healthwatch
Norfolk

Dementia Carers

Support for carers of those living with dementia

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Who we are and what we do

Healthwatch Norfolk is the independent voice for patients and service users in the county. We gather people's views of health and social care services in the county and make sure they are heard by the people in charge.

The people who fund and provide services have to listen to you, through us. So, whether you share a good or bad experience with us, your views can help make changes to how services are designed and delivered in Norfolk.

Our work covers all areas of health and social care. This includes GP surgeries, hospitals, dentists, care homes, pharmacies, opticians and more.

We also give out information about the health and care services available in Norfolk and direct people to someone who can help.

At Healthwatch Norfolk we have five main objectives:

1. Gather your views and experiences (good and bad)
2. Pay particular attention to underrepresented groups
3. Show how we contribute to making services better
4. Contribute to better signposting of services
5. Work with national organisations to help create better services

We make sure we have lots of ways to collect feedback from people who use Norfolk's health and social care services. This means that everyone has the same chance to be heard.

Acknowledgements

Healthwatch Norfolk would like to thank Norfolk Community Health & Care for their help and advice in developing our questions for carers.

NHS
Norfolk Community
Health and Care
NHS Trust

We would also like to thank all the carers who took time to provide feedback through our survey and speak with us in person.

Finally we would like to thank all those running the Dementia Cafés we visited for welcoming us and providing the opportunity to speak with carers in person.

Summary

Healthwatch Norfolk was commissioned by Norfolk Community Health and Care NHS Trust (NCH&C) to find out what they can do to further support the needs of carers of those living with dementia when they are an inpatient in hospital. We aimed to gather feedback around carers experiences of times where their loved ones were inpatients and understand how those experiences could be improved.

The Alzheimer's Society estimate that there are around 700,000 unpaid carers of people living with dementia with two-thirds reporting that they desperately need more support to protect their own health and wellbeing. Locally, it is estimated that there will be 21,400 people living with dementia by 2030, so we can expect that there will be similar numbers of unpaid carers. It is important that we identify ways in which we can support these carers to help reduce any negative impact on their own health and wellbeing.

We gathered feedback through various methods including focus groups, interviews with individuals, a survey, and through conversations with carers attending dementia cafés across Norfolk. From these we were able to identify themes in carers experiences around where improvements can be made when their cared for is an inpatient and what additional support they would like to receive.

We heard from 45 carers of those living with dementia. We received 25 responses to our survey, spoke with a focus group of seven, interviewed four, and gathered additional comments from nine whilst attending dementia cafés.

We found that carers had mixed experiences with the care their loved ones received. We also found that carers had mixed experiences being acknowledged and treated as carers. There were some examples of good practice and teams that were supportive and understanding of dementia care and needs. However, this was not widespread. Respondents felt that more support in caring for their loved one could be provided to allow them some respite. Additionally, they felt that more could be done in acknowledging them as carers and listening to their knowledge and views concerning their loved ones health and wellbeing.

Communication could be improved both with carers and between professionals. Respondents felt they often had to initiate communication with healthcare staff to find out what was happening with their loved one’s care and treatment. Discussing with carers about how and when to best give them updates on their loved one’s condition could help alleviate stress at an already stressful time. Carers also felt that they were having to retell their stories again and again when new professionals became involved in their loved one’s care. Ensuring that all staff have access to up-to-date information would help this.

More information is needed in terms of their loved one’s care, their rights as a carer, and signposting information for additional support. Carers found that there was not enough of this and felt that having an information pack, or similar, would be helpful. Additionally, this could help in answering some questions carers may have and reduce staff workload.

Finally carers felt that more could be done to support their needs. Feeling that they, or a family member, had to be present all the time to provide personal care and advocate for their loved one which meant that they could not get much respite for their own health and wellbeing. Having a point of contact/dementia ‘expert’ available for them to liaise with would help ease some of the pressure and reassure them that their loved one is being cared for when they need to leave.

A concern that carers had was about what support there is should they themselves become ill and have to go into hospital. Looking into, and consulting with carers, what support can be provided to those living with dementia at times such as these would go a long way to help reassure carers that their loved one will be looked after.

We have made recommendations for consideration by NCH&C and all the acute hospitals in Norfolk. More detail on these can be read in the full report.

1. Dementia Care Training – Evaluate effectiveness of existing training, deliver to all staff, and improve understanding of dementia, dementia care, and carers rights.
2. Dementia ‘Expert’ – Consideration into ensuring a dementia ‘expert’ is present on each ward and that carers are made aware of them.
3. Clear Patient Information – Encourage all relevant wards to record all relevant information in a way that is easy for other clinicians to access as required. Allowing carers, whenever possible, to only have to tell their story once.
4. Carer Consultation – Consult with carers regarding their loved ones health and care needs as well as their own needs.
5. Continued and Improved Communication – Keep carers updated whenever possible. Look into implementation of regular updates. Have discussions with carers to meet their communication needs.
6. Carers Information Pack – Development of an information pack for carers, detailing what they can expect whilst their loved one is an inpatient.
7. Carer Inpatient Support – Investigate and consult with carers, what provision can be given should the carer become an inpatient themselves.

Introduction

Read about the background to this work and how we gathered feedback

Why we looked at this

Healthwatch Norfolk was commissioned by Norfolk Community Health and Care NHS Trust (NCH&C) to find out how they can best support carers of those living with dementia, when the person they care for is an inpatient in hospital.

The aim of this project has been to:

- Explore the experiences of carers of those living with dementia when the one they care for has been an inpatient in hospital.
- Understand what support they have received and what more support they would like and would benefit them and their cared for.
- Provide NCH&C with insight into these experiences, identify what is working well and where improvements can be made.

Dementia is a term that covers a range of conditions associated with an ongoing decline of brain function (NCC, 2021a & UK Parliament, 2021). The most common being Alzheimer's disease and Vascular dementia (UK Parliament, 2021). Conditions grouped under dementia can cause loss of memory, and can effect/impede problem solving, language, and other cognitive abilities and be so severe they interfere with an individual's daily life and independence (NCC, 2021a).

There were an estimated 748,000 older adults living with dementia in England in 2019, and there is a predicted increase of 55% between 2020 and 2040 meaning that around 1.15 million people will be living with dementia by 2040 (NCC, 2021a & UK Parliament, 2021). The Norfolk County Council Joint Strategic Needs Assessment (JSNA) (2021a) also makes note that not only will the number of people living with dementia increase, but their care needs will become more complex.

An unpaid carer is anyone who looks after a family member, partner, or friend who needs support because of an illness, frailty, disability, mental health problem, or an addiction (NCC, 2021b). Carers UK and the University of Sheffield recently conducted research on the value of unpaid care (BBC, 2023) and estimated that the care they provide amounts to £162 billion a year. Speaking on the importance of unpaid carers the deputy director of the University's centre for care said: "*The economic contribution made by unpaid carers paints a stark picture of the savings they make to health care budgets.*

Without unpaid carers, our health and social care systems would collapse"

The Alzheimer's Society (2021) estimate that there are around 700,000 unpaid carers of people living with dementia, just under the 2019 estimate of people living with dementia. These carers are doing all they can to ensure that people with dementia have the quality of life they deserve, the Alzheimer's Society quote that the numbers of hours unpaid carers spend selflessly has risen to 1.3 billion per year (Alzheimer's Society, 2021). They found that two-thirds of those surveyed desperately needed more support to protect their own wellbeing. Unpaid carers who provide such high levels of care are more than twice as likely to suffer from poor health when compared with those without these responsibilities (NCC, 2021b).

> "'The need for investment in carers' support is more acute than ever. People must be supported properly through the introduction of measures to ensure carers are identified earlier as well as provision of respite for them" – Fiona Carragher, Director of Research and Influencing at Alzheimer's Society (Alzheimer's Society, 2021).

For Norfolk, the JSNA (NCC, 2021a) estimated that, by 2030, there would be around 21,400 people living with dementia. If these figures are comparable to the national estimates then the number of unpaid carers for people living with dementia will also be close to 21,400. According to the 2021 census, 25,713 people provided more than 50 hours of unpaid care per week for illness, frailty, disability, mental health problem, or an addiction (NCC, 2021c).

Norfolk County Council acknowledge that carers, and those living with dementia, need more than just online information and a helpline, requiring more face-to-face support as well (NCC, 2021a). The need for support was further exacerbated by the COVID-19 pandemic, with carers noting strong negative impacts emotionally, on their mental health, and on their relationships, leaving them struggling to care for themselves and their loved one (NCC, 2021a).

There are a number of support services for carers, some of which are listed on these websites:

- https://www.alzheimers.org.uk/categories/support/support-carers
- https://www.norfolk.gov.uk/care-support-and-health/get-help-with-looking-after-someone/support-for-carers

- https://www.nnuh.nhs.uk/patients-visitors/carers/organisations-offering-support/

Healthwatch Norfolk have conducted this piece of work to identify how carers are currently supported, what further support carers would like and if there is anything that can be improved. We want to make sure that those caring for people living with dementia are themselves supported.

How we looked at this

Approach

The project aimed to collect views and feedback to explore what further support is wanted from, and can be provided to, carers of those living with dementia when their cared-for is an inpatient in hospital.

The target audience for this project were carers of those living with dementia who have had recent experiences of their loved one being in hospital. We did not limit feedback to just users of NCH&C services, and instead welcomed feedback for experiences for any of the acute hospitals in Norfolk.

Feedback was gathered through various means including focus groups, interviews with individuals, a survey, and through conversations with carers attending dementia cafés in Norfolk. The survey was developed and hosted online using SmartSurvey and paper copies were available and handed out to attendees of dementia cafés and at the NCH&C Norfolk Community Hospital.

Feedback was collected over a two-month period from March 2023 to the start of May 2023.

Interviews and Focus Groups

Working with NCH&C, Healthwatch Norfolk developed a set of questions that formed discussion guides for interviews and focus groups. Theses guides sought to find out:

- What support they had received during their most recent experience and what they would have liked.
- If they were acknowledged as the main carer, if they felt listened to, and if there was flexibility to visit their loved one.
- What communication and information they received from the ward their loved one was on.

A copy of the interview and focus group discussion guide can be found in Appendix 1.

Survey Design

Healthwatch Norfolk adapted the questions from the discussion guides to develop a survey that could be completed as an alternative to interviews and focus groups. As carers have little time for respite, we chose this approach to allow them the chance to provide feedback in their own time. A copy of the survey can be found in Appendix 2.

Participant Involvement and Consent

To encourage participation Healthwatch Norfolk developed promotional materials, which were distributed through Healthwatch Norfolk's well-established network, with a goal of reaching as many individuals, and groups as possible, including those seldom heard. Healthwatch Norfolk promoted the project by means of social media posts, links on GP news pages, a dedicated webpage on the Healthwatch Norfolk website, and in the Healthwatch Norfolk newsletter.

Additionally, Healthwatch Norfolk visited local dementia cafés in Norfolk, where attendees could speak to us as part of focus groups, individual conversations, or take and complete paper copies of the survey.

All participants had to give their consent for their feedback to be shared in this report anonymously.

Sample Size

The sample size for this project was discussed with NCH&C, initially to be a minimum of one focus group of 5 – 12 people for the data collection period. In total we heard from 45 carers from across Norfolk. We received 25 survey responses, conducted four interviews, spoke with nine individuals in dementia cafés, and held one focus group of seven people at a dementia café.

Analysis

We designed a range of questions (including multiple choice, closed-ended, and open-ended); therefore, analysis was broad to reflect this, and results and comments are reported on in the next section. To ensure originality any comments used as direct quotes in this report have been left unchanged, only names have been removed to keep anonymity.

Additionally, we collected demographic data to better understand the reach of this survey, help us make sure that we engage with people from different backgrounds and that we understand the needs of different groups in our community. A summary of this demographic data can be found as Appendix 3.

Please note that numbers are rounded to the nearest whole number.

Limitations

The Healthwatch Norfolk team visited several dementia cafés across Norfolk, where participants could complete surveys in person, take surveys away to complete in their own time, or share more detailed experiences with a member of the team. Whilst we gathered data through an online survey, in person conversations at dementia cafés, through a focus group, and through interviews and tried to reach people who are digitally excluded, we may not have reached all those who are digitally excluded if they did not attend a dementia café.

Whilst there were a number of ways for carers to provide feedback, we acknowledge that they have limited time to complete a survey or speak to us. Additionally, for some carers the dementia cafés provide respite and so there was difficulty in forming focus groups due to the number of carers who would drop-off their loved one and then pick them up at the end of the session. Some dementia cafés host 'Carer Support' sessions which are more suitable for holding a focus group.

We contacted twelve dementia cafés across Norfolk with the aim to collect data from as many as possible. However, some we contacted requested that we did not visit as they felt those attending have recently been involved in lots of research and are over surveyed.

Key Findings

Read how people responded to our questions, and what they told us about their experiences.

What we found out

45

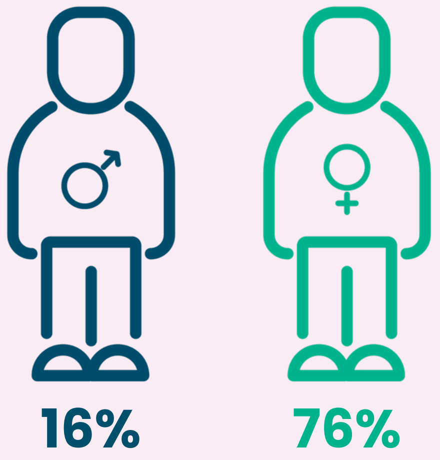
people told us about their experiences receiving support as a carer of someone living with dementia, when the one they care for has been an inpatient.

We heard from a total of 45 carers from across Norfolk. We received 25 responses to our survey, spoke to a focus group of seven individuals, interviewed four people and gathered additional comments from nine others whilst attending dementia cafés around the county.

Demographics

For the 25 who responded to the survey:

- Over three quarters (19, 76%) were female, four (16%) were male, and two (8%) did not respond.
- The majority of respondents were aged 56 and over (13, 52%). Six (24%) were aged under 55, and a further six (24%) did not answer.
- Most (19, 76%) identified as 'White British/English/Northern Irish/Scottish/Welsh'.
- Over half (15, 60%) did not consider themselves to have a disability. Only five (20%) considered themselves to have a disability.



16% of our survey sample was **male** and **76%** was **female**.

For more detailed information regarding the demographics of survey respondents see Appendix 3.

Experiences of Care

Carers we spoke with told us about their most recent experiences of when their cared for had been an inpatient in hospital. They told us about the care and support both they and their loved one received.

The positive experiences we heard about related to care received whilst on a ward, in other departments of the hospital, and in the community. In terms of care and support whilst on a ward, those we heard from praised staff who were trained for or had knowledge/personal experience of dementia. One told us how staff were "*quite attentive*" of their cared-for, and would "*go and check on him every so often*" when the carer wasn't able to be there. They also told us how supportive the end-of-life team were, making sure that family were kept informed. A member of the focus group also told us they had found the dementia team at the Norfolk & Norwich University Hospital to be "*very good*". Another carer told us about the great support they had from a ward sister, consultant, and mental health nurse in getting their loved one discharged to their own home.

> There were some really good experiences, so there's a brilliant, brilliant nurse. [...] she's a urology nurse and she was absolutely fantastic. She was so attentive. And so in tune to, you know, to dementia patients.

Outside of care on a ward, those we heard from also told us that they had received great support when accessing A&E. Two of those we spoke both felt the "*staff seemed more supportive than some of the ward ones*". One said they felt the staff at A&E were "*better at explaining*" processes of what was going on with care. The other felt that support was good because the A&E staff allowed them to stay with their cared-for; "*In accident and emergency we were allowed to have somebody with her all the time*".

We were also told about the positives of care and support received from community nurses. One carer told us how they had a community matron visit to assess what support could be given. They told us that "*everything changed from there on in*" and that the community matron was "*absolutely amazing*". Another carer told us that they had good care at a physiotherapist outside the hospital. They told us that "*they understood who she was*" and "*who I was as the main carer at that time*", they also said they felt that they "*Never got that as an inpatient*".

Case Study: Benefits of a Point of Contact/Key Contact

One of the carers we spoke with, in our interviews, shared their experiences with us and told us about how things improved after they established a single point of contact through a community matron.

They told us how their loved one developed an infection, after a recent period in hospital, which required treatment to be administered every two days. For this they would have community nurses visit to help, but they never knew who was coming or at what time. This was particularly difficult for them as their loved one could become stressed when meeting new people.

> *“it could be anywhere between three and four different people within the in the week and […] that causes the stress […]. I like to make sure that [my husband] was as well prepared as he could be. But, every time that was happening, you know, you couldn't plan or couldn't do anything until after that.”*

Then a community matron got in touch with them to see how best they could support them as a carer and their loved one living with dementia. They told us how they felt that everything then changed for the better. Saying how the matron gathered all the information about the person living with dementia to get a better understanding and picture of them and how they could better support them.

> *“everything changed from there on in. She came, she was absolutely amazing. Wanted to know all what [my husbands] care was, how it was, how it happened, what I did, etcetera, etcetera. If I had any support. So she looked at the whole picture”*

They also told us about how the community matron helped them in caring for their loved one, by giving them the knowledge of how to administer some treatment so that they could reduce the strain on community nurses and lessen the stress of their loved one.

“she then said “what could, what would make our lives easier.” And cutting a very long story short. She trained me, at my request. She trained me to do [my husbands] dressing. She observed me doing it over, I don't know, 3-4 sessions. […] I was then able to take that over […] this helped the nurses on the Community because they no longer needed to come in. We no longer had to have, you know, the day disrupted or not being able to plan or do anything, because of waiting.“

Having the community matron as a single point of contact and support greatly helped them in caring for their loved one’s health and wellbeing. They told us that they felt it had helped, on multiple occasions, reduce their loved ones need to go back into hospital. Having previously had poor experiences as an inpatient both were glad that they were able to avoid being admitted.

“So this is why the bond and the trust that I was able to build with the Community matron has proved invaluable because up until then, there was nothing, nothing at all. I couldn't. I couldn't take the risk of what could have happened.”

The most valuable thing for them was having someone who could look at all the information and history of their loved one, rather than making an assessment at a time that their loved one is under stress from being around new people.

“to look at how [my husband] and I live and what our life is like. And then base decisions around that.”

They spoke to us about how the community matron joined up all the information and looked further into what support they were able to provide. In particular they mentioned how the community matron researched and arranged for equipment to be brought in that would make both patient and carer feel safer and more at ease.

“She then looked into it and provided a little mattress, a little air mattress, which is a single mattress which fits on his side. It's only about 2-3 inches high, which enables us to still stay together, but would prevent any form of pressure or anything in the future, you know. [...] it sounds as though it's something minor, but that was that was a major thing [...] because obviously we stay together, he feels that I'm still near, but I'm also protecting him and preventing what could be a future hospital admission.”

Another example the carer gave, about how valuable having a key contact is, was where the community matron summarised information for other professionals to be able to access. Which has made things easier for the carer, and reduced their need to retell and repeat information and their story.

“they have a form that they have to fill in and they have to ask, you know, lots and lots of questions [...] they then pass that on to out of hours doctor or whoever you then have to go through all of that process again.

it's the repetitiveness, whereas what the community matron has done, she'll, she's now put on one page, on the system that I care for, [my husband] that I do have standby antibiotics that he doesn't have to send a sample, you know, and this.

Well, that one change that just makes things so much easier [...] it's a simple change.”

In terms of negative experiences, carers told us about an issue they encountered whilst on a ward, both with the care for their loved one and with the lack of support offered to them. One felt that the care was “*non-existent*” meaning that they and their father were having to provide care “*round the clock*” during the time in hospital. They told us there had been no “*instructions*” given about what their “*dad should be doing for my mum*”. Another told us about how, through dementia community groups, they knew that “*there should be things in place to help people with dementia*” but when going into hospital found that “*there absolutely weren’t.*” Whilst carers expressed frustration at the level of care being provided, they were understanding of the pressures the NHS is currently facing but still found it “*truly shocking*” that the support for dementia patients was not better.

> “ there was absolutely nobody to help, nobody to turn to, nobody to say what should we do”

Carers also told us that they found the support for them as a carer was lacking. Several we heard from told us that they had to be there “*all the time*” and had to have other family from other parts of the country come to help. Carers also found that they were not informed of anything that would be provided to them, one told us that they only knew about the parking available to carers from speaking to other carers, and another told us that they were not offered any food despite knowing that carers should get something. They told us that their father, who was the primary carer, “*did get a carers box of goodies*” which was good but what they could have done with was more support in caring for their loved one.

Case Study: No Respite for Carers

One carer told us about their experience, where their mother was an inpatient and they and their father were having to provide 'round-the-clock' care. They told us about how neither of them were able to get any respite for their own health and well-being.

They told us that on admission to the hospital they were given no clear information or instructions on what they should be doing to help with caring for their loved one, and no information on what care the hospital would provide in terms of dementia care. They said they understood the pressures that the NHS is currently facing but would have liked more support in their loved one's care.

"it's nobody's fault. It's just under resourced and you know they're just doing the best they can, but it means that the care that my mum got was non-existent, which meant that my dad and I were round the clock looking after my mum in hospital"

One thing they told us that was particularly poor in their experience was that they found they couldn't cope with the change in their loved one's personality. They said that their loved one was "*agitated, frustrated, in pain*" and because of their dementia this made them become aggressive. It had got to a point where they had to ask for their loved one to be sedated because they just couldn't cope.

"And so her dementia really went from like. You know, saying the odd strange thing and to being aggressive and I was sort of in shock really.

But there was absolutely nobody to help, nobody to turn to, nobody to say what should we do, and we even asked for her to be sedated because we couldn't cope. Two of us couldn't cope with her being aggressive."

They told us they also found there to be no support given to them as carers whilst they were there "*all the time*", any support they received they had to ask for – it was not freely given. One example they gave was that they were not offered any meals whilst they were there caring for their loved one.

"I was taking food in and flasks in and then I got told off because I shouldn't actually be taking in stuff from outside. I don't know if it's a covid thing, but whatever. So then I got told off for doing that, which was a bit weird because it's like, hang on, my dad's been here since, you know, whatever time this morning, he hasn't had anything to eat and he's actually looking after my mum and doing you a favour. Because nobody else is looking after her."

With their father being at the hospital all the time they found that his health and well-being was being affected and he was exhausted. On one occasion they spoke with staff to try and arrange so their father could go home to get some rest/respite, but when he had left their loved one had a fall. They told us that their father received a call about it and felt he was made to feel guilty for leaving despite having spoken to staff.

"So basically, my dad was in there, all the time. I actually asked, I said to one of the nurses once you know, can my dad, I want him to leave earlier tonight because he was, there for about just under a week. OK. And I said, can he leave a bit earlier tonight because he exhausted, so, you know, he didn't stay right until the, you know, bedtime and stuff. And then he actually got a phone call later on from the ward and my mum had had a fall and so and they actually phoned to almost tell him off to say, hang on a minute. You didn't. We didn't know you'd gone and your wife has had a fall. Making him feel really guilty, even though he said I couldn't find anybody to tell them that I was leaving."

They felt that they had to be responsible for their loved one's care 24/7 whilst in hospital and were worried that if they weren't there their loved one wouldn’t receive the care they needed. They told us that they understood that staff were busy, but felt that they did not have time for “*normal care, let alone dementia care.*” When they got ill themselves they then also had to get family from other parts of the country to come and help provide care for their loved one.

There was some support that they received, but mostly when they pushed for it or knew about it from other sources. Ultimately, however, they felt that they could have had far better support as carers.

“a carer should actually be provided with a meal and there should be other things [...] I told my dad about the parking cause, you know, obviously as a carer, he should get parking for the week and stuff as well, because I think there's a voucher system and all that.

He did get a carers box of goodies which was, you know, nice, but he really didn't need that compared with the support that he could have done with."

A common issue that we heard about concerned food, particularly about those living with dementia not eating during their time as an inpatient and their health declining. Carers told us about how food would be delivered but then taken away uneaten. One told us that, when a nurse checked, the person living with dementia would answer that they had eaten even when they had not. They felt that part of the problem was that the person living with dementia was presented with lots of choices and was "*incapable of making a choice*" about meals, meaning that the food might not have necessarily been something they liked. They tried to resolve this as a family member sat with them to go through the menu options and choose suitable meals, but they then found that this "*was ignored*". A member of the focus group also told us about how their loved one had drastically lost weight whilst being an inpatient for similar reasons. One carer told us that their loved one was discharged despite "*not eating or drinking"* and when they approached staff about it "*their* [the staff's] *answer was "well, that's a social problem. It's not our problem""*.

So they recorded, falsely, all the time that she was eating when she wasn't eating or drinking.

One thing we heard from carers was that they had issues with continuity in their care. Whilst they were understanding that services are stretched, one told us that their loved one struggles with new people. They were very appreciative of community nurses coming to help them, however they would never know "*what time they were coming*" or "*who was coming*" and that there could be "*between three and four different people within the week*" which was stressful for them and their loved one. They were worried that nurses would not see the "*true representation*" of the person living with dementia due to being "*either agitated or extremely wary*". Another told us that hospitals can be "*a bit overwhelming*" for both the carer and their loved one, and there is a lot of information "*they don't understand*". Similarly, a member of the focus group also told us that the number of different departments and staff they got passed around did not help with their loved one's confusion.

For some, they told us that their experiences of their loved one being in hospital were so poor that they were worried about having to go back in; "*We don't want to go through that again*". Another told us that they had a lot of issues with the discharge process, even though the hospital staff were supportive in getting them home they had problems with social services trying to get them discharged to a care home. They said that "*because of the trauma*" of their experience it made them "*reluctant to accept any external support*".

Recognition

We wanted to know if the hospitals acknowledged carers as their loved one's primary carer. Those we spoke with told us that, typically, they were acknowledged as primary carers with only one telling us that, despite having a Carers Passport, they were not acknowledged as a carer. In terms of survey respondents, just over half (15, 60%) told us that the hospital acknowledged them as carers with 10 (40%) telling us that they were not (Figure 1).

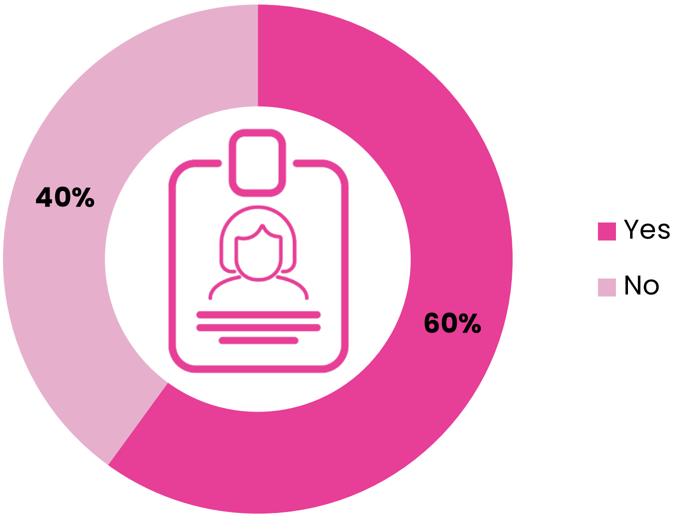


Figure 1. Survey responses to the question 'Did the hospital acknowledge you as a carer of your loved one?'

Even though in most cases carers were acknowledged by hospital staff as the primary carer, some found there were still issues. One carer we spoke to told us that due to their marital status there were barriers despite having been together for "*50 years*". They said they were told that their views would be taken into account but found that they were not. Another told us that they were acknowledged as carers but "*there was a bit of confusion about who the relatives were*" and they felt that "*it took a little while for the penny to drop*" that more than one relative was considered a carer.

Additionally we asked if carers were aware of the 'Carers Identity Passport' which is available through Carers Voice (https://www.carersvoice.org/carers-identity-passport/) and hospitals recognised when acknowledging someone as a carer. There were some who were aware of this who already have one (10, 40%), and a further 11 (44%) who were not aware of this, four of which said they would apply to get one.

We asked carers if they felt that they were listened to by hospital staff. From the survey, we found that 12 (48%) felt that they were not listened to and only seven

(28%) felt they were (Figure 2). Of the 15 who told us that they were acknowledged as carers, seven felt that they were listened to, four felt they were not, and a further four were not sure.

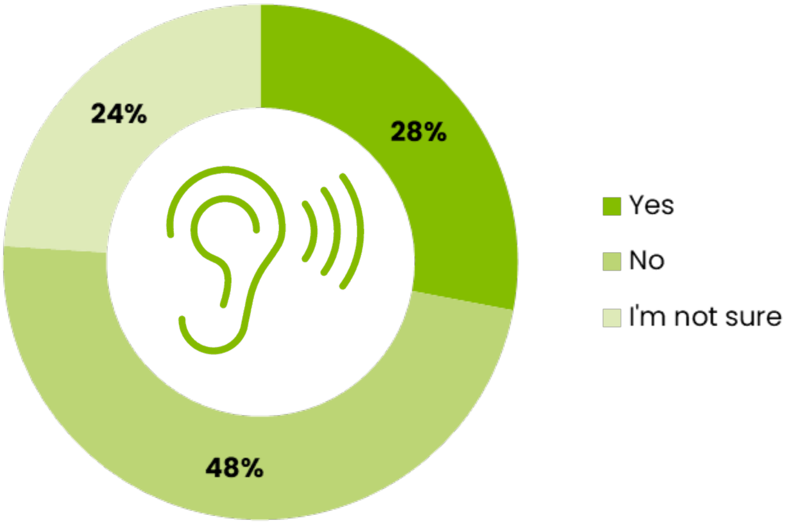


Figure 2. Survey responses to the question 'Do you feel that you were listened to as a carer?'

Carers we spoke with in person also had a mixed experience. Most felt they were listened to but in some cases even when they were listened to, they were left feeling unsure if their views had been taken on. One told us that despite their father, the primary carer, being there all the time they often felt that he was "*just kind of ignored*". Another told us how they tried to "*set up a system*" so that staff "*knew who the key people were*" they would always contact family that were unable to answer phones.

Several survey respondents, who told us they did not feel listened to, commented that they felt dismissed by staff. They told us they felt the "*hospital had the attitude that they knew best*" and "*how dare I comment as a lowly carer when Drs and nurses know better*". Others told us they felt that "*My concerns were not heard*" and that "*None of the information we provided was used*". One told us that they "*didn't always feel respected*" despite having been with their loved one for "*over 40 years*" and living with their loved ones condition 24/7.

Those who told us that they were unsure mentioned that they did feel that it "*Very much depended on staff attitude*" and "*varied according to the individual*". They felt that nurses did listen to them but doctors did not, one said they felt "*The consultant dismissed me.*" Another felt that even though nurses listened to them they still "*had to tell the story to each nurse that called*".

The ones who told us they did feel listened to felt that "*The ward staff, dementia team and the safeguarding team always listened and tried their hardest*". However, one also said that they were not always sure staff understood, and another raised the concern that "*some patients do not have someone to do this for them*".

Visiting

We also wanted to know if hospitals were flexible with carers visiting their loved ones. Most who answered the survey (16, 64%) told us that they were able to visit when they wanted to, however seven (28%) told us that they were not (Figure 3). Looking at those who were acknowledged as carers, 11 told us that they were able to visit when they want to, with only two saying that they were not, two were unsure if they were able to or not.

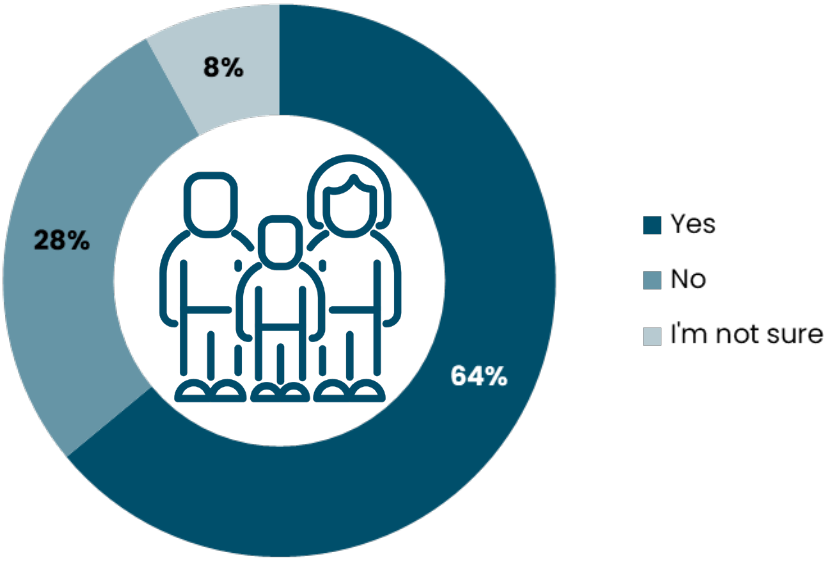


Figure 3. Survey responses to the question 'Were you able to visit your loved one when you wanted to?'

Those we spoke to also told us that typically they were able to visit their loved one when they wanted. One told us that despite COVID restrictions they were still able to and that staff were "*quite flexible from early on*". Another told us that the ward staff were "*quite happy*" and "*worked with*" them to be able to come and go as needed to help with their loved one's personal care as they were uncomfortable with staff carrying this out.

Survey respondents told us that visiting was "*Very good and flexible*" but they also tried to fit "*with visiting times as much as possible*". They also told us they felt that staff did "*appreciate my help*" as "*the staff were very busy*". However, some told us that they "*often had to argue and fight fir* [sic] *this right*". One told us that, due to their loved one's condition, they had to insist that "*legally he was allowed a responsible adult with him at all time*".

Both those that were not sure if they were able to visit when they wanted, and those that said they were not able to, told us that there seemed to be "*different rules being followed*" or that visiting "*constantly changed*". They felt that "*nobody seemed to really understand the 'rules'*" for visiting someone living with dementia. Others told us that there were "*strict visiting times only*" and thought it "*would be better to allow carers in at meal times to help feed*".

> "I feel the hospital is not a safe place for him. He has vascular dementia and cannot remember things or communicate his wishes so feels extremely isolated and very depressed when he is in hospital."

Communication & Information

We wanted to know from carers what the communication was like during their most recent experience of their loved one being an inpatient. This included communication with them from the hospital and ward staff as well as internal communications between staff and record keeping.

We asked survey respondents how they would rate the communication between them and the ward their loved on was staying on. Over half of respondents (14, 56%) rated the communication as 'Poor'. Only five carers (20%) thought that the communication was 'Good' and four (16%) said it was 'OK', two respondents (8%) answered 'Not Applicable' for this question (Figure 4). Those who were acknowledged as carers had mixed experiences with communication, six told us that it was 'Poor', five told us communication was 'Good' and three said it was 'OK'.

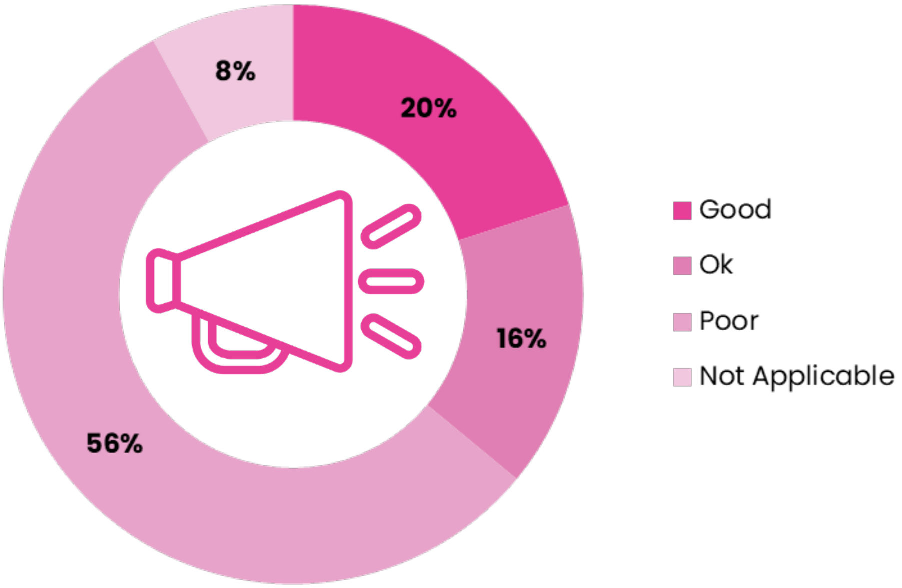


Figure 4. Survey responses to the question 'How was the communication between you and the hospital ward your loved one was staying on?'

Those that found communication with the ward was 'Good' told us that staff kept them "*informed as much as they could*" and that they would "*get in touch whenever and* [sic] *'incident' occurs*". One said that whilst communication was good they felt "*it can be difficult to talk to staff because it feels that they are always so busy*." Some of those we spoke with also told us they had good communication, one told us that they "*were able to ring in every morning and every evening and get an update*" on how their loved on was doing. Another told us how great the communication was with their community matron, who made sure that contacts were "*put in place*" for the carer to ring in her absence.

Communication was varied for those who responded that it was 'OK', they found that "*There wasn't a great deal of communication*" and "*Usually had to ask*". But they also said that they "*appreciate that they* [the staff] *were busy*" and that there was "*Limited resource especially in evenings*". Communication also varied for those we spoke with, one told us that it was *"depending on who I* [they] *spoke to at the particular time*". Another told us that, whilst the communication they received was good, the communication from other parts of the hospital, such as A&E, was better. They also felt that a lot of the doctors they interacted with seemed "*fairly junior*", and whilst the doctors "*were quite good*" they would have preferred someone a "*bit more senior*" provide more explanations.

More than half the survey respondents rated communication as 'Poor'. Some felt that there was "*Not enough contact*" and the little they had was "*during the day*" when the carer was there to "*initiate it*". Others also found that "*Contact was only made*" if they "*requested it*" and even then "*it was difficult to speak to anyone who knew any answers*". Several told us they had issues when phoning for updates and information but found "*They hardly ever answer*". Some of those we spoke with also found that there was little communication from staff telling us that "*nothing was really explained to us*". They told us that they did not find out details of their loved one's treatment until they "*actually pinned down a doctor*" to be able to ask. Another told us how staff would continually ask the person living with dementia questions, understanding that it was part of patient consultation, but they did not involve family or carers in the discussions; "*that absolutely did not happen*".

> "I was made to feel that I was always asking too much and being a nuisance. Sometimes I felt staff did not understand dementia care."

Carers also told us about how they felt the communication between staff and record keeping of information they had provided was poor. One said that the lack of communication between staff meant "*Having to repeat the same story over and over again*" something which they said can be quite "*traumatic*" as it is reliving "*coming to terms with somebody that you've spent your life with suddenly not recognising you*". They found that they would answer "*lots and lots of questions*" but when passed to another doctor they would "*have to go through all of that process again.*" Another told us how when they went into hospital they had to explain that their loved one had dementia, even though they had recently just been in, so they believed nothing had been put on their notes from the previous stay. They were informed this would be updated but then found that "*the healthcare assistant didn't know*" when they came round. One carer we spoke to told us about the problems they had because the hospital staff "*didn't have access to her* [their loved ones] *GP medical records*". They told us that the staff "*would never accept*" that their loved one had a dementia diagnosis.

> So I had the paperwork from her diagnosis and I had the statement from her GP, […] I physically gave it to them. So they had it in front of them with a date of diagnosis and everything. It didn't make any difference.

Signposting

We also wanted to know if carers felt that there was enough information available and given to them. As well as if there was any signposting to support for them as carers or other services at the time of discharge.

We asked survey respondents if they felt they were given enough information by the hospital where their loved one was an inpatient. More than half the respondents (14, 56%) told us that they felt they weren't given enough information from the hospital. Only six (24%) felt they were given enough information, and a further five (20%) were not sure (Figure 5). For those who were acknowledged as carers only five told us they felt they weren't given enough information, six felt that they were, and four were not sure.

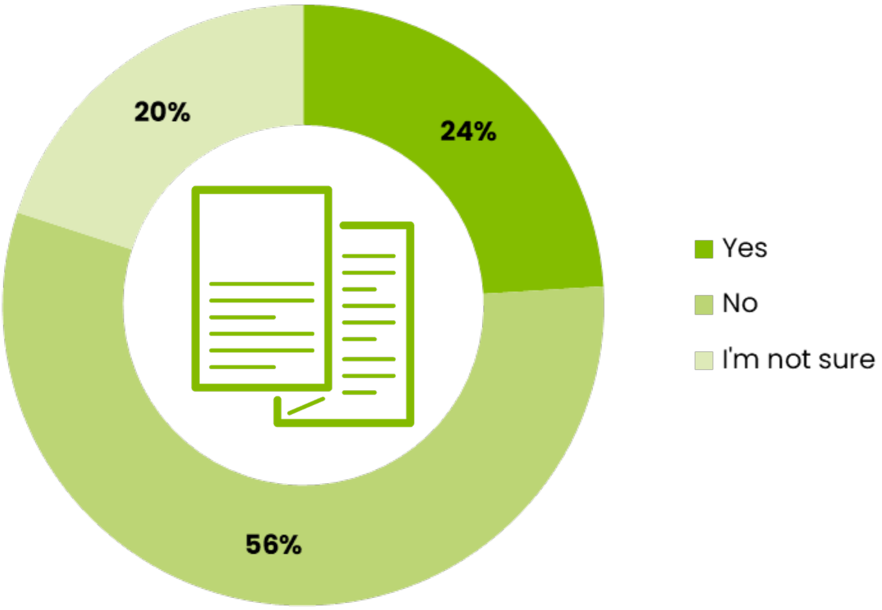


Figure 5. Survey responses to the question 'Do you feel you feel you were given enough information from the hospital?'

Respondents who felt they were provided enough information told us that there was "*Plenty of information regarding partners care*" and that they had "*regular meetings/ contact*" with staff.

Most respondents, and those we spoke with, found that information and signposting was lacking. As with communication we heard that there was "*Limited information unless requested*" and receiving information "*Very much* *depended on staff attitude*". One respondent told us that "*Each day I* [they] *had to question staff*" just to get information on their loved one's care. Others told us that they were not given information on when their loved one was moved "*to different wards*" and that no staff seemed to know the "*rule around visiting someone with dementia*" and that some tried to stop carers from visiting. Carers also found that no information was given to them about support for them, one told us that they "*knew more information about the rights of the carer than the ward*" and another told us they weren't "*given a car pass untill* [sic] *the ward receptionist spoke to me* [them] *about it*."

> "Not much information was relayed to me. It would be nice just to be told what is wrong with my partner, how long they may potentially be in hospital, etc. I was uncomfortable asking many questions as they were so busy."

Similarly, those we spoke with also said that information was available "*Only if you asked for it, it wasn't sort of freely given*". They found that they had to look for information themselves particularly about the rights and benefits of carers. Fortunately, they were aware of what should be given to carers from going to local support groups and speaking with other carers. One of the carers from the focus group told us they found there was no signposting to support in their community, they told us how great it has been attending their local dementia café but they had to find this on their own and thought it would be beneficial if health services signposted others to them. Another told us how, on discharge, no information or support was given to them in finding a care home or home care for their loved one. They only way they knew is because "*there was a pop up banner*" for a service that would help get their loved on into a care home, but it was not pointed out or mentioned by staff at all.

In terms of information around discharge we also asked survey respondents if they felt there was enough information on this. Again, over half (17, 68%) felt that there was not information, five (20%) felt there was, and three (12%) were not sure (Figure 6).

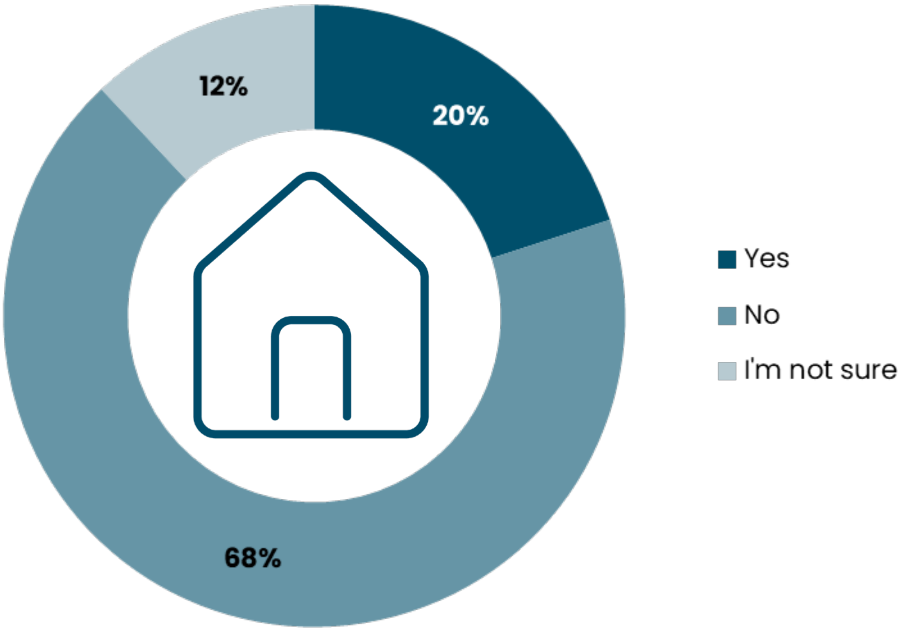


Figure 6. Survey responses to the question 'Do you feel there was enough information about discharge?'

Those who felt there was enough told us that they were "*told the day before so had time to sort some things*" and they felt the "*Dementia team & O/T all tried to help*" get loved ones home. Those not sure if there was enough information told us they found the process "*chaotic, disjointed and very frustrating*" and "*a long process*" which was possibly due to too "*many different teams*" being involved.

Many, however, told us that there was a lack of information on discharge and their general experience around discharge was poor. They said that information was "*Vague and unhelpful*" and they were "*Unsure who was doing what part of discharge*". Others told us that there were issues with transport for getting their loved one home and for some there was no transport available. Several told us they had issues with discharge times, with one telling us that "*Doctors agreed he could leave but nurses didn't action anything for 24 hours*". One of those we spoke with told us that the ward tried to discharge their loved one before they were ready. They told us that, on one visit, as they left the ward staff had phoned another family member to inform them they were discharging their loved one despite them not eating or drinking.

Support

We asked carers if they felt that their needs were supported by the hospital when their loved on was an inpatient. We also wanted to know if there was anything more that they felt would support them better during this time.

Those who responded to our survey mostly (16, 64%) felt that their needs as carers were not supported by the hospital. Under a quarter (6, 24%) felt that their needs were supported, and a further three (12%) told us they were not sure (Figure 7). Looking at the 15 who told us they were acknowledged as carers; seven told us they felt there weren't supported, six felt they were, and two were not sure.

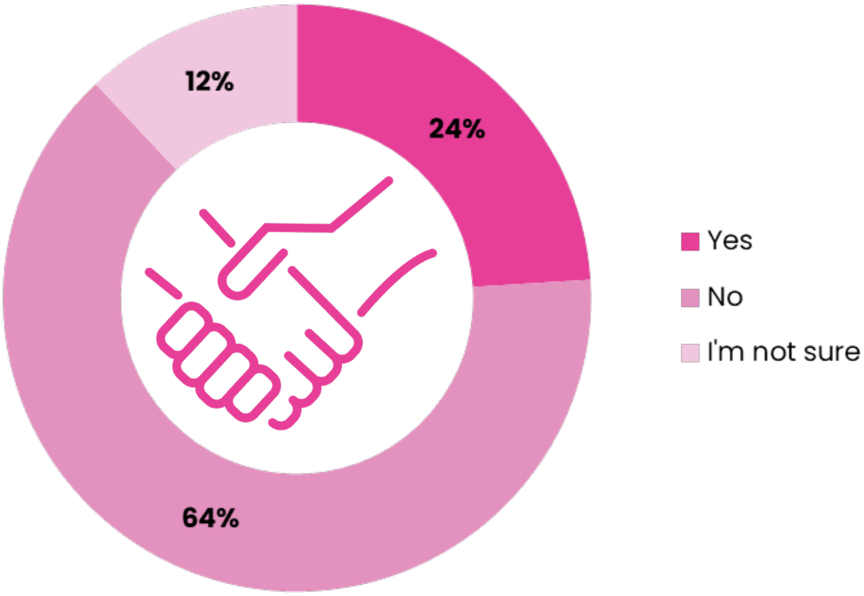


Figure 7. Survey responses to the question 'Were your needs as a carer supported by the hospital?'

Survey respondent who told is that they felt their needs weren't supported said the "*care for partner was great*" but the support for them, such as "*communication with me as the carer*", "*was not*". Another felt they were only "*Sometimes acknowledged*" and their needs were *"not met all the time*". One told us there was no support and simply responded *"None*". A respondent who said they were not sure told us that support was "*Very hit and miss*", telling us that "*some wards*" were good but "*others a battle to be listened to.*" They also told us that a "*Carers pack* [was] *never offered*" and they had to "*ask for on all ocasions* [sic]".

Those who told us that they felt their needs were supported said that "*staff on the ward, along with the dementia team and safeguarding team were fantastic*", and said that the dementia team were "*friendly, kind & caring*" when they interacted with them. However, they also told us it was difficult to interact much with teams as "*unfortunately there were not enough of them to support all those in hospital with dementia.*" Another told us that they felt supported as they were provided plenty of "*Information about condition and welfare*" of their loved one, and had "*Updates about trying to find care following discharge*". One felt their needs were only "*Somewhat*" supported and would have like "*there to be more care given for partners 'personal care'*".

> my father was in hospital a long time, and the ward staff are not there to fulfill [*sic*] the needs of someone with dementia, they are there to help get people better

Carers we spoke with also told us about their negative experiences with receiving support from the hospital. Those that had negatives experiences told us they found that they had to be there caring for their partner all the time as staff were stretched and "*so busy*" they were concerned they wouldn't be able to provide dementia specific care. They told us that they thought that they had to be responsible for their loved one 24/7 whilst in hospital. This meant that the carers themselves had no respite during a time where they were more emotional and stressed. Several we spoke with told us that if they had help with the personal care of their loved one that would let them have some time for themselves.

What is wanted

Carers told us about what further support they wanted from hospitals when their loved one is an inpatient. Overall, the things that carers most wanted from hospitals included better understanding and training around dementia care for staff, better information and communication with carers, and a key contact who understood dementia and dementia care.

One of the biggest things carers would like, in terms of support, is to be able to get some respite whilst their loved one is in hospital. They told us that they want to know that the care for their loved one is there so they can be confident that they are ok in hospital and feel safe leaving them. Carers told us that they felt they had to be at the hospital at all times to ensure their loved one was being cared for.

> that's the most important thing, like knowing that there's somebody going to be, you know, watching her so that we don't have to be there 24/7.

Carers told us that they felt there was a lack in staff understanding of dementia and that training for all staff on dementia care could be better. Members of the focus group told us that they felt staff needed to understand that what is said by the patient may not be true, they gave the example that whilst their loved ones may say they are not hungry it is often that they just require some persuasion to agree to eat something. Similarly in interviews people told us that staff believed the patient had been eating their meals and "*nursing staff completely did not accept that she* [the patient] *wasn't eating or drinking,* […], *she was losing so much weight*".

Others we spoke with told us how good they thought the dementia support teams were but often found that there was "*maybe one*" member of staff and expressed worry that they wouldn't be able to "*cope with a few dementia patients*". They told us that if there were more staff they knew were trained for dementia care they would "*be more comfortable leaving*" their loved one at times. Another told us they felt that "*the dementia training of medical staff is inadequate*" due to other experiences they have had in hospital. They gave an example of time when their loved one was an outpatient and they were taken for a test but the carer was not allowed to accompany them, their loved one was then asked if they knew the way back and left to go on their own, which resulted in them becoming lost.

Those who responded to the survey also told us that they felt hospitals could be "*better prepared to cope with patients*" living with dementia. They said they felt the "*level of dementia awareness between wards was vast and shocking*". They also felt that those with good knowledge of dementia care were "*amazing*" but felt that if they "*can't have more staff then we need to find a safe acceptable way to provide 1/1 support for dementia patients on a ward*" or allow more access for "*carers / family or their paid support on wards*".

> " If they haven't actually physically experienced living with somebody with dementia, they don't understand."

Carers also told us that they wanted better communication with, and information from, hospitals. One carer who responded to the survey told us that they wanted to "*be listened to and communicated with*" as they had had to "*struggle*" with visiting and getting information. They told us: "*It is a difficult time which seems to be made more difficult by the hospital.*" Another told us they would like if they were "*Spoken to honestly*" and not "*brushed to side*" as they have a "*tough job*" as a carer and know the person living with dementia better. Another survey respondent felt that as a carer they should be "*respected &*

listened too [sic]" because of the level of commitment they give to their loved one's care. They told us they "*Often felt dismissed as 'The Wife' !!*"

Others we spoke with told us that they felt there should be better information given to them as carers for what to expect in terms of dementia care. Two suggested that there should be "*a little care or a little something*" or an "*informative sheet*" given to cares on admission that can let them know "*what is expected*", what they as a carer will or won't get, and information on staff roles and acronyms. One carer told us that they found older patients and carers "*don't get that HCAs are healthcare assistants*" and when HCAs are mentioned the patients "*don't understand what they're talking about*".

Carers also told us that they felt there could be better recording of the information they provide to staff. One told us they "*thought there should have been more information sharing about who the relatives were*" and this would have helped in making sure they were all kept updated with information on their loved one's condition. Another carer suggested that there could be "*an advanced consent thing*" that would let the hospital know people living with dementia "*need to have a family member*" with them if they need to speak to them about care or choices.

> "It would be nice if the hospital could encourage doctors to talk to the carers of dementia patients and appreciate that carers are also part of the team and know the dementia patient well so can be really helpful."

Another thing that carers told us would be useful is a single point of contact or a dedicated person who would be able to make sure all the information about their loved one is all together and available any time they may have to go back into hospital. They told us that having someone who understands dementia as their point of contact would be beneficial particularly for carers who may not "*have the knowledge*" or "*the health and the strength*" to advocate for their loved one themselves. One said they felt "*there should be somebody*" who is a "*dementia expert*" available when they need help and are concerned for their health of their loved one.

> "A one to one contact would be very helpful. I feel that a hospital works to a totally different time scale to the outside world."

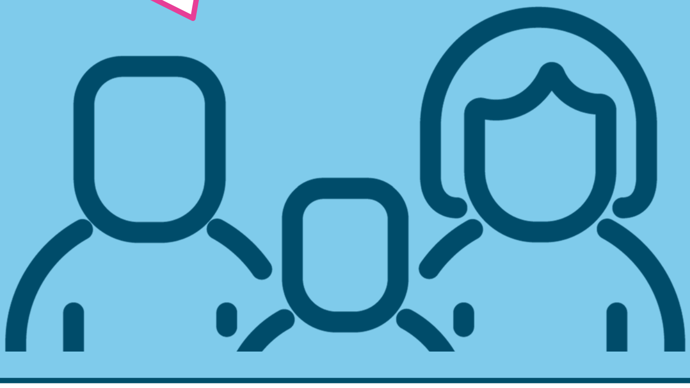
Something we heard from several carers was that they were worried about care for their loved one when they themselves were ill or an inpatient. Their concern is that their loved one will need someone "*there more than 2/3 times a day*" as they may not have family who can be there at other times and felt there are some parts of care that they wouldn't want other family to have to do. One carer we spoke with told us that they were "*very aware*", from attending a dementia café, that they could see "*the carer going downhill faster than the cared for*".

Below are some of the comments we heard from carers:

"What support is available for carers when they themselves get ill or are in hospital? I am fortunate to have family to care for my loved one but others aren't."

"What about when we carers go into hospital?"

"What care is available if something happened to me?"



What this means

We heard from 45 individuals who are carers of someone living with dementia about their experiences of support whilst their loved one has been an inpatient in hospital. There are consistent themes in the experiences of those who have spoken with us and responded to our survey concerning the available care, recognition as carers, communication and information, the support available, and the support they would like.

Experiences of Care

Overall carers told us that they had mixed experiences at hospitals, regarding the care their loved one received and the recognition/acknowledgement and treatment of themselves as carers.

Carers felt that there were certain teams at the hospitals which were more supportive, attentive, and 'in tune' with the needs of those living with dementia. This included dementia support, safeguarding, end-of-life, palliative, and A&E teams. One carer we heard from also commented on the amazing experience they have had since having a dedicated community matron providing care and support for them. Whilst some praised the support they received from ward staff other found there to be difficulties, feeling that there was a lack of understanding of how best to care for those living with dementia whilst they are inpatients. We would like to see some consideration towards evaluating existing dementia care training for staff and reflecting on its effectiveness. We would also like consideration into ensuring all staff working in hospitals have received some level of dementia care training. This could help carers feel more supported and make them feel more at ease at a time that is emotional and stressful for them.

Whilst most carers told us that they were acknowledged by staff as being the primary carer of their loved one, many found that there were still issues despite this. Several told us that they felt dismissed or ignored by staff when it came to being involved in decisions about their loved one's care. As carers and family members they felt that they had more knowledge about their loved one that could be helpful to treatment and care but did not always feel that this was taken on board. Ensuring that carers are consulted and making sure that they are present when decisions are being made concerning their loved one's health and care is important to help carers feel acknowledged and respected. Ultimately this could improve the health outcomes of these patients.

Communication and Information

Many carers we heard from felt that communication, not only with them but between medical professionals, could be improved. Some told us that staff kept them as informed as they could and appreciated that they were doing their best given the current national situation with staffing. However, some found that they would often have to be the one to initiate communication to find out about their loved one's condition, what was happening with treatment and care, and get answers for any questions they had. We would like to see a continued effort to communicate with and update carers where possible and to consider implementing regular updates for carers where treatment is ongoing. Consider having early discussions with carers about their communication needs and set up a system that works for both staff and carer.

Carers also felt that they had to retell their stories again and again to health professionals as they moved around wards or new staff came in or became involved in their loved one's care. This is something we know is common in a lot of healthcare settings, but can be particularly upsetting for those caring for someone living with dementia. Ensuring that all patient information is in one place and easily accessible to clinicians, e.g. through the shared care record, would help in alleviating this stress for carers. The shared care record brings together a patients important records from the different organisations involved in their care and allows frontline care professionals to access this at the point of care (https://improvinglivesnw.org.uk/our-work/healthier-communities/digital/shared-care-record/)

Information for carers whether it be regarding what to expect in terms of care for their loved one, the rights and benefits for carers, or signposting to support services in and outside of the hospital could also be improved. Many found that there was not enough information provided to them and also found that they had to request information rather than it being freely available to them. Carers also struggled with signposting to care homes and home care for when their loved one was due to be discharged, with many telling us that they had to find this on their own with no support from the hospital. Providing an information pack to carers, which could contain information on care expectations, who may be part of the care team, carers benefits and rights, and signposting options for care outside of the hospital, as well as community and peer support they could access, would help answer some of the questions carers may have for staff and help them going forward with their loved one's ongoing care needs.

Support

In general carers felt that their needs were not supported by hospitals. Many felt that they, or a family member, were having to be there all the time and they were not able to get any respite for their own health and well-being. Carers were accepting that ward staff were often busy with patients but found that they could not even leave to get themselves a meal, as they were not brought one, due to their loved ones condition and needing them to stay by their side. Where possible we would like to see some consideration to there being a system in place where carers are able to have the option of being away from their loved one and reassure them that their loved one is being cared for, whether this be through 1/1 support, a point of contact/dementia expert present on the ward, or more access allowed for other/paid for carers to be present.

Finally, one of the main worries that carers have regarding support is about what is available if they themselves are an inpatient in hospital or otherwise incapacitated. Many carers of those living with dementia are partners and of an older age group and therefore this is a big concern for them. Not all carers have other family they are able to rely on, and paid carers are not always able to spend full days with those living with dementia. Investigating options for how care can be provided to those living with dementia if their carer becomes an inpatient will be an important step into alleviating this worry.

Recommendations

From the findings of this piece of work several recommendations can be made for Norfolk Community Health & Care and all acute hospitals to consider regarding improving support for carers of those living with dementia at times when their loved one is an inpatient.

1. Dementia Care Training – Evaluate effectiveness of existing training and deliver to all staff to improve understanding of dementia and dementia care. To include best practice and understanding of different types of dementia. Additionally, this could include staff knowledge/awareness of carers benefit/'perks' and rights.
2. Dementia 'Expert' – Consideration into ensuring a dementia 'expert'/Champion is present on each ward and that carers are made aware of them. This person can act as a point of contact/key contact for carers if they have questions or need support for themselves or their loved one.
3. Clear Patient Information – Encourage all relevant wards to record background information and ongoing developments, including about discharge, in a way that is easy for other clinicians to access as required. Allowing carers, whenever possible, to only have to tell their story once.
4. Carer Consultation – Consult with carers regarding their loved ones health and care needs as well as their own needs. E.g. allowing carers to be involved in meal choices as those living with dementia may struggle with decision making.
5. Continued and Improved Communication – Continue to keep carers updated whenever possible regarding their loved ones condition and look into implementation of regular updates to help keep carers informed. Have early discussions with carers on admission to wards to find the best approach to meet their communication needs.
6. Carers Information Pack – Development of an information pack for carers, detailing what they can expect whilst their loved one is an inpatient. Key staff they need to be aware of, rights and benefits of carers, and internal and external support available to them.
7. Carer Inpatient Support – Investigate what provision can be given to support the person living with dementia should the carer become an inpatient themselves. Consulting with the carer to ensure that the most appropriate support is provided.

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Appendix

Appendix 1: Interview and Focus Group Discussion Guide

Focus Group Discussion Guide

Project: NCH&C Focus Groups (Facilitated by HWN)

Question	**Notes**	**Complete**
Welcome and start recording Introductions (all attendees)	Confirm attendees are happy for session to be recorded for transcription purposes. Recording will be deleted once the write up is complete and any direct quotes will be anonymised. 'Healthwatch Norfolk is the independent voice for patients and service users in the county. We gather people's views of health and social care services in the county and make sure they are heard by the people in charge. Our work covers all areas of health and social care. This includes GP surgeries, hospitals, dentists, care homes, pharmacies, opticians and more. We also give out information about the health and care services available in Norfolk and direct people to someone who can help.'	
Purpose of focus group	Healthwatch Norfolk are exploring people's views and experiences as carers whilst their loved one with dementia is in hospital. We want to spend some time speaking to small groups carers in Norfolk. For the purposes of this discussion you should be the carer of someone	

	who is living with dementia and has been an in-patient with one of the Norfolk hospitals. This session will run for up to 2 hours to explore carers experiences. We want to hear what it has been like accessing services for the person you care for, what support you have received, and what further support you would like. We'd like to hear what has been positive and where you would like to see improvements or changes. There are no right or wrong answers at this session, we are just really interested in hearing peoples' personal experiences and opinions. The information we take away from the discussion can be anonymised and will be used in a report to be given to service providers so they can find out what is working well and where improvements can be made. We ask that attendees share with us what they feel happy and comfortable doing so and respect the privacy of other attendees by treating information confidentially.	
Any Questions?		
Focus Group Discussion		
Can you tell us about your most recent experience having the person you care for as an in-patient? What has been beneficial and helpful in terms of		

support for you as a carer?		
What support was given to you as a carer? Did the hospital acknowledge you as the carer? Were your needs supported? Do you feel like you were heard?		
How was the communication between you and the ward? Was there enough contact with the ward? What could be better?		
Do you feel you were given enough information (written, verbal, signposting) from the services? Was there enough information about the ward? What additional information do you feel would have helped?		
Was there enough information about moving		

towards discharge? Do you feel you were involved?		
What expectations did you have for admission and discharge? Were these met?		
What support do you feel that you need? And What support would you like to have received?		
Was there enough flexibility to meet your needs as a carer regarding visiting?		
Have you heard of the Carers Passport*?		
Is there anything else you can think of that you would like from NCH&C or other hospitals as a carer?		
Focus Group wrap up and conclusion		
Additional Feedback	Do any attendees wish to share any other experiences/views before the end of the session?	

Summary of themes	Feedback themes to group	
Thank you	Thank you to attendees and staff	

**Carers Passport* "People looking after family members or friends have said they want to be recognised as their carer when they are in healthcare settings. In order to help support carers with this a Carers Identity Passport is now available via Carers Voice Norfolk and Waveney, to ensure carers are recognised and can get the help and support they require." – Carers Matter

Recognised by NCH&C services. More details available here: https://www.carersvoice.org/carers-identity-passport/

Appendix 2: Survey

Dementia Carers Experiences

Introduction and Consent

Who is Healthwatch Norfolk?

Healthwatch Norfolk is the independent voice for patients and service users in the county. We gather your views of health and social care services to ensure they are heard by the people in charge.

What is this survey about?

Healthwatch Norfolk is exploring people's views and experiences as carers whilst their loved one with dementia is in hospital.

We want to spend some time hearing from carers of those living with dementia in Norfolk.

For the purposes of this you should be the carer of someone who is living with dementia and has been an inpatient with hospitals in Norfolk. An inpatient is someone who has stayed in hospital for a period of time whilst they received treatment .

We want to hear what it has been like for you as a carer of someone with dementia, what support you have received, and what further support you would like. We'd like to hear what has been positive and where you would like to see improvements or changes.

There are no right or wrong answers, we are just really interested in hearing peoples' personal experiences and opinions.

How the information you share will be used

Survey responses are being collected and analysed by Healthwatch Norfolk. You can read our full privacy policy at:
www.healthwatchnorfolk.co.uk/about-us/privacy-statement.

All responses will be anonymous and will be used to make recommendations to health and social care providers. The report will also be publicly available on our website and may be used in other Healthwatch Norfolk communications.

Want to keep in touch?

To stay up to date with what we are doing at Healthwatch, you can sign up to our newsletter via our website: www.healthwatchnorfolk.co.uk

If you do not use email, you can call Healthwatch Norfolk on **01953 856029** to ask to receive our newsletter via post.

If you would prefer to do this survey with us over the phone or would like to speak to us in more detail regarding your experiences, please call Healthwatch Norfolk on **01953 856029** and we will arrange a time to ring you back to complete the survey. Alternatively, please email: enquiries@healthwatchnorfolk.co.uk for further support.

Please tick to confirm *

☐ I have read and understood the above statement

Healthwatch Norfolk produce newsletters about health and social care in Norfolk. If you'd like to receive this newsletter please leave your email here:

Your Experience

Thinking about your recent experience of the person you care for being an inpatient, please answer the following questions:

1. Did the hospital acknowledge you as a carer of your loved one?

☐ Yes
☐ No

2. Were your needs as a carer supported by the hospital?

☐ Yes
☐ No
☐ I'm not sure

If yes, please tell us what support was given to you as a carer:

3. What further support do you feel that you would need and want as a carer when your loved one is an inpatient? (What support would you like to have received?)

4. How was the communication between you and the hospital ward your loved one was staying on?

☐ Good
☐ Ok
☐ Poor
☐ I'm not sure
☐ Not Applicable

Please tell us more (E.g.Was there enough contact? What could be better?)

5. Do you feel that you were listened to as a carer?

☐ Yes
☐ No
☐ I'm not sure

Please tell us more (Were you able to voice concerns and tell them about your loved ones needs?):

6. Do you feel you were given enough information (written, verbal, or signposting) from the hospital?

☐ Yes
☐ No
☐ I'm not sure

Please tell us more (E.g.Was there enough information about the ward? What additional information would have been helpful?))

7. What expectations did you have concerning admission, visiting, and discharge? Were these met?

8. Were you able to visit your loved one when you wanted to?

☐ Yes
☐ No
☐ I'm not sure

Please tell us more:

9. Do you feel there was enough information about moving towards discharge?

☐ Yes
☐ No
☐ I'm not sure

Please tell us more (Do you feel you were involved?):

10. Carers Voice have what is know as a 'Carers Passport':

"People looking after family members or friends have said they want to be recognised as their carer when they are in healthcare settings. In order to help support carers with this a Carers Identity Passport is now available via Carers Voice Norfolk and Waveney, to ensure carers are recognised and can get the help and support they require." – Carers Matter

This is recognised by many health care services in Norfolk. More details are available here: https://www.carersvoice.org/carers-identity-passport-leaflet/
Please select all that apply to you:

☐ I was already aware of this and have a Carers Passport
☐ I was already aware of this but do not have a Carers Passport
☐ I was not aware of the Carers Passport
☐ I would apply to get a Carers Passport
☐ I would not apply to get a Carers Passport

Please explain your answer:

11. Is there anything else that you would like from hospitals as a carer?

About You

In this next section we will be asking you some questions about yourself and your life. All these questions are optional.

Why we ask these questions
Your answers help us make sure that we hear from people from different backgrounds and that we understand the needs of different groups in our community. Remember: all your answers are strictly confidential and the survey is anonymous.

What is the first half of your postcode (E.g. NR18)?

☐

How old are you?

☐

What is your gender?

- ☐ Male
- ☐ Female
- ☐ Non-binary
- ☐ Genderfluid
- ☐ Genderqueer
- ☐ Intersex
- ☐ Prefer not to say
- ☐ Prefer to self-describe:

Do you consider yourself to have a disability?

- ☐ Yes
- ☐ No
- ☐ I'd rather not say

What is your ethnic group?

Arab:

- ☐ Arab

Asian / Asian British:

- ☐ Bangladeshi
- ☐ Chinese
- ☐ Indian
- ☐ Pakistani
- ☐ Any other Asian / Asian British background

Black / Black British:

- ☐ African
- ☐ Caribbean
- ☐ Any other Black / Black British background

Mixed / Multiple ethnic groups:

☐ Asian and White
☐ Black African and White
☐ Black Caribbean and White
☐ Any other Mixed / Multiple ethnic groups background

White:

☐ British / English / Northern Irish / Scottish / Welsh
☐ Irish
☐ Gypsy, Traveller or Irish Traveller
☐ Roma
☐ Any other White background

Other:

☐ Any other Ethnic Group
☐ Prefer not to say

If other, please specify:

Appendix 3: Survey Respondent Demographics

		Percentage of Respondents	Number of Respondents
Age	36-45	8%	2
	46-55	16%	4
	56-65	36%	9
	66-75	12%	3
	76-85	4%	1
	No Answer	24%	6
Gender	Male	16%	4
	Female	76%	19
	No Answer	8%	2
Ethnic Group	British / English / Northern Irish / Scottish / Welsh	76%	19
	Any other Asian / Asian British background	4%	1
	Any other Mixed / Multiple ethnic groups background	8%	2
	No Answer	8%	2
	Prefer not to say	4%	1
Do you consider yourself to have a disability?	Yes	20%	5
	No	60%	15
	I'd rather not say	8%	2
	No Answer	12%	3

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