

Twenty-seven per cent (72) of residents agreed but held some reservations, alongside the 45% of residents who strongly agreed that they felt supported with their dental hygiene. There was a substantial reduction in the percentage of relatives and friends, with 66% (174) stating that residents received sufficient support for care of their dentures or teeth, especially compared with their response to other questions about residents' personal care and support.

Only five of the 76 relatives and friends who agreed that sufficient support was provided actually made comment about teeth and dentists. Of these five comments, one said their relative could care for their own teeth and the four other comments were not totally positive about the care received. The percentage of family and friends (49) stating that they disagreed or strongly disagreed was also higher than with other responses in this section, at 18%.

"In the three years my mother has been a resident, she has lost the majority of her teeth because they have never been cleaned. She has never been offered dentistry care. I have raised this issue on every care review I have attended."

- Resident

"My teeth didn't get brushed for nine months until I asked them - I mentioned it and they do it when I remind them."

- Resident

These results suggested that access to dentists and the treatment of residents' teeth and oral hygiene by carers is well below an acceptable standard in some care homes. No care home has been identified, but it is an issue which needs to be addressed - all care homes should ensure that carers provide proper oral care for residents, and the provision of dentists for residents in care homes should also be addressed.

Case study 4 - "Mrs C"

After a difficult childhood, Mrs C married when she was 20 and was married for 56 years. Her husband died six years ago of cancer. They brought him home from hospital and she nursed him at home, although he had to be given air because of the pain he was suffering. When she lost him, she "was in a dark place" and one day thought "I had to get out of this and I started to do things I hadn't done before. I started to talk to friends, and it helped as they knew how I feel".

After her husband died, she lived initially with her son, and after some time came down to Suffolk to stay with her daughter. While living with her daughter, Mrs C had a serious fall, needing 10 stitches. Her daughter thought the house dangerous for her. She then fell down the stairs and broke her hip, needing to be in hospital for five weeks. They repaired her hip, but the social worker said she should not go back to her daughter's, and suggested that as there was one place in a particular home, she could move into there. She did try to go back to her daughter's but couldn't get up the stairs. She was having a lot of falls, telling us that her "feet wouldn't work as fast as my arms".

Eventually, when she fell again, the doctors said she should go into hospital as she might have concussion. She declined and declared that she was going into her chosen care home, as it looked "a nice place". She added that "the staff are all lovely and they will do anything for you. They really are nice and very kind". She has been here for five years.

She is visited by a relative, W, who lives locally and visits twice a week. W does all her washing as Mrs C doesn't like the home washing her things "because they are always creased". W's mother had been in the home, so she knew all about it and knew it was a lovely place. When they are free, W takes Mrs C out in her wheelchair and they often go for a coffee. Everything is so close to the home, it is really convenient.

Mrs C told us that "when I first arrived they greeted me, made me tea and biscuits and made me very welcome". She lived upstairs on the third floor for over four years, and then everyone was moved downstairs because of a fire risk upstairs. She has been living in her current room for five or six weeks. All downstairs and her room need a bit of work, but she has been told it is not major and they are redecorating everywhere. Her room has new curtains, and she will be having nets fitted as there are seats outside and people can see in. However, she has been informed that the rents are going up.

Mrs C's relative, W, gave her a lovely teddy bear because "everyone should have a teddy" and so it is very special to her and has pride of place in her room. She says she has everything she needs. Mrs C says the food is wonderful, and she has made friends in the home. If they fall asleep in the afternoon, she watches television or falls asleep herself. She takes part in the activities the home offers and enjoys herself with her friends. She likes everything in the home and explains that the "companionship is better than living on my own".

During the COVID-19 crisis, the residents have continued to meet together socially, although no visitors are allowed in and the residents are not allowed out. They

have activities such as quizzes, jewellery-making, storytelling and she enjoys them all. She speaks to her relative on the telephone, and W leaves a box of fruit for Mrs C every Friday when they speak together through the window. There have been no cases of COVID-19 in the home, and Mrs C confirms they are all well. She is still happy in her room and feels cared for, especially regarding the food on offer because she can choose what she wants to eat - salad and jelly are her favourites. The thing she misses most is going out for coffee with her relatives.

10. Food and drink

This section consisted of four questions for residents only. It was towards the end of the survey, and although there was not a free text comment option specifically attached to this section, 59 of the final comments mentioned food (22% of all the comments made).

Those who rated the food choices poorly were more likely to make comments about the food available (75%) than those who agreed or strongly agreed that it was good (20%).

While there were no specific questions regarding food directed at relatives and friends, some offered observations regarding the provision in the care home, and these are included here.

Choice

Ninety-three per cent of residents agreed or strongly agreed that they were offered a good choice of food. Very few residents were uncertain about their answer to this question (1%), though some are unhappy with the food they are offered (5%) (these percentages do not come to 100% due to rounding errors).

> *"The chef knows what I like and if there's a day with no options I like he knows and we agree a different meal option, he's lovely."*
>
> *- Resident*

Quality

A high percentage of residents (90%) said that they agreed or strongly agreed that the quality of the food was good, though 9% disagreed. Again, a very low number of residents were unable to say whether their food was of acceptable quality (1%). One resident who responded that the food was low quality did comment that this judgement was due to the implementation of a medically necessary low salt diet that they didn't like at all. The delivery of food was also highlighted by one resident.

> *"The food is sometimes very bland and tasteless. It'd be good to have the choice of spicier sauces."*
>
> *- Resident*

Dietary suitability

A large proportion of residents agreed that the food provided by their care home suits their needs (89%), however this question has the lowest approval rating in the section and the highest level of uncertainty (6% don't know).

Access

Ninety per cent of residents agreed that they could have food and drink when

they wanted it. However, 5.5% of residents were uncertain ("I don't know").

"When the hostess staff are on, it's brilliant. When it's the carers then it's a bit hit and miss at mealtimes... hot food on cold plate, cold food on a hot plate, missing utensils. Carers don't have the time to do two or three jobs at once. But the hostess staff only have the meal delivery to do and know how to do it."

- Resident

Residents were very positive about the food and drink provisions in their care homes, but the provision of choice is not universal, and the "good cooks" are valued by residents and missed if they leave.

11. Environment and complaints

This section covers two areas of care home support for residents:

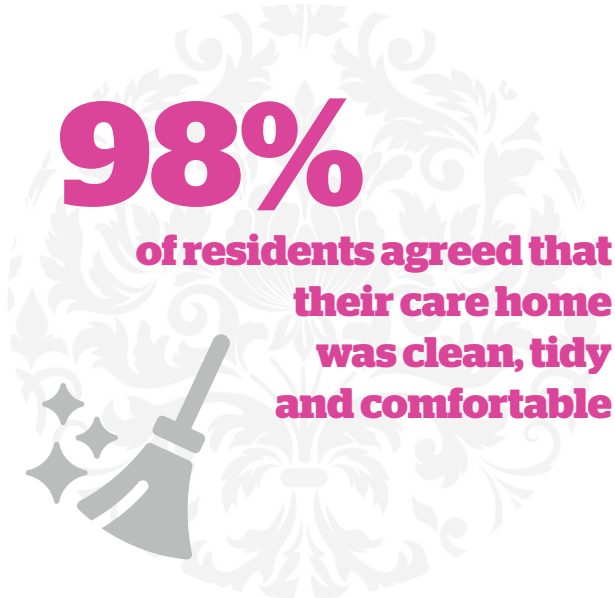
- Whether the environment in the home is clean, tidy and comfortable, and if the home is easy to navigate for residents.
- And whether residents or their family and friends would feel comfortable making a complaint regarding their life in the care home.

Environment

Overwhelmingly both residents (98%) and their families and friends (96%) agreed that the care home was clean, tidy, and comfortable.

However, there were still issues around cleanliness in some homes, with some comments mentioning urine bottles in view of the bed, unclean carpets, and unpleasant smells.

When it comes to getting around the care home, residents were more positive about the ease of navigation (94%) than their family and friends (90%). Family and friends are rather more negative (10%) than their resident family member (4%).



> *"I am dependent upon assistance to leave the home and don't feel there is enough support to get out and about. Because of this I can get a little depressed."*
>
> *- Relative*

Complaints

Residents and their families and friends are equally likely to feel comfortable making complaints to their care homes if things are not as they should be (87.5%). Residents are more likely to feel uncomfortable (8.5%) whereas their friends and family are more likely to be uncertain (6.4%) as to whether they would make a complaint.

Some responses expressed a reticence to complain, while some were cautious of the consequences of complaints. However, some highlighted that complaints and suggestions go unresolved.

Many were encouraged to identify issues and feel confident talking to staff, and others have experienced the positives of resolving issues together.

Residents were very positive about their care homes. Environments are described as clean, tidy, comfortable, and easy to get around. If anything isn't as it should be, residents and their families and friends feel comfortable making complaints.

However, getting feedback and a positive resolution once a complaint is made is sometimes hard work. Where homes have supported residents to resolve issues, they are very complimentary about their home.

"We have made complaints to the manager, we've never had follow-up communication."

- Relative

"I did complain initially about a member of staff but after discussion and conversation this was addressed, and we now have a positive relationship with that person."

- Resident

12. Visiting professionals

Care homes who had participated in the residents and relatives survey were asked to promote the surveys amongst their visiting professionals.

The survey was promoted amongst community health services (physiotherapists, occupational therapists, district nurses etc.) through contacts at Suffolk Community Healthcare. Healthwatch Suffolk also promoted the survey to the target professionals through our links with GP surgeries, social media, and our connections throughout the local community.

Who responded?

Ninety-eight responses were received in total. Only 55 of the respondents offered any opinion on care homes visited, so 43 of the responses are blank on all other fields and discounted from this point on.

Where have they been?

Nineteen responded about only one home, three responses covered multiple sites (given in free text of the home name), 21 responded about two homes and six responded about three (the maximum possible). Thus there are 82 location responses.

Responses relate to 48 individual care homes. There are very few responses from North Suffolk, and the East is disproportionately represented.

The majority of professionals visit one to five homes in their work, but one response stated that they visit 86 different sites.

What did they think of those places?

More than two thirds of the care homes visited by professionals were judged to be

Role	Full response	Not full response	Total
Nurse	20	10	30
Social worker or support	17	10	27
Paramedic, EMT, or ambulance crew	2	8	10
Oversight and management	2	4	6
GP	5	1	6
Activities-related	3	2	5
Health professional	2	3	5
Religious or spiritual leader	3	0	3
Speech and language therapist	2	0	2
Physiotherapist	0	2	2
Advocate	0	1	1
Podiatrist	0	1	1
Blank	0	1	1

Area	Responses received	Percentage of total (may not equal 100% due to rounding)
East (inc. Ipswich)	43	52%
West	19	23%
North	6	7%
Not disclosed or unclear	14	17%

"good" or "very good" (59, 72%).
Eleven per cent of care homes visited were judged "poor" or "very poor" (nine).

Homes visited	Number of visiting professionals
One to five	28
Six to 10	18
Over 10	6
Blank	3

Rating	Number of visiting professionals
Very good	32
Good	27
Neither good or poor	14
Poor	8
Very poor	1

Challenges to working in a care home

Many different challenges were identified as barriers to working by the professionals visiting care homes.

These different barriers were then coded into nine categories, which are listed in the following bulletpoints:

- Staff not knowledgeable
- Unavailable staff
- Poor communication
- Not getting support from other agencies
- Management or leadership
- Safety concerns
- Not enough time
- Not enough space
- No challenges

One care home comment may be coded against more than one of these categories. An example comment is given below with the rating given to the care home and the categories the comment was assigned for analysis.

"Not having enough time to carry out holistic care. Care home staff shortages. Lack of training for some care staff."

Although the professional rated the home as generally "good", it was assigned the categories of "not enough time", "staff not knowledgeable" and "unavailable staff".

"Staff do not support with getting a private area for the review to take place. Staff do not offer feedback or knowledge of the person. Staff frequently interrupt the review or assessment."

This was rated "poor" under categories of "not enough space", "poor communication" and "staff not being knowledgeable".

Challenges in carrying out a role with the home

The largest category of challenges faced by visiting professionals was "poor communication", but the challenges vary depending on the rating that the visiting professional has given to the home they are responding about. Responses highlighted the areas of challenge that was given by the visiting professionals.

In some care homes, we found that the greatest challenge was "unavailable staff", rather than "poor communication". While homes judged to be "poor" and "very poor" present greater levels of challenge, "staff not being knowledgeable", "unavailable staff" and "poor communication" are universal challenges to the visiting professional.

"Staff members do not always know the residents very well."

- Rated as "neither good nor poor"

"Recording is often poor, and handwritten records can be very difficult to interpret."

- Rated as "neither good nor poor"

Challenges in carrying out a role with the home

Visiting professionals were asked for up to three examples of good care that they had observed in the care homes they visited. Two hundred and one descriptions of good care were given, and these were coded into nine categories:

- Staff available
- Good communication
- Kind, nurturing, and welcoming staff
- Good leadership or management
- Knowledgeable staff with good record keeping
- Engagement with and support for residents is good
- Good food
- Nice place or environment
- Clean

Interestingly, comments about "good" or "very good" homes tend to include information coded into more categories than those about "poor" or "very poor" homes.

What does good care look like?

The visiting professional's comments were coded into the categories listed previously and counted to produce the chart on the next page.

Given that staffing levels are identified as a significant challenge to visiting professionals the availability of staff is not frequently mentioned as a hallmark of good care. In fact, it was mentioned only 12 times (the lowest count for all the categories). Whilst visiting professionals find a lack of staff a challenge to their own work, other aspects of "good care" count more highly.

The top two categories are "kind, nurturing, and welcoming staff" (56

homes) and "knowledgeable staff with good record keeping" (45).

> *"All members of staff I have spoken to in different roles know each resident personally."*
>
> *- Rated as "good"*

Staff were commended on being kind to residents and visitors, supporting residents to maintain some independence, and being friendly. Comments on knowledge related to knowing about good practice, having training to ensure skills are up-to-date, as well as knowing the names of residents, their preferences, and some of their history. And engagement covered the availability of activities, entertainments, and the support for participation.

Concerns

Visiting professionals were asked for up to three examples of anything concerning that they had observed in the care homes they visited.

One hundred and thirty-eight concerns were given, and these were coded into eight categories:

- Staff not available, no time
- Poor communication
- Poor leadership or management
- Poor records, knowledge or skill level of staff
- Low engagement
- Diet management poor
- Poor facilities
- Not clean

The comment on the next page highlights a lack of awareness that environment can significantly impact mental health. A poor personal space is unlikely to be a

***Graph**: "What is good care?"*

positive space. Not doing anything about this suggests that staff are not empowered to engage with an occupant to encourage this to change.

There are fewer comments about "good" or "very good" homes, and they tend to be more specific, including fewer categories, than those about "poor" or "very poor" homes. The table below demonstrates this.

Visiting professionals have more concerns about care homes they judge to be "poor" or "very poor" than in homes that they judge as "good" or "very good".

Concerns	Number of care homes
Staff not available	30
Poor communication	23
Poor knowledge, records, or staff skill	37
Poor leadership or management	15
Low engagement	13
Poor diet management	7
Poor facilities	14
Not clean	5

Given that staffing levels were identified as a significant challenge by visiting professionals the same issue being raised as a concern when visiting care homes is understandable (30 homes). However, it is not the category with the highest number of comments, that was "poor records/ knowledge/skill level" of care home staff (37).

Safeguarding

Visiting professionals were asked whether, if they saw or heard anything they were concerned about in a home, would they know who to refer this to.

Fifty-five responses said yes, and 43 were left blank. All the professionals that responded with care home observations knew who to address concerns to.

Twenty-nine per cent of respondents had raised a safeguarding query (16). Four per cent of respondents, however, said that they did not know.

The fact that someone may not know if they had raised a safeguarding issue is, in itself, concerning. Something could be amiss somewhere, if such a potentially important intervention is not clearly acknowledged, confirmed, or followed up to some extent.

Over two-thirds (69%) of those that said they had raised a safeguarding referral found it to be "easy" or "very easy". Just under a fifth said it was difficult (19%), with the remaining 12% saying it was neither easy nor difficult.

13. Summary - what works well?

Visiting professionals visited a wide range of care homes in Suffolk, and more than two thirds (72%) of the homes they visited they judged to be "good" or "very good".

Residents, and family and friends, were asked to give the care home they were responding about a star rating - five stars for "very good", and one star for "very poor". Eighty-five per cent of those that responded gave their care home four or five stars.

Ninety-six per cent of responses said that they feel that their resident, relative, or friend was safe in their care home. Eighty-three per cent of residents and 89% of family and friends believed that their care home provided a range of activities that the residents could participate in.

Unfortunately, the approval ratings dropped when asked if the activities were accessible (73% of residents and 80% of family and friends), stimulating (71% of residents and 59% of family and friends), or available outside of the home (64% of residents and 58% of family and friends). Activities were available, but they may not have been accessible or suitable for many residents.

When it came to the relationship between staff and residents, and their family and friends, the approval ratings were very high, as 97% of residents and 91% of their family and friends agreed that there was a good relationship between staff and residents.

There were similarly high ratings for respect of privacy and dignity (94% of residents and 92% of family or friends), and positive communication (90% of residents and 91% of family or friends). The availability of staff for residents and their family and friends was highly rated (88% of residents and 85% of family or friends).

Personal care and support were very positively regarded too, with 93% of residents and 88% of family and friends saying that the resident was well supported. Mealtime support was good too (91% of residents and 86% of family or friends).

Bedtime was a choice rather than an imposition (94% of residents and 76% of family or friends). Support for accessing other services was good (87% of residents and 89% of family or friends). However, access to dentistry services and support of oral hygiene generally was not as good (72% of residents and 66% of family or friends).

Residents were offered good choices of food (93% agree or agree strongly). It was of good quality (90%), suitable (89%) and available (90%).

The quality of the chef's skills in the kitchen was valued by residents and if a chef who is deemed good left a home, their absence was strongly felt.

Ninety-eight per cent of residents and 96% of their family and friends agreed that their care home was clean, tidy, and comfortable. Homes and gardens were easy to move around (94% of residents and 90% of family or friends).

Family and friends said that they were broadly satisfied with the support given

96%

of residents said they had a good relationship with care staff

to a resident who has dementia (87%), including the provision of activities suitable to their needs. However, the families and friends of residents with dementia were less positive that they are listened to (49%) than the families and friends of residents without dementia (58%).

Families and friends of residents with NHS Continuing Healthcare-funded places felt less involved in decision-making (77%) than the group as a whole (90%). Residents and their family and friends were confident that if they needed to complain, they would (87.5% for both groups).

While 86% of relatives and friends were involved in the decision to move a resident into a care home, less than half (49%) of the residents said they were involved.

Family that were looking for support for an elderly relative with dementia (96%) or with funded nursing care (75%) were more likely to factor in the CQC ratings given to homes compared with the sample as a whole (60%). In contrast, very few potential residents who were involved with choosing their care home were likely to refer to CQC ratings (18%).

The data suggested that there is some correlation between funding stream and having a choice in care home selection. Whether self-funded (67%), partly council-funded (58%), fully local authority-funded (46%), or NHS-funded (45%), each group responded differently to the question of whether they had a choice when it came to care home selection.

14. Ideas for change... and recommendations

When it comes to improving the environment in care homes for staff, residents, visitors and professionals, there were a few things that homes could look at.

1. Communicating clearly with the visiting professional regarding any changes, be they onsite (e.g. door entry codes) or whether residents are not available, as well as having documentation or information ready and to hand to support the work of the visiting professional. This could be as simple as staff being knowledgeable about the residents in their home, knowing where residents are, or their relevant medical history and current needs. Staff could also be available to support visiting professionals, letting them into the home and guiding them to the appropriate resident, thereby ensuring that the visit time is used effectively.

2. Provision of activities suiting the residents in the home can be a challenge, but the lack of stimulating activities can be distressing. Sometimes it can be as simple as taking the time to have a chat. Some more mentally alert residents noted the limited access to challenging games (e.g. bridge). With increasing focus on online activities, it is surely possible for homes to provide support for virtual gaming, possibly linking up with residents in other homes who would benefit from the same challenge.

3. Care homes need to improve their support for residents with their oral hygiene and dentistry. While many residents were positive about this (77%), for those who experienced a lack of toothpaste, have dentures that have not been cleaned, or are missing dentures, the support was not good enough.

4. Supporting residents at mealtimes was important to the atmosphere in a home, residents and their families and friends commented that seeing others struggle could be difficult and drive an able resident away from a shared dining experience. Staff being seen to care for others is valued by residents and their families and friends, not just caring for the resident who responded to the survey.

5. Environments need to be suitable for residents. Being able to support isolated residents to make their rooms personal to them is one way to make a care home into home.

6. Although residents and their family and friends were confident to complain, achieving a resolution (or possibly as simple as being informed of a resolution) was sometimes frustrating. Having a communication channel, like a regular meeting with residents, was suggested. However, as one resident noted: "I don't complain about anything, I just ask for it to be different, and they do listen".

7. Although specific areas of need were supported satisfactorily, some relatives and friends noted that staff capabilities in dealing with some of the issues that arose were inconsistent and that training would be welcomed, allowing staff to have a better

understanding of their residents.

8. Access to needs assessments conducted by social services was poor. Thirty-one per cent of relatives and friends agreed that a review had happened, but 35% said it had not and, unfortunately, 34% did not know if one had happened at all. At best, this evidenced a communication failure, and at worst, a failure to support very vulnerable adults. These findings are reminiscent of national research published by Healthwatch England in 2019, which found that fewer than half of people with dementia using social care were getting the regular care reviews they were entitled to.

9. Being "caring" or otherwise was a repeated theme throughout the survey responses. A lack of care was often cited as evidence for many different failings (e.g. not feeling safe due to staff attitudes and knowledge, or not getting to know residents and supporting them to do what they like to do).

10. On the other hand, when asked to identify good care in homes, the visiting professionals picked up on caring and nurturing behaviours, as did residents, family and friends. Taking that time to "care" encompasses so many other things - observing your residents, understanding how they respond to the world and each other, and knowing the "family" that lives in the care home. If care home staff had the time to observe and learn about their residents, everyone saw the "care" that given and valued that very highly.

Research recommendations

On survey design and data collection, should commissioners wish to undertake similar work in the future, the use of facilitators to support resident's impartial completion of surveys was invaluable.

While residents answered questions directly, it was often in the chat between questions where facilitators gathered insights that were added to the final "anything else to say" question at the end of the survey. Residents also commented that it was "nice to talk to someone".

For visiting professionals, Healthwatch Suffolk would recommend allowing views to be relevant to multiple sites or general experiences as well as site specific responses.

Appendix 1: Issues and themes around COVID-19

Twenty-three homes in Suffolk were contacted over a period from the beginning of June until 19 August 2020. Care home managers made the comments used to write this section as either part of a conversation or by responding to email requests for comment and reflections on their experience.

The information detailed is based on the conversations with all 23 care home managers and the 12 replies received to an email request.

Increasing use of technology

Following lockdown, all the care homes had used technology to maintain contact between residents and their relatives or friends, including Alcove, Zoom, Facebook, Skype, smartphones, tablets, and even letters and cards with photos.

Other innovative means of communicating with loved ones

Care homes had established "wave" windows where residents and loved ones could see each other and try to converse through the glass.

The idea of a "drive-by" was used by one care home, and instead of picking up coffee or fast food, visitors waved to their loved ones through the care home doors. A circular drive is useful. One gentleman refused to use technology because it would be too painful.

Several of the homes had started or were planning an appointment system whereby relatives can make half-hour appointments and can visit their loved ones in the garden whilst continuing to socially distance from each other.

The role of support from communities on morale and provision of equipment etc.

Several homes mentioned the support they had received from the community, including supplies of washable gowns, visors and treats such as a supply of pizzas and of course, the big clap. They were all hugely grateful and impressed with the level of support from their local communities, which was described by one home as "fantastic". Only one did not mention community support.

One care home said that they had arranged a Zoom meeting with relatives to keep them in touch, and another had provided weekly updates for families.

How staff coped with the changed circumstances and continued to provide care

All care homes said that they and their staff had coped well in extremely difficult circumstances. Several spoke about the commitment of their staff to the residents in their care, despite their fear for themselves and their families. One care home stated that the confused messages initially had made things difficult, particularly having to communicate so much information to so many people. One central point would have been less complicated.

Several care homes said that there had been confusing messages and one mentioned that they had no clear direction from government about re-opening care homes.

Rates of infection in residents?

It should be noted that many care homes were contacted at least two weeks previously, when most of the care homes spoken to were COVID-19 free. One care home which cared particularly for frail residents recorded that they had seen six cases. Three of these residents had died and three survived. Another had only one resident with COVID-19, and this resident had survived.

One care home had experienced an outbreak and had several residents ill with COVID-19 in the first few weeks. Of these, those that had been tested survived. Two were certified as having died of other issues that they thought were actually related to COVID-19.

Testing staff and residents

Testing for some had been an issue, with it being described as "not timely" by one care home, and several just finishing the testing process in early June. One home said that all residents and staff had just been (in June) tested, and those results that had been returned showed staff and residents were free of COVID-19. However, one care home stated that they had had to wait two weeks for results, and because they didn't know where the testing was carried out, they couldn't chase them up.

One care home stated that they received testing kits with no instruction but said it was easy to work out. They also pointed out that testing was difficult to access earlier and were worried that patients going into A&E may not have been tested when they arrived.

Another home said it was due to their directors' interest and commitment that they had received testing kits, and not the government.

One care home commented that staff would initially have had to travel to Stanstead for tests, although testing was later transferred to Newmarket.

A care home had been refused more tests because two of their residents had been tested positive, and it was described as an outbreak.

PPE

PPE was not raised as a specific issue during all the conversations, but was addressed in the emails. Some care homes had not had problems, but others mentioned difficulties in finding suppliers and receiving contradictory instructions about PPE, with one care home reporting that they had been OK but had used the disruption supply. Others were grateful for help from the community, with aprons made by the public and masks made from a 3D printer being received.

When orders were renewed, there was some difficulty in finding supplies and the prices had risen. Two care homes stated that they had received PPE as a result of their directors' efforts. One had spoken to their supplier and been told supplies were going to the NHS, and one was still awaiting government supplies.

Self-isolation

Some homes appeared to have self-isolated each resident and found it useful, but this was not part of all the conversations. One care home reported that they closed down early to protect residents and had a deep clean of the home. The majority noted that the self-isolation procedures were followed assiduously by the care staff whilst trying to maintain a caring and professional attitude towards the residents in their care.

A care home that had had the outbreak completely isolated all their residents, which whilst most residents were understanding, those with dementia were difficult to manage.

Co-operation with professionals during the lockdown

Only one care home had not needed any interaction with outside agencies, and one who had had problems with GPS. All others spoke specifically about how the online consultations with GPs had worked and also phone calls with hospitals. Most had maintained good contact with doctors online and by telephone. District nurses had either visited or stayed in touch. One care home reported problems in accessing dentists and opticians. Five care homes specifically reported difficulties with hospitals who tried to discharge untested patients and those with COVID-19 back into the homes.

One manager reported feeling "bullied" and had to bring her directors into the discussion as so much pressure was being placed on her to admit residents who were either untested or who had COVID-19.

Good support is now being received from Suffolk County Council, the local Clinical Commissioning Groups (CCGs), Adult and Community Services (ACS) and through the bed capacity tracker. However, one care home did state that dealing with one named organisation or person would have made life easier.

Main themes arising from the comments made by care home managers

1. All care homes quickly and efficiently adopted technology, and all available means of communication were used to ensure that residents and loved ones maintained contact during lockdown.

2. The support from local communities had proved immensely important and links should be encouraged on an ongoing basis.

3. All government agencies should be made aware and appreciation should be shown of the skill and commitment shown by staff in care homes during the lockdown, who continued to provide a high standard of care in the most difficult of circumstances.

4. The levels of infection were kept to a minimum because of the care and attention to detail of the staff in care homes. Deaths appear to have been confined to those most vulnerable.

5. Testing was erratic and often late. Testing should be available in a timely manner and all staff and residents should be tested regularly. No patient should be discharged from hospital into a care home untested or with COVID-19.

6. The provision of PPE was also erratic with homes dependent on local communities for support. All homes should be supplied with sufficient PPE and to have specific and known supply routes.

7. The online communications with GPs in the majority of cases worked well. It was less clear with other professionals, and communications with dentists, opticians, and pharmacists were raised as an issue. Clarity of message across all organisations, government agencies, health and local government and professional bodies should be clear

and consistent from the beginning. Confusing messages caused problems and delays in implementing correct procedures.

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