Adult Social Care for the over-65s

Report for Norfolk County Council

July 2024

healthwatch Norfolk

Contents

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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.

Summary

This is a report on the first year of a three-year project, commissioned by Norfolk County Council. The project is focusing on areas of current and expected high demand for adult social care for the over-65s in Norfolk. It focuses on three main areas of people's experiences: how well older people are listened to by adult social care, adult social care's role in hospital discharge, and experiences of adult social care after a dementia diagnosis.

We used a mixture of in-depth interviews with people receiving support, their Carers and professionals, and a survey. We interviewed 61 people receiving services and their Carers, 30 health and social care professionals, and received 270 responses to the project survey.

In the listening theme, we found that most people felt well listened to by social care services, and were happy with the information that they were provided. A minority had less positive experiences. For example, 14 per cent felt that they were not understood when first contacting Adult Social Care, and 14 per cent had problems with understanding or discovering their care options during their needs assessment. People told us in the in-depth interviews that they wanted help to navigate the large number of organisations and services in the sector, and wanted to know what social care could offer them, so that they would know what to request. They also wanted professionals to guide them through the information, and wanted information about how much they would have to pay for care when the time came for them to pay for it.

Most people were happy with their Care Act Assessments, but a 19 per cent of respondents (26 people)told us that not all of the people they wanted were involved in their assessments. Ten people in the in-

depth interviews told us thatthey thought they had been signed-off too early after their assessment, and wanted someone to check in with them to see if their care package was working well.

The NHS is the lead partner in discharging patients from hospital, and is responsible for ensuring that patients and their Carers are involved early in discharge planning conversations. We found that much progress remains to be made in this respect, as significant proportions of people said that neither they (33 per cent or 31 people) nor their Carers (46 per cent or 37 people) had been consulted about what care (if any) they would receive after leaving hospital. 48 per cent (58 people) said that they did not receive information about care in good time for their discharge. Women were significantly more likely to be unhappy with discharge communications. People also reported some miscommunication over who would pay for their care after they left hospital.

On dementia, we asked people about their experiences of receiving support after they had been diagnosed with a condition. We found that significant proportions of respondents felt that there was insufficient support to learn more about their future (33 per cent or 22 people), or support to plan for the future (47 per cent or 32 people). People told us that they wanted more information on the progression of their condition and on who would pay the costs of care, and regular check-ins from professionals. Some people mentioned problems with care providers commissioned by the local authority, particularly with domiciliary care agencies' performance in caring for people with dementia and a mental health condition. Many people and their Carers also reported that they had lost most or all of their social connections since they had developed a care need (61 per cent or 71 people).

We make a number of recommendations based on these findings, focusing on the three main areas of the project.

To improve listening we recommend that new ways of providing people with information on the adult social care 'offer' could be considered, including providing hard-copy information as well as more timely information on who will pay for people's care. For the longer-term, we also recommend more check-ins from professionals and that recent efforts to ensure all the people who need to are involved in assessments are reviewed in future project years.

To improve the hospital discharge process, we suggest that patients and their Carers are consulted explicitly and early about their care options and how care will be paid for, and their preferences written down. We also propose that the engagement project investigates the gender disparity in these findings in order to identify possible causes and solutions.

To improve people's experiences after a dementia diagnosis, we suggest more learning support to be given to people upon diagnosis, especially about the progression of their condition, and about how care will be paid for. We also recommend check-ins from professionals, and measures to help people to stay socially connected, including replacing support groups where these have had to close.

Why we looked at this

Healthwatch Norfolk was commissioned to undertake this project by Norfolk County Council's Adult Social Care department. We were asked to deliver a rolling programme of engagement with people over 65 receiving support, their Carers and staff, over a three-year period. The project is looking at three main themes:

1. How social care services listen to older people and respond to their views.
2. How social care supports people to leave hospital and to find sustainable placements in the community (whether in their own home or not).
3. What support people with a dementia diagnosis, and their Carers, need, and what role social care can play in supporting them better.

These three themes were selected because they are areas of current high demand for social care, and areas in which demand is expected to rise. The global population is ageing, and the world is facing unprecedented challenges stemming from the proportion of people who are older, and the length of time people are living (Buch, 2015). These changes mean that the question of care and caring is a fundamental challenge faced by many nations.

In the UK, at the last census, 19 per cent of the UK's population was aged over 65 years old, and had an average (median) age of 40 years old. In Norfolk, 24 per cent of the population (or 223,762 people) was over 65 (Subnational ageing tool, Office of National Statistics). The average age was significantly above the national median in all areas of Norfolk except Norwich:

Table 1

Average ages, percentage of population over 65 and Old Age Dependency Ratio in different areas of Norfolk

Area	Average age	% of population over 65	Old Age Dependency Ratio[1]
UK	40.3	19%	288
Norwich	33.5	15%	217

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[1] The Old Age Dependency Ratio compares the number of people over the state pension age to the number under it. More specifically, it refers to the number of people of the state pension age and over for every 1,000 people aged between 16 years and the state pension age.

Broadland	48.1	26%	435
North Norfolk	54.3	33%	607
Kings Lynn and West Norfolk	47.9	26%	453
South Norfolk	46.2	24%	403
Breckland	46.8	25%	424

Source: Subnational ageing tool, Office of National Statistics

Norfolk's older population is expected to rise significantly in coming years. The ONS projects that by 2040, 30 per cent of the population (308,140 people) will be over 65.

In 2022-2023 the number of over-65s receiving long-term social care support in Norfolk was 10,900, and the number accessing short-term care in order to maximise their independence, was 5,500. There were around 30,400 new requests for care and support from people over 65, which is slightly higher than the national average rate of requests (NHS England).

In recent years, demand for social care has gone up and people's needs have become more complex, as the UK population has aged. Social care costs have also been increased by high inflation rates, challenges in recruiting staff, increases to the National Living Wage, and the challenges faced by the NHS. Meanwhile, social care departments have been asked to make significant savings from their budgets (ADASS, 2023). Analysis by Age UK suggests that, in 2019, an estimated 1.6 million people over 65 had unmet needs for care and support (Reeves et al., 2023).

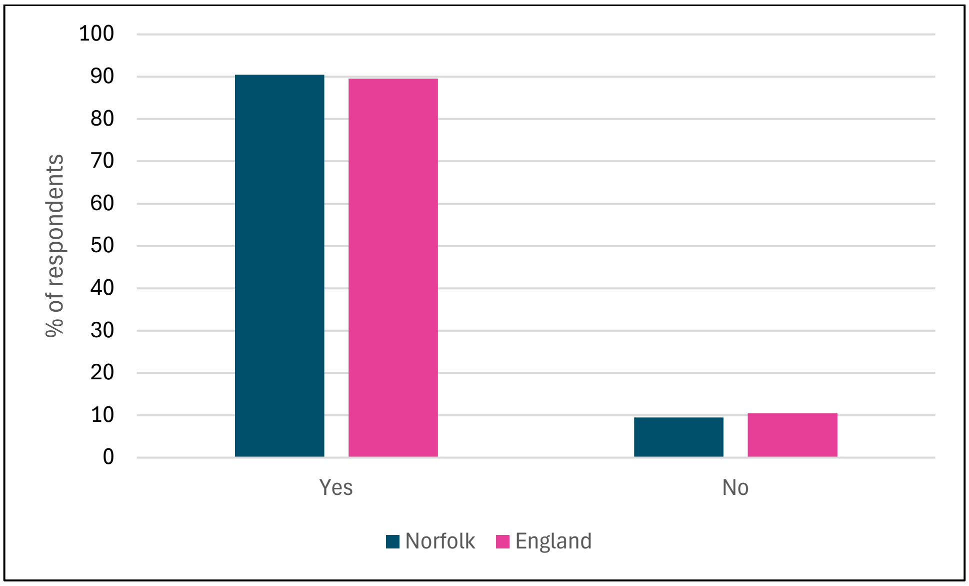

Figure 1: Do care and support services help you to have a better quality of life? Percentage of respondents

Source: NHS Digital https://digital.nhs.uk/data-and-information/publications/statistical/personal-social-services-adult-social-care-survey/england-2022-23

In the 2022-23 survey of people over 65 receiving support from Adult Social Care in Norfolk, 90.5 per cent of respondents (238 people) said that it helped them to have a better quality of life, which was almost the same percentage as for England as a whole.

It is in this context that this project is seeking the views of people receiving support and their partners, about which aspects of their support they are happy with, which aspects they are unhappy with, and what changes they would like to see. The objective of Year one of this project was to review older people's experiences of a wide range of different support across the county. This was to make recommendations about those areas, but also to identify particular areas where people were experiencing particular problems, that increased engagement with people in years two and three could help find ways to improve.

There were a number of areas we wanted to address in each part of the project, which are summarised in the following sections.

Older people's voice, choice and rights

In this project theme, the aim was to try to understand at quite a general level how, and how well people were listened to, and responded to, when they had contact with social care services and with associated services commissioned by adult social care, such as care homes and domiciliary care agencies. As with the other parts of the project, we started with semi-structured interviews with people receiving support and their Carers about their experiences, and used these to develop the themes we would pursue in the survey.

People's experiences of trying to have their voices heard by adult social care is inevitably shaped by what they know about social care services, and what they think their options are. Under the Care Act 2014, local authorities have a duty to provide information about how social care services work, what people's options are, and options for funding their care. There is also a duty to help people to understand these options (Reeves et al., 2023). The chart below, based on the results of the 2022-23 survey of people supported by social care in England, shows how easy or difficult people over 65 in Norfolk found it to find information and advice about support, services or benefits, compared to older people in England overall:

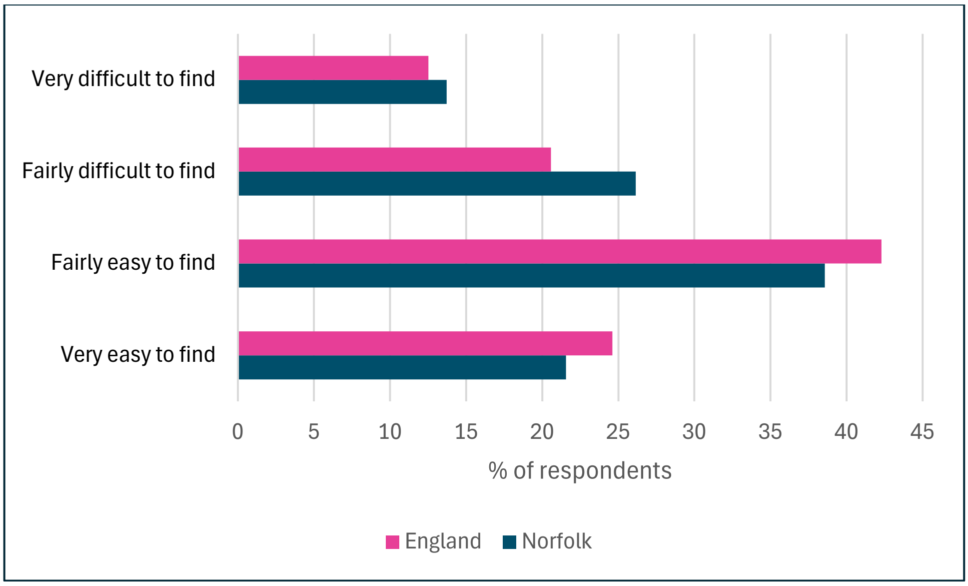

Figure 2: In the past year, have you found it easy or difficult to find information and advice about support, services or benefits?

Source: Personal Social Services Adult Social Care Survey, England, 2022-23, NHS Digital

As the chart shows, respondents in Norfolk found it harder to find information and advice than respondents in England as a whole, with 40 per cent of people finding it fairly or very difficult, compared to 34 per cent nationally, and 61 per cent finding it fairly or very easy, compared to 67 per cent nationally.

The same survey also asked people whether they felt that they have choices about the care and support services they receive. Although this is a slightly different question than about how well people felt they were listened to by services, it does tell us something about how much control they felt they were able to exert over their support. As the following chart shows, a slightly greater proportion of people in Norfolk (33 per cent) said that they did not have enough choice over their care and support services, than the average for England as a whole (29 per cent).

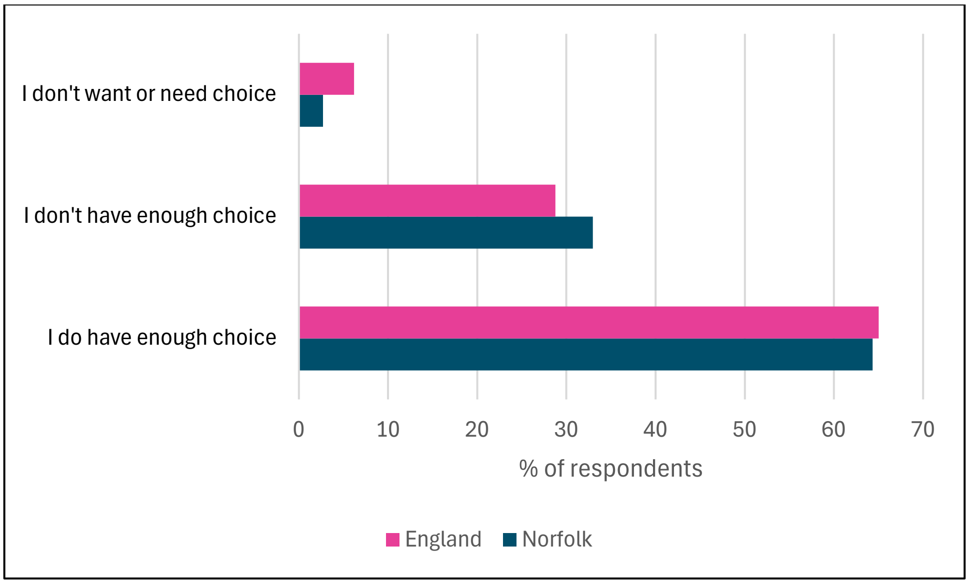

Figure 3: How much choice do you have over the care and support services you receive?

Source: Personal Social Services Adult Social Care Survey, England, 2022-23, NHS Digital

On the other hand, a slightly greater proportion of people in Norfolk (82 per cent) felt that their care and support services helped them to have control over their daily lives, compared to the average for England (80 per cent).

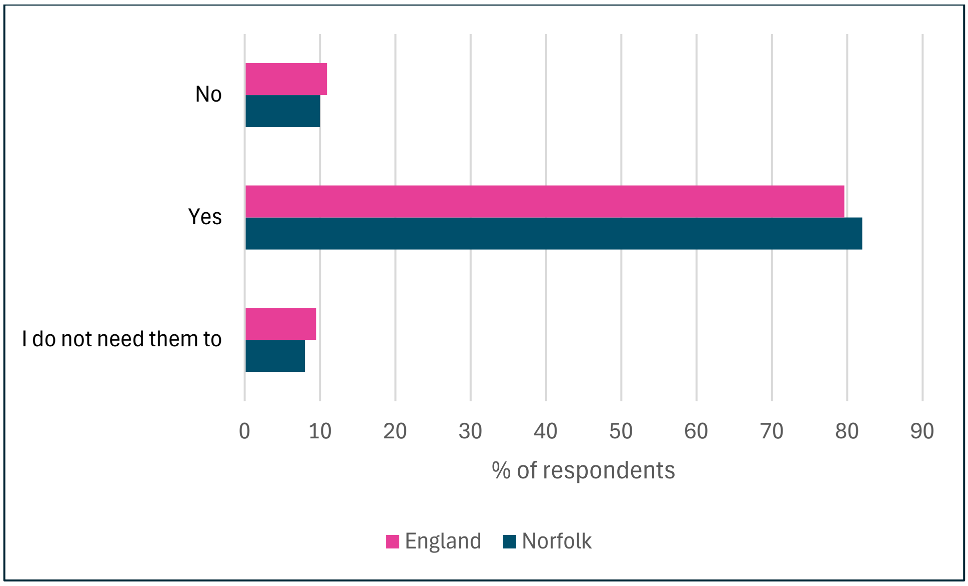

Figure 4: Do care and support services help you in having control over your daily life?

Source: Personal Social Services Adult Social Care Survey, England, 2022-23, NHS Digital

In this part of our project, we sought to go beyond these questions, to elicit more detailed information about people’s experiences of certain key aspects of people's 'journey' with adult social care, where they should have the opportunity to have their voices heard. These were:

1. People's first contacts with adult social care.
2. Participating in a needs assessment or annual review.
3. Receiving social care services.
4. Contacting adult social care with the assistance of a voluntary sector organisation.

The first three of these questions were tackled using qualitative and quantitative data from people receiving support and their Carers, the last one was mainly tackled by asking voluntary sector professionals about their experiences of contacting adult social care services on behalf of a member of the public.

Social care's role in hospital discharge

Delayed hospital discharges have long been a policy concern in the UK, due to the negative consequences for health and social care services, and their impact on patients' health and wellbeing. This is a particular concern for older people: over 40 per cent of hospital admissions in the UK are of people over 65, and around two-thirds of hospital inpatient beds are occupied by people from this age group (British Geriatrics Society, 2023).

Research has found that delayed discharges can have a wide range of damaging effects on older people, including hospital-acquired infections, fractures, urinary tract infections, confusion and depression, was well as often leading to a long-term decrease in health and capacity (or "deconditioning"), leading to a greater risk of having to be admitted to a care home after discharge, and may also lead to greater dependence and social isolation (Landeiro et al., 2019).

To attempt to help people to leave hospital earlier, NHS England began to implement the 'discharge to assess' model in 2016, and in March 2020, the government began requiring acute and community hospitals to discharge patients as soon as it was medically safe to do so (Willett et al., 2020). The objective is to provide people who no longer need to be in hospital, but who may still need assistance to leave hospital, with short-term support in their own home or in another community setting, for the purposes of recovery or reablement. Their social care needs would then be assessed by a professional shortly after discharge while they were in a community setting, rather than while they were in hospital.

People are discharged on four different "pathways". The NHS is the lead partner in discharging patients from hospital, and acute hospitals identify which patients are likely to need support when they leave hospital. It is estimated that around 50 per cent of patients are discharged on pathway 0, with no or minimal support, 45 per cent on pathway 1, with support from community health and social care services (usually in their own homes), and 5 per cent on pathways two and three, usually to a care home or nursing home (Healthwatch England & British Red Cross, 2020). The decision-making process involves co-operation between acute and community hospital staff and integrated teams in a "Home First Hub", based away from the hospital, including clinical leads, practise consultants, occupational therapists, physiotherapists, community assistant practitioners and social care assistant practitioners.

Delayed hospital discharges are still a problem nationally, including in Norfolk. The chart below gives a snapshot of the number of people who were still in hospital in Norfolk and Waveney in May 2024, despite no longer meeting the medical 'criteria to reside' in hospital.

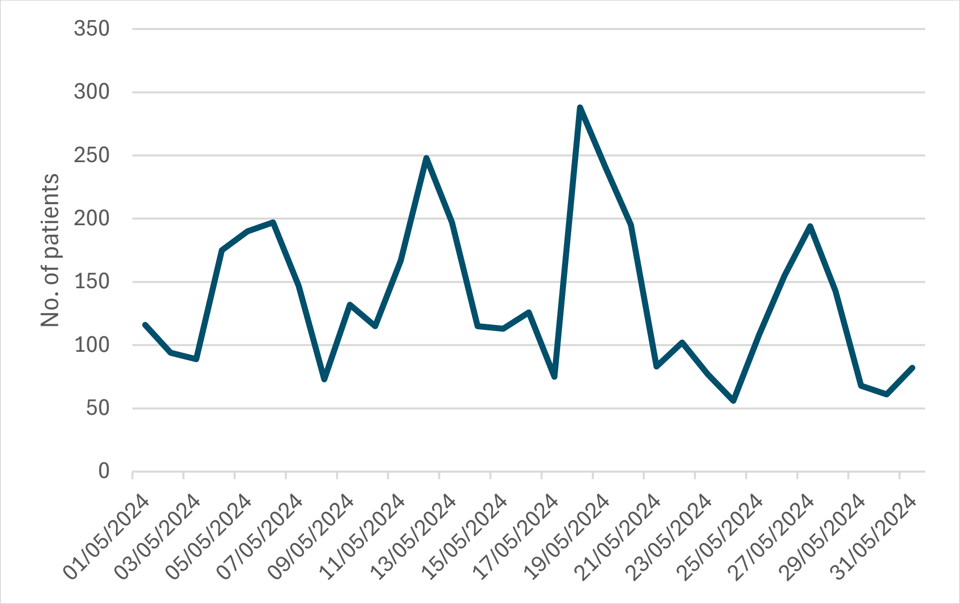

Figure 5: Patients remaining in hospital in Norfolk and Waveney without criteria to reside

Source: Acute daily discharge situation report, NHS England

In terms of where patients were discharged to in May 2024, most patients – 6,301 - were discharged to their own homes, without any reablement support. The others were discharged to the following settings:

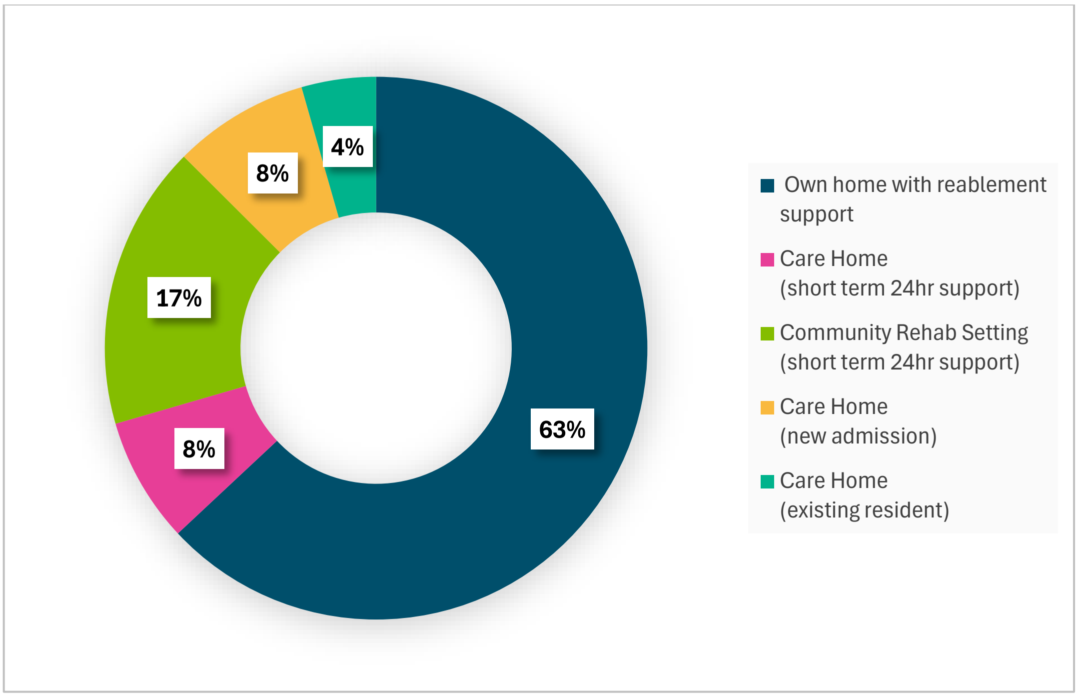

Figure 6: Patient discharge destinations, Norfolk - May 2024

Source: Acute daily discharge situation report, NHS England

The following table gives a snapshot average from one week in May 2024, of how many people per day had stayed in hospital more than 14 days who no longer met the criteria to reside, but had not been discharged. It shows what they were waiting for before they could be discharged (or other reasons for the delay):

Table 2: Status of cases of delayed discharge, Norfolk and Waveney, May 2024

Waiting for	Number of people
A medical decision/intervention	4
Community equipment/housing adaptations	2
Medicines to take home	2
Therapy decision	3
Transport	3
Person/family not in agreement with discharge plans	2
No discharge plan	3
Confirmation from discharge hub that referral received	34
Referral to discharge hub	13
Resource for assessment and start of care at home	51

Rehabilitation in community hospital or similar	73
Bed in residential or nursing home (likely permanent)	53

Source: Acute daily discharge situation report, NHS England

As the table shows, there remain challenges in meeting needs across all discharge pathways, including intermediate care, where someone needs a long-term placement, and in some discharge processes between the hospitals and hubs.

Healthwatch England carried out research with patients on their experiences of discharge to assess in 2020, and again in 2023 (Healthwatch England, 2023). In 2023 it identified a number of ongoing issues:

- Nearly one third of people felt unprepared to be discharged, with Carers more likely to say that they did not feel prepared (44 per cent of carers vs. 25 per cent of patients).
- 51 per cent of people were not given contact information for accessing further help or advice when leaving hospital.
- 24 per cent said their experience of discharge was excellent, and 37 per cent said they had a mixed or neutral experience.

In this context, the project has tried to understand how well the discharge to assess process is being supported by social care in Norfolk, by talking to both professionals and people receiving support. We set out to answer the following questions by talking to professionals:

- How well do professionals in health and social care think integrated working is functioning?
- How do different categories of professional assess the risks of discharge for different patients, and how does this affect the discharge process?
- What has been the impact of having fewer social care professionals and less local authority representation in hospitals?

When talking to patients, we wanted to understand the role that social care could play in supporting them at all stages of their journey, from before they were admitted to hospital, through to their ‘exit from the discharge pathway’, meaning some kind of long-term living arrangement in a community setting. More specifically, we wanted to find out:

- How could adult social care or voluntary sector organisations have helped to prevent admission?
- What was the relation between pressure on Carers and the causes of admission?
- How well are Carers communicated with during the hospital stay, to help them support discharge?
- Are patients' preferences for discharge heard and recorded?
- What are patients' and carers' experiences of integrated working?
- How do they experience decision-making processes during the discharge process?
- What does a successful discharge process look like for service users and their carers?
- What kind of support could have allowed an earlier discharge?
- What is people's experience of having a needs assessment at their community placement after discharge?

Social care support for people with a dementia diagnosis

A growing number of people in the UK have been suffering from dementia, and the number of people living with dementia is set to rise. 944,000 people are estimated to be currently living with dementia, and this number has been projected to rise to one million people by 2030, and 1.6 million people by 2050 (Luengo-Fernandez & Landeiro, Forthcoming). 1 in 14 people over the age of 65 are estimated to have dementia in the UK (Wittenberg et al., 2019), and 65 per cent of people living with dementia in the UK are women (World Health Organization, 2021. All statistics in this paragraph cited at https://dementiastatistics.org/about-dementia/prevalence-and-incidence/).

In Norfolk and Waveney, 11,030 people over 65 have received a dementia diagnosis. However, many people have dementia but do not have a formal diagnosis, and there are estimated to be around 17,946 people over 65 living with dementia in Norfolk and Waveney (NHS Digital). All people with dementia are supposed to have an annual review with their GP, where the doctor should ask questions, review medication needs, check for new symptoms, and discuss planning ahead and how Carers might be best supported. In Norfolk and Waveney, 39.2 per cent of Carers reported having had an annual review in 2022 (Fingertips Public Health data). NHS Digital data from the latest Survey of Adult Carers (2021-22) suggests that dementia has a significant impact on Carers, with 66.2 per cent in Norfolk and Waveney saying that they felt stressed, 27.1 per cent saying that they felt socially isolated, and 41.4 per cent saying that they spend more than 100 hours a week supporting their cared-for person (NHS Digital; all statistics in this paragraph are cited at https://www.alzheimers.org.uk/about-us/policy-and-influencing/local-dementia-statistics).

In this context, in which dementia is so widespread and people and their Carers are so severely affected by it, we wanted to better understand the experiences of people with dementia in Norfolk, and their Carers, in order to understand any opportunities for ASC to support people newly diagnosed with better advice, information and support to people to make their own plans and know who to contact when needed in the future.. More specifically, we wanted to discover:

- The experience of people with dementia (and their Carers) who are using NCC-commissioned social care services (domiciliary care, residential homes and nursing homes)
- What challenges people living with dementia and their carers face, including:
    - Knowing more about their dementia
    - Planning for the future
    - Being supported to be involved in decisions about their lives
    - Maintaining relationships and connections to their local community
    - Support to carers
    - Managing behaviours that may challenge others
    - Living positively with risk

The next section gives details on how we collected data on these three topic areas.

How we did this

The main objective of this project is to understand the experiences and wishes of people over 65 who are receiving support from Adult Social Care. We therefore started with a broad approach which would allow us to understand what mattered most to people in the three project areas, or what people were particularly struggling with, and to use this knowledge to do more focused research in years two and three of the project.

We therefore took an approach in year one that started with quite broad, exploratory, in-depth interviews with people receiving support and their Carers, which gave us an idea of what issues were important to people. We then used the results of these interviews, along with the three project themes, to plan a survey to try to understand how a larger number of people across the county were experiencing these issues.

In-depth interviews

We aimed to complete 20 in-depth interviews for each of the three project themes, trying to recruit respondents from across the county and different demographic groups. Our recruitment strategy sought to take account of how older people tend to access information, where they spend time, and the sorts of social networks that they inhabit. This meant some focus on using digital platforms to recruit people, but also focusing on organisations working with older people and trying to speak to people in person.

We used the following digital avenues to try to recruit interviewees, including both our own methods and enlisting the help of voluntary sector partner organisations:

- Healthwatch Norfolk website, social media and newsletter
- Carers Voice newsletter
- Community Action Norfolk
- Norfolk Anglican Diocese
- Individual church mailing lists

The following organisations also circulated interview invites (including project flyers) to their clients in person:

- Age UK Norwich
- Age UK Norfolk
- Assistive Technology team (NCC)
- Sensory Unit (NCC)
- West Norfolk Deaf Association
- Community Action Norfolk
- Hanseatic Union
- North Norfolk District Council community connectors

We also carried out our own visits to the following venues, in order to meet people and arrange interviews for a later date, either on the phone or in-person:

- Libraries
- Church events
- Community lunches and community cafés
- Sheltered housing communal area events
- Supermarket (Iceland over-60s event)
- Food banks and social supermarkets
- Multiple visits to the discharge lounges of the Norfolk and Norwich University Hospital, Queen Elizabeth Hospital, and the James Paget University Hospital
- North Walsham Hospital

The in-depth interviews for the dementia theme were carried out by Carers Voice on behalf of Healthwatch Norfolk. 21 of these interviews were carried out, and interviewees were recruited through Carers Voice's own communications and newsletter lists. A separate report from these interviews was produced by Carers Voice, and is included in the annex to this report.

These interviews began with very broad questions, to give interviewees the chance to raise any issues that they thought were important – for example, "Could you tell me what led to you approaching adult social care in the first place?" They were then asked a series of questions based on the project themes and research questions detailed in the previous section. 61 interviews were carried out in total.

The interviews were transcribed using rev.com's transcription service, and these interviews were coded using NVivo, starting with open coding, in order to capture any and all issues that interviewees raised. Common themes, and their sub-themes were then identified from these issues, and these form the basis of the qualitative themes discussed later in the report.

Survey

The survey questionnaire was developed, using a mixture of the themes identified in the qualitative interviews, and questions based on the project themes. The questionnaire included a mixture of closed multiple choice and open-ended questions. The questionnaire was developed to be dementia-friendly in how the multiple-choice options were formatted (except for the questions to be answered by Carers). The online version of the survey was put on Smart Survey online, and a paper version was also produced. An Easy Read version was available upon request. The paper version of the survey is included in the annex of this report.

The survey was distributed using a mixture of online methods for the digital survey. These included:

- GP Footfall websites, and SMS messages sent out by GP practices in East Norfolk
- Healthwatch Norfolk website and social media
- Targeted Facebook adverts for people likely to be Carers for their parents
- Through Patient Participation Groups in GP surgeries
- Parish clerks
- Voluntary sector organisations email lists and websites
- West Norfolk Borough Council housing
- Ask Lily website

Hard copies of the survey were distributed through:

- A mailout from NCC's Living Well service, to people who had recently had a Care Act Assessment or annual review
- Care homes
- Day centres
- Copies of the survey were available to pick up at all Norfolk libraries
- Great Yarmouth Borough Council sheltered housing communal spaces

Demographics

The survey was completed by 270 people. The demographic profile of people filling in the survey was as follows:

- 57% Carers; 43 % people receiving support
- Gender: 60% women; 37% men (3% prefer not to say)
- Health conditions and disabilities:
    - 33% had a disability

  - 61% had a long-term health condition
  - 26% had dementia
- Ethnicity:
  - 95% White British
- Age:
  - 65-74: 43%
  - 75-84: 39%
  - 85-94: 15%
  - 95+: <1%

The geographical spread of responses across the county was as follows:

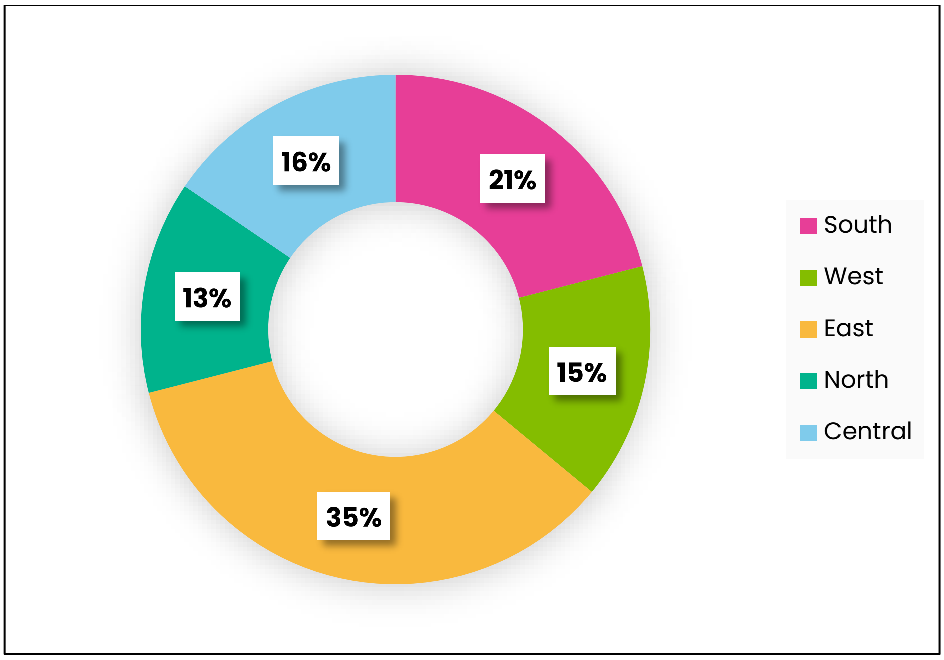

Figure 7: Geographical spread of survey responses across Norfolk

The data was downloaded, cleaned and analysed using Microsoft Excel, apart from the open text responses, which were coded using Smart Surveys analysis function (and excluding the non-eligible responses). The responses to all questions are reported in the "What We Found Out" section below.

Ethical considerations

This project was not put before an ethical scrutiny committee, because according to the Health Research Authority (HRA), it does not constitute formal research, and therefore does not require ethical scrutiny (see the HRA decision tool here: https://www.hra-decisiontools.org.uk/research/).

However, care was taken to ensure that consent was obtained from all people participating in the research. Participants were told what the information would be used for, how long it would be kept before it was deleted, and that they would be able to withdraw their consent to participate at any time before publication of the report. People were made aware that all responses would be anonymised, and any identifying information removed before it was mentioned in the report. The data was stored in password-protected hard drives, and hard copy survey responses were stored in a locked drawer at the Healthwatch Norfolk offices. The data collected will be deleted at the end of the project, and participants were made aware of this.

People participating in the interviews were signposted to a range of different services after the interview ended, to help them to find support with the issues they raised during the interview.

Limitations

Respondents to our interviews and survey were not randomly sampled across the population and do not wholly match the demographics of the population. The number of survey responses we received (270) also mean that the sample would not produce statistically significant findings. There were 223,900 people aged over 65 in Norfolk in 2021 (2021 census figures, Norfolk Insight).

Some groups are over- and under-represented in the survey responses. The most significant of these are that 60 per cent of respondents were women and only 37 per cent were men, whereas in the population of Norfolk, 53 per cent are women and 47 per cent are men (2021 census figures, Norfolk Insight). In terms of geographical coverage, it seems that East Norfolk is over-represented in responses, and Norwich is under-represented. In addition, no-one who cannot speak English has shared their experiences with us, and nor has anyone who is homeless.

Given the characteristics of the population group that we were trying to speak to, it is likely that many of these people were either inaccessible to us, or were unable to speak to us. People who were socially isolated, for example, were harder to reach for in-depth interviews, and people with cognitive impairments or severe dementia would be unable to speak to us. This is perhaps why most of our survey responses came from Carers, rather than people receiving support themselves. This could also mean that people with no living relatives were less likely to be represented in the project.

Nevertheless, the project’s findings do give us significant insight into the experiences of a wide range of different people’s experiences, and provide a strong indication of what issues in the system are likely to be most important for different categories of the population.

It is important to note that health and social care responsibilities are often shared across the NHS, primary care, adult social care and the voluntary sector, and are delivered in an integrated way. As a result, it can be difficult for people and their Carers to distinguish individual providers’ responsibilities. The feedback we gathered was therefore not always specific to adult social care, but is valuable nevertheless, and can be used to make system improvements.

What we found out

Listening

First contact with adult social care

For many people, their first contact with adult social care is through the main customer service phone line for adult social care, which is staffed by the Social Care Community Engagement team (SCCE).

We asked two questions about this service in the survey, the first being "How easy was it to get through to the service you wanted to speak to?" Most people who answered this question said that it was either "Easy" or "Neither difficult nor easy" to get through to the right service (65 per cent or 76 people out of 117). Around one third of people said that they had found it difficult to get through. These proportions were mostly similar across different population groups, with the exception of Carers for people with dementia, 44 per cent of whom (14 out of 32) found it difficult to get through.

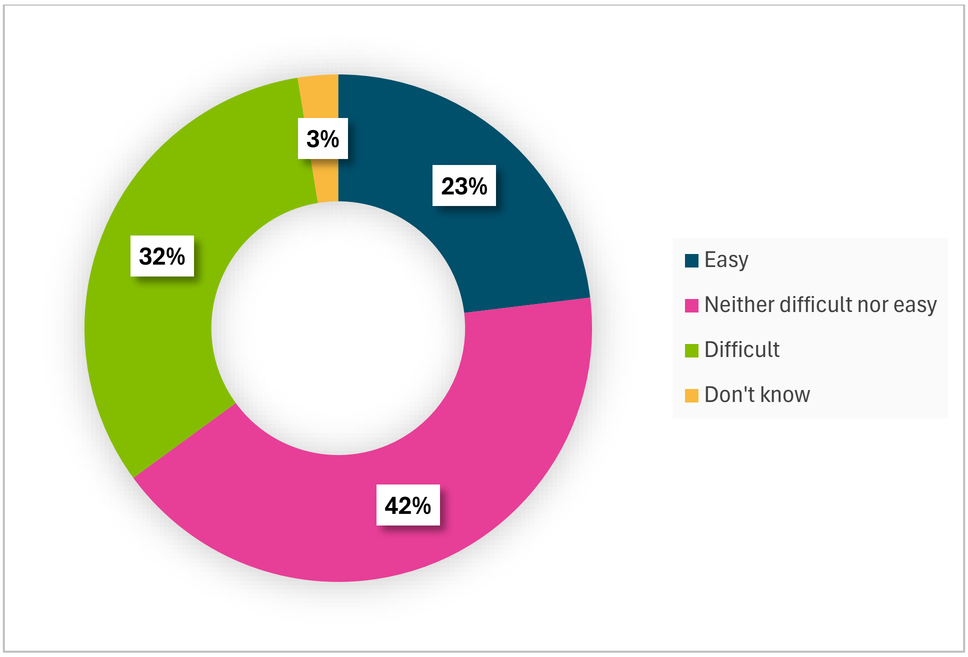

Figure 8: Q4. How easy was it to get through to the service you wanted to speak to?

The second question that we asked here was, "Did you feel the person you spoke to understood what you were trying to tell them?". A large majority of people answering this question thought that they were either well or adequately understood – 80 per cent (or 92 people). Of these 32 (28 per cent) felt that they were understood well, and 60 (52 per cent) felt that they were understood adequately. 16 people (14 per cent) said that they were not well understood.

Twelve people gave us some more information about what they felt the service had done well. People were happier when they were confident they had been listened to. For example, one person said, *"They went over what I had said so this reinforced to me they had understood what I had said to them".* Others replied simply that they were happy because they were able to easily get the information they were seeking or the help that they needed. One person singled out the empathy they felt from the person they spoke to: *"As I get older, [there's] so much to think about, plus caring for someone 24/7, it's nice to speak to someone who understands what you're going through".*

For people who were not happy, the most-mentioned difficulty was not being understood, or not listened to. From the caller's point of view, it was not always clear which was the case. As one person said, "I am unsure if they chose to ignore what I was saying rather than not understand." The other frequently mentioned difficulty was getting through to the service people wanted to speak to, reasons including high demand on services, being put straight through to voicemail, or the caller misinterpreting the options given to them at the beginning of the call and going through to the wrong department.

We also asked more general questions about people's experiences of contacting adult social care (whether through the SCCE service or not). In the survey, we asked people how long they had had to wait for someone to get back to them after their first contact. For around a third of people, this was not relevant, presumably because their query was resolved during their initial contact. Of the other people answering this question (135), 43 per cent (58) waited 1-6 days, 37 per cent (50) waited 1-3 weeks, and 20 per cent (27) waited four weeks or more. We asked people what the impact was for them of waiting a long time for a response, and for the 61 people who answered this question, nine people said that there was no significant impact, but 12 others mentioned the impact of the worry and stress of waiting, 11 mentioned the impact of having their needs unmet for a period of time, and six mentioned the workload of having to chase up a response.

Seven people mentioned having to provide care for a family member whilst waiting for support, and of the stress this caused them. One person wrote:

“Giving my parent 24 hr care by myself without any experience. I was afraid doing things wrong, I suffer from a bad back and I was lifting without any help. My mental health was on a low, [it] was constant. I [was] worrying all the time, I was away from my family for 10 days, I had to book time off work. It made a negative impact on my life.” For three people, this situation led to a family member experiencing a crisis or injury that could have been avoided if help had been accessed sooner.

In the in-depth interviews we carried out, people spoke in more depth about some of the impacts waiting times can have, and an important theme for some was the financial impact of waiting to be assessed for financial support. One person told us, “*I contacted them in probably January, February, and I kept on contacting 'em up to March and that's when I thought, oh, this is ridiculous. I've got to get the work done. So, I just went ahead and started doing the work, knowing very well that if I did the work before I got approved, any loans or anything, you don't get the money back.*”

For some people, the reasons for these delays seemed to be the scale of demand on the system. For others, it was related to miscommunications within adult social care, or between adult social care and other services. One person told us about a situation where the full details of a financial dispute were not being communicated between the finance department and NP Law (NCC’s legal firm), when it could have been easier for him to talk directly to a solicitor:

> Well, this is a very arm's length discussion because I haven't been able to talk directly to the lawyer who's given this advice. All I have been able to do is to talk to people in the finance team … my wish is that we could have a professional discussion between two people who know what they're talking about to debate the issue and actually come to an agreement that both people respect.

Other people told us about miscommunications between different services, such as between adult social care and care agencies (“*he said that, oh, it was left because an agency had been told to be in contact with me, but they never did*”) and between GPs and ASSD.

Another important theme that came up in the in-depth interviews was the sharp learning curve that people experience when they first get in touch with adult social care. For many older people and their Carers, they have never had any contact with social care services until they are older, and many people told us how difficult it was to understand how the system worked at first. As one Carer told us:

> I mean, there's so much rigmarole that ordinary people are unaware of, all these different things because we've never met up with any of this before. Some people have had sick people to deal with all their lives or what benefits you get for this, that and the other. I mean, it has just not been part of our lives. As I say, you're in at the deep end, but you're not sure where you're going. You do need help along the way.

For some, an important initial difficulty was that they did not know what help adult social care could offer, and so did not know what to request. One person commented, *"I think the problem is you wouldn't know what you were looking for until it's put on a piece of paper and said, 'you can have this'. And you think, 'Yeah, that might be beneficial'. No, you wouldn't know."*

Other people mentioned that professionals use terms and refer to services with the assumption that people are already familiar with them, and people do not always feel confident to ask for clarification. "*It's a pity, really*," one person said, "*because it doesn't help the situation does it if you're not really sure of what they're on about, but you don't dare ask*."

In a related point, some people had the impression that, unless they used the correct terminology, they would not get the help that they asked for. At a group discussion at a dementia café, people discussed how they found it helpful to get assistance (in this case, from Age UK Norfolk) to fill out forms asking for help to make sure that they used the right words to get help – but that this help should not be necessary.

Another person had the impression that, "*they [adult social care] just follow protocol and don't use their initiative. You have to jump through their hoops*." As mentioned, above, most people in the survey felt that they were listened to well or adequately, but where this did not happen, problems seemed to arise when protocols and procedures were prioritised over a more holistic approach to listening. One person, who had over a decade of experience as a Carer for a family member supported by adult social care, commented:

> But, on the whole, social services, that must be an awful job they have to do anyway, if you know what I mean. So, most of the time that was very good from 'em and just the odd occasion where I think if they listened to what people were asking, rather than having this blanket thing where you can have this or no, you can't have, if they listened and judged each case on its own merit, so to speak.

Some people who did already have experience of the system, were concerned about how their experience might have differed under other circumstances. One carer remarked, "*My only concern is that my parents have got me and they've got my daughter to talk for them. And I would say if that was somebody on their own, that would be very difficult.*"

Another difficulty some people mentioned, was the large number of different services that were offered. There are many different NHS, social care and voluntary sector services offering support, and people told us that it was a significant challenge for them to navigate them. One Carer commented that, "*there's so many services that contact you like yourself. And I think the call that I've just had was somebody from Age UK or something. I'm sorry, but it gets like soup.*" This could get particularly difficult because different organisations could interpret situations in different ways. "*Each entity we went to had their own different interpretations of rules", one person said, "It was, oh, terrible*".

Where people had a more positive experience of this, it was when they had someone to guide them through this complexity, and people particularly mentioned advice provided by Age UK Norfolk, and by Alzheimer's UK support workers. Others mentioned that, while they were given information about services, there were still too many services for them to navigate alone, which seems to be why people found the advice of people who already know the system so valuable.

Care Act assessment and annual reviews

For people who receive support from adult social care, an important event in their journey is the Care Act Assessment. These are conversations between social workers and people seeking support, and often include people's family members or friends. They look at different aspects of someone's life, including aspects that they need support with, what is important to them in their lives, and what is good in their lives, including friends and family who support them. On the basis of these conversations, a care and support plan should be written with the assistance of a social worker. A personal budget will also be made, estimating the cost of the support needed, and a financial assessment will be carried out, which determines who will pay for the care.

In the survey, 147 people told us that they had undergone an assessment of their care needs in the past 18 months. The reasons given for undergoing an assessment are given in the table below.

Table 3: Reasons for needs assessment (respondents could select more than one)

Reasons for assessment	Number	Percentage
New medical condition	23	16%
An existing medical condition deteriorated	62	44%
Family Carer could no longer cope	27	19%
Due to being discharged from hospital with help from adult social care	34	24%
It was a review of my care needs	44	31%
Other	21	31%
Don't know	3	2%
Total respondents	104	

We asked people whether all the people were involved in the assessment that they wanted to be involved. Most people replied that they had, but a significant proportion (19 per cent, 26 people) replied that they had not, as shown in the chart below:

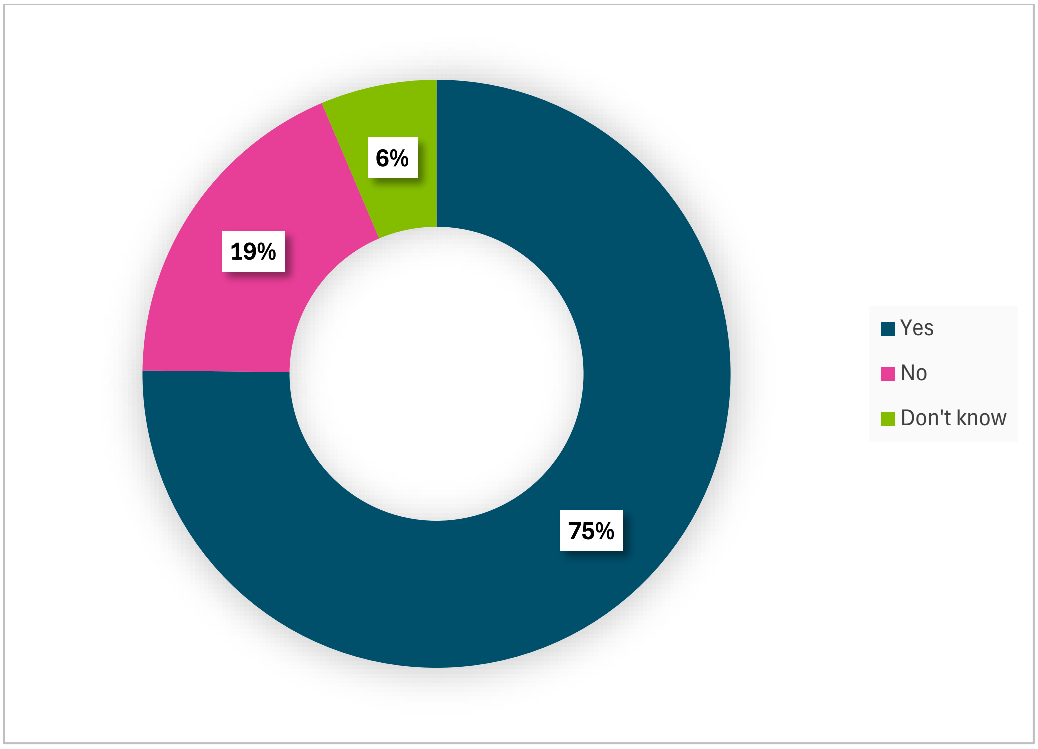

Figure 9: Q9. Were all the people you wanted to be involved in your assessment (such as a Carer, relatives or friends) included?

One person who we interviewed told us about the impact of being excluded from their relative’s (who had dementia) Care Act Assessment. This was perhaps an extreme case, but shows the sort of impact that not including the right people in the assessment can have:

> So anyway, basically I was totally, I felt sidelined, chopped off after 55 years of marriage. It was a terrible time … And I was thinking too, he's all alone in that respite with a social worker. He doesn't know [why he’s] being told his wife doesn't want him to come home. I mean, it was just horrible. I did try to actually speak with [the social worker]. I said, ‘Can I meet with you?’ And that was ‘no’. I mean, all of it was very cut and dried when we got to the appointed social worker. It was almost, ‘Okay, so you said you can't have him back home. Okay, now I'm in charge.’

We also asked people whether their care options were presented to them in a way that they could understand easily. The results are shown below:

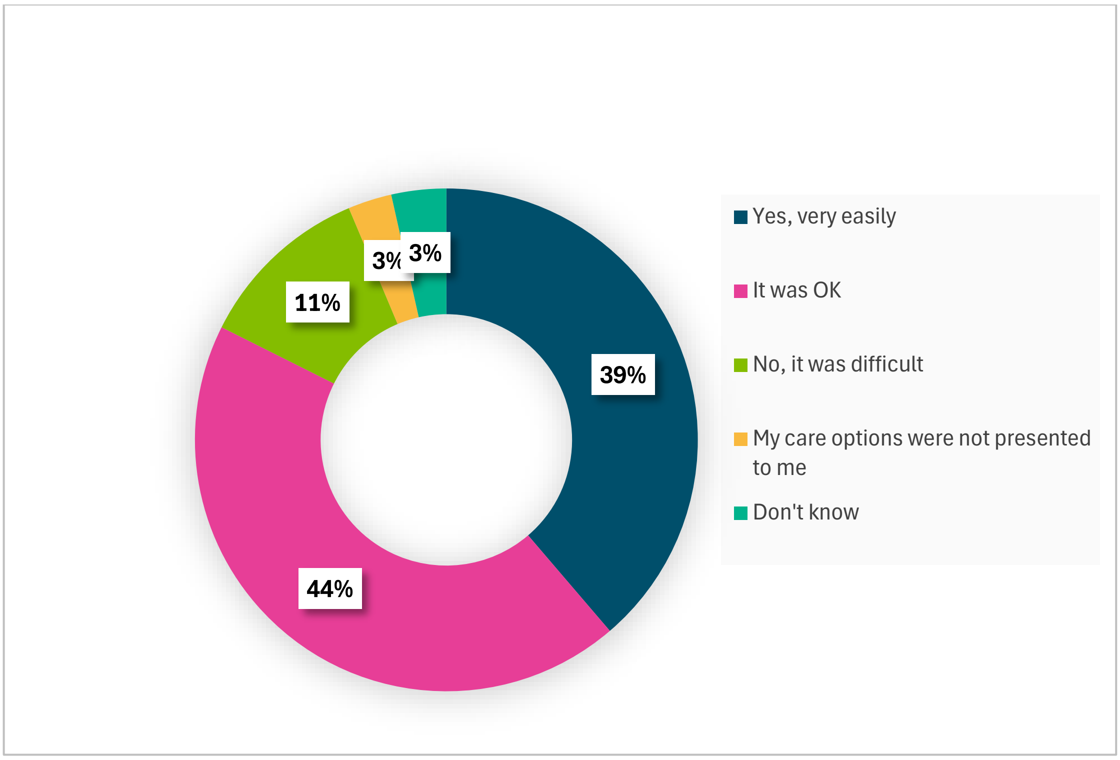

Figure 10: Q10. Were your care options presented to you in a way that you could understand easily?

A large majority of people, then, found that they could understand their care options – 83 per cent (117 people). There was some variation here between people receiving services and Carers. Fewer people receiving services found it difficult to understand their options (two out of 50 people, or 4 per cent), compared to Carers (14 out of 93 people, or 15 per cent). This number was higher for Carers of people with dementia (9 out of 41 people, or 22 per cent).

Finally, we asked people to suggest what would have improved their experience of their assessment. The most prominent responses were that people wanted to have more information on their care options, as they did not know what services that adult social care could offer, that they wanted a faster assessment process, and that they wanted to be listened to better, or with more compassion.

In the in-depth interviews, people generally did not have much to say about their assessments when they had gone well. However, one aspect that some people were keen to emphasise was a preference for face-to-face assessments, rather than doing them over the phone. People told us that they appreciate the effort and care that this demonstrates, and also that it helps to reduce misunderstandings. One person gave us this example:

People had more to say about the things they would like to see improved, and these points were often related to communication problems. Three people we interviewed were not aware that they were having their needs formally assessed. They told us that this was because they had a lot of different services coming in over the same time period, and were not always aware of which people were coming from which organisations.

Two Carers told us about communication problems between family members, the cared-for person and the social worker. In both cases, Carers had told the social worker sensitive information that was relevant to the assessment, but that they did not want the cared-for person to know about because they would find this upsetting. This had ended up in the written assessment which was sent to the relative. In one of these cases there was the additional problem that, in a case where the cared-for person deferred to her relative to tell the social worker many of the details of her situation, the social worker had not put these in the assessment, including details of problems with a care agency, changes in the person’s memory, and anxiety and medication problems.

A key theme of all of the feedback that we received on all topics was that people would have liked more follow-up contact after their main contact with adult social care. Ten people told us that they felt that they had been signed off too early, and would have liked someone to check in with them after their assessment, to see how the care package was going. For some people this was because their care package was not working well, and they would have liked to change things. One person told us that they thought it would have been too difficult to get someone to take up the case again after a sign-off, and so did not contact adult social care to tackle a problem. For others it was so that they would feel less alone, and like someone was looking after them.

Some typical comments were:

> “The social worker we did have at that time was someone from Norwich and then we only had so many weeks and then they disappeared and that was it.”
>
> “I wasn't left with a feeling that I could ring him again. I haven't got a contact that I can call.”

“The lovely social worker that we did have in Norwich, he was so good and then within about four weeks he was changed and they didn't have a replacement.”

“I don't know that they could have done, it's more somebody to talk to, isn't it? Well, you would, if you've got a social worker.”

For another person, whose mother had complex mental and physical health needs, she felt that a task-based approach to social work was not going to support her needs adequately. She said, “*it seems as though it's just, they've almost taken this ‘refer-allocate task-discharge’ attitude to people like Mum*”, when her condition is an ongoing and complex one, which cannot be resolved in a short period of time.

Financial assessments and disputes

We received feedback on a number of different topics associated with the funding of people’s care. These were often related to the functioning of specific care services, such as residential, domiciliary and reablement care, and these issues are covered in the relevant sections below. We also received some more general feedback in interviews about financial assessments and disputes, which are summarised in this section.

We heard from three people about the impact of delays to financial assessments, where they had resorted to paying for the care themselves while waiting for their assessment. This caused them considerable worry, because they were not sure whether they would be able to get this money back or not. For someone whose relative needed two carers to come in four times a day, it meant a large bill was accrued very quickly.

One of these people was waiting for a financial assessment for over nine months, and ended up paying for home adaptations for his wife, and resigned himself to paying for them, even though he was not sure whether he would have to. For two of these people, part of the problem was not receiving much information on how much they would have to pay, or how the systems worked, once their relative’s savings dipped below the threshold for receiving care funded by NCC. This level is currently set nationally at £23,250, and we heard from several people that they were told to re-contact social service once their savings reached this level, and were not offered much information or advice until this happened. This left people facing a degree of uncertainty about what the future would look like.

As one person commented,

> I don't mind paying for it as long as I know that that's the system. And I've got no idea what the system is and you can't really make a decision on what to do … I need to know what the future holds for us, how the system works … not generally how it works, how it works in relation to our specific situation, our savings, our living environment, and our illnesses sort of thing. We just need to know from them … what their responsibilities would be. That's fine. I can work with that, but I just don't know at the moment, and I can't make decisions.

Some of the most pressing problems people told us about across different themes seemed to happen in atypical situations that systems were not set up to deal with. One person told us about a financial assessment that they were not happy about for two reasons. Firstly, the Carer was struggling with their mental health on the day that the financial assessment was scheduled, and the assessment went ahead without them, and the person being cared for did not have the capacity (in the opinion of their Carer) to participate in the assessment without support. Secondly, the outcome of the assessment was that they would not receive support, because they had a house which they were trying to sell. The house had recently been flooded, however, forcing them to move out, and it was proving complicated to sell it. This person told us that the house was treated as 'money in the bank' during the assessment, whereas, in reality, it was going to take some considerable time to sell the house, leaving them unable to afford suitable care in the meantime.

It is worth noting that others had positive experiences of dealing with the financial side of things. When people had positive experiences, what they valued was a quick, flexible and personalised response from NCC, and having a single point of contact. For example, one Carer told us,

> There's a person that I speak to on the phone about the money side of it who's brilliant for every time I've spoke to him, he's been friendly, nice. And

> when I've spoke to him about having slight problems with this, that and the other, and he says, yeah, we can up the care that side. Brilliant.

Finally, one person told us about a recent change in how cleaning is paid for, for a person they support. They had been told that cleaning can no longer be done by domiciliary care agencies, rather, a cleaning company has to be paid to do this, using the money received in benefits. For this person, who has learning disabilities, this was a problem because a cleaning company would do the cleaning *for* them, rather than *with* them, as domiciliary carers would. For some people receiving care, being helped to do everyday tasks for themselves such as cleaning is important for maintaining and developing capacity, and this recent change could have an adverse effect on them.

Experiences with domiciliary care

Sixty-two people told us how well they had been listened to by domiciliary care services. 36 people (or 56 per cent) said that they were listened to well or very well, 15 people (or 24 per cent) said that they were listened adequately well. The remaining 11 people (or 18 per cent) said that they were listened to poorly or very poorly.

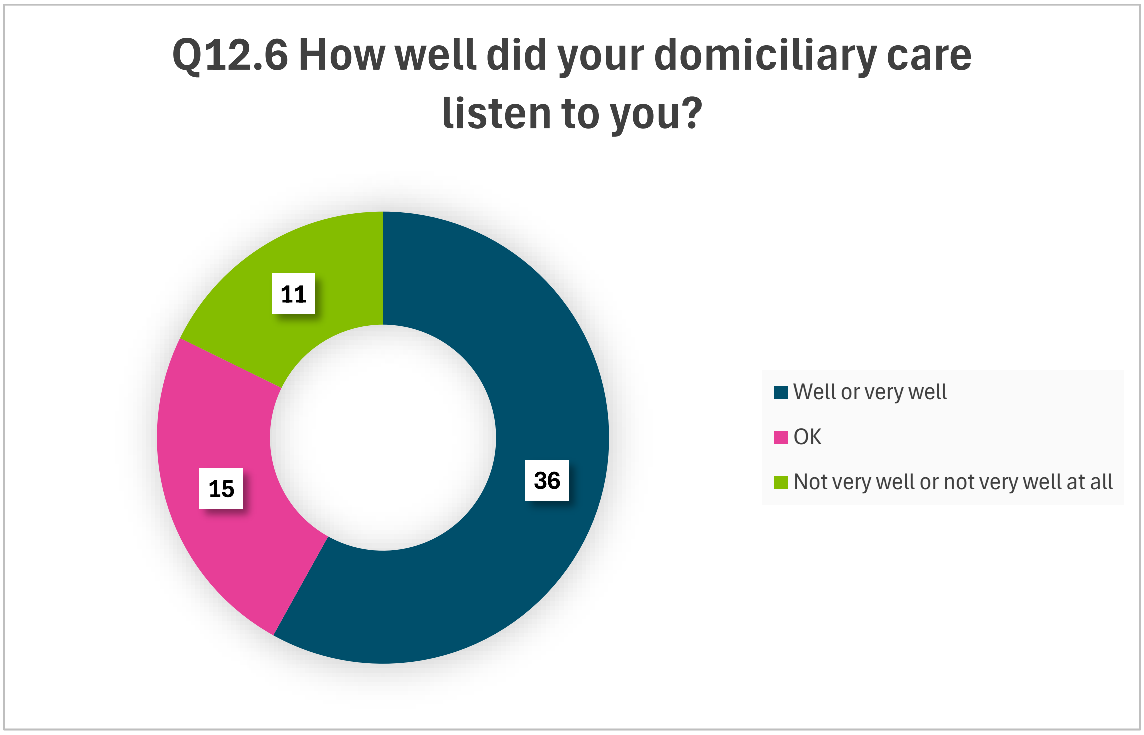

Figure 11: Q12.6 How well did your domiciliary care listen to you?

The most consistent comment that people made about domiciliary care, is that the quality of care is mixed. People tended to say more about the negative aspects of their experiences, but people's positive comments did give a picture of what most people think good domiciliary care looks like. The most common positive comment was that the carers were kind, compassionate and friendly. Some typical comments were:

> The staff and the owners are lovely people. There's lots of love there. There's just not enough resources.
>
> I mean, they were just lovely with her. Absolutely lovely. You could never have wished for better girls. They were really good, really caring. Whereas sometimes you get some care would come in quite abrupt.
>
> All of them friendly and willing and chatty to my husband. They're really, really good at their job.

People also told us that they appreciated care staff who listened and responded well, and who responded quickly to requests. They also wanted care staff who were able to establish good rapport with the people they were supporting, and who could communicate with them well. Listening well was partly about asking people what they wanted done for them, rather than making assumptions about what needed to be done, and about what someone was able to do, or not able to do, for themselves. People also expressed a preference for care staff who lived locally, so that they would not arrive stressed and short of time from a long journey.

When people told us about the aspects that they were not happy with, they had a clear awareness of the constraints on the system. In particular, the difficulties that domiciliary care agencies have in attracting and retaining good staff. Norfolk County Councillors recently warned that there are over 1800 vacancies for carers in the county (*Alarm over Number of Care Vacancies as County Faces Surging Dementia Numbers*, 2024). From the perspective of people being supported by these services this can mean that it is difficult to find a care agency to take them on, the quality of carers can be poor, care is often delivered by many different carers rather than consistently by a few carers, agencies struggle to cater flexibly for people's needs, and carers are often exhausted and stressed due to the demands placed on them.

Difficulties in finding a care agency in the first place were common for people across the county, and some people told us about the perceived lack of support in finding an agency, particularly if they were self-funding. Some typical comments were,

> We've got to find a carer for my husband just in the mornings because these people I think they pull out at the end of this month. And because we're self-funding, we've now got to find our own, which is I've found very difficult with every care provider I've phoned, and I've phoned about, what eight I should think, already, and they've got no capacity for Kings Lynn at the moment.

> Agencies won't come out. And they're right. In a way, it's very, very difficult to get agencies to guest work. And if you want, really spend some money, [names a care agency] are great, but they don't like to come to Wick because I then have to pay about 22 pounds before they get here for travel.

> Brian* had full capacity to right through to the very end, he had full capacity. So, they understandably gave him a book and said, 'These are your options'. So, he was very much left on his own. He kept, every now and then, he'd look at the book and phone himself [but he was] too exhausted to even go part way through the book.

* Not his real name

As these quotes suggest, there are some parts of the county which seem to have a particular problem with a lack of capacity. The limited supply made it difficult for some people to find agencies, whether they had adult social care's support or not, as these two quotes suggest:

> But that's not going to happen because I've already asked, I've already asked social services and basically what social services are saying is what it is what it is. There's a shortage of carers in the East Anglia and at the end of the day, if you're not happy, go somewhere else.

> And of course, it doesn't matter how much money you've got, it's actually incidental, because you're looking for hen’s teeth when you're looking for carers.

However, when looking for the right care staff, and particularly for continuity of care from the same care staff, some people told us that they chose to pay for care themselves, rather than to use agencies which adult social care would fund.

A lack of continuity of care seemed to pose particular challenges for people with complex needs. Three people told us of the negative effects of this on the mental health of the person receiving support, as they struggled to get used to new people.

In a related point, one person told us of how multiple changes in care agencies, due to one going out of business, and others failing to provide suitable care, led to the deterioration of the mental health of their cared-for person. They experienced more anxiety and volatile behaviour and increased compulsive behaviours, leading in turn to increases in medication. This had knock-on effects for the person’s willingness to receive visits from care staff, and for care agencies’ willingness to keep providing care, with serious consequences for the person’s well-being. The Carer thought that some of these effects could have been avoided, if there had been a thorough handover process between the different agencies, to make sure they understood the needs and preferences of the person receiving support.

A common complaint from those unhappy with their domiciliary care was the perceived lack of skills and experience of some care staff. Some Carers told us that this could be exhausting because they would have to constantly be telling them how to do the job. Another person told us that some of the people coming to care for him seemed to be “one step up from unemployment”, and “seem to be here under duress”. As he said:

> There are some really good ones, and some really bad ones. I'll get a call in the morning, and I'll get a feeling of confidence when I hear the voice on the end of the line, or I'll get a feeling of aggravation.

Some people partly attributed this problem to the high turnover of staff, meaning that new staff were constantly visiting who had not yet had the time to complete all their training.

Five people mentioned that they thought that some carers coming from abroad faced additional challenges when learning how to care for people in the UK, and that they were not sufficiently supported by care agencies in this respect. Two challenges in particular were mentioned: one was that some Carers who spoke English as a second language had accents that cared-for people did not understand, or their English language skills made it difficult to build a friendly relationship with them. The other was about cultural competencies, particularly around understanding what food people enjoyed and how people like their homes to be maintained.

It is, of course, relevant to note that cultural diversity, in the case of workers from abroad, could be a risk factor for racism and discrimination in the UK care sector, as noted in a recent review of the research on this topic (Turnpenny & Hussein, 2022). This review further notes that, while cultural and linguistic complaints can be disguised expressions of racism, there is also evidence that a lack of aptitude in these areas can harm relationships between care staff and those they support, and lead to worse outcomes for the latter.

Other concerns people mentioned to us which are related to the limited supply of care staff, were about the timing and length of visits. One person told us about the lack of flexibility of the care agency she used, because sometimes she wanted them to come late at night, but this was not a service that they offered. Four people told us about problems with carers coming at the wrong time, either because the agency couldn't offer flexibility with the rota, or because care staff turned up after they were supposed to. One person said,

> "The rota is continually a problem, they send carers on days we don't need them and vice versa". Another said, "The time changes 9 times out of ten. The sheet said 7am, but they didn't turn up until 8:45. That happens a lot. I

can't get myself ready to go until they've come. It's annoying. They don't even phone me up to say that the time has changed. I start panicking, I like things to run on time. I know we don't live in a perfect world but…"

Three people told us that visits were shorter than they were supposed to be. For example, one person told us that her husband's care staff would only stay for ten or twenty minutes:

I know they are extremely busy and he's not the only one, the only patient that they're seeing. But I was told by the social worker that his calls would be for 45 minutes, and I know that nine times out of ten, they'll come in and they'll say to George*, do you want anything? And he'll say, no, I'm fine, thank you. [My social worker] said to me, they should be with him for 45 minutes, even if he doesn't want anything, but they [should] just sit and have adult conversation with him because he doesn't get any other adult conversation apart from me and our two children.

*Not his real name

In this case it seems to be because the staff were so busy. In another case, it seemed to have been planned by the care agency:

They rushed in, rushed out and left. They were supposed to do on a Saturday. I gave them an opportunity to do the lunchtime and the evening shift. They did the two combined and tried to get her to eat lunch and dinner in a one-and-a-half-hour visit. What? Yeah, but the council were okay with that so long as they get everything done in the time they're there, the council were happy with that. They've told me that.

People told us that the shortness of visits compromised the quality of care that they received, and that they thought this was because of the working conditions of the care workers. Five people told us that care staff were often coming in stressed and exhausted, and the fact that agencies were not paying them for travel time seemed to be the main cause of this, as these two people suggested:

> The carers are coming in exhausted. Some carers are completely lost. They're asking me to help. So, you've then got three people in the room and they're late as well. Basically, they're running behind and behind and behind. Some are walking, some are walking carers [meaning they don’t have their own transport]. The company don't leave any travel time for anybody.

> I mean, often the carers are under so much time pressure, you would have thought for someone with complex needs, they might give them some more breathing space. Well, and it is a very low paid job.

To sum up, most people we talked to were happy that domiciliary carers who supported them, and said staff listened to them well. However, people also expressed concerns about domiciliary care, and common themes were: having inexperienced carers, the poor quality of some food preparation, the timing and length of visits, and the lack of continuity of care from the same care staff. These all impacted on the quality of care people received, and how personalised it was for them.

Experiences with residential care

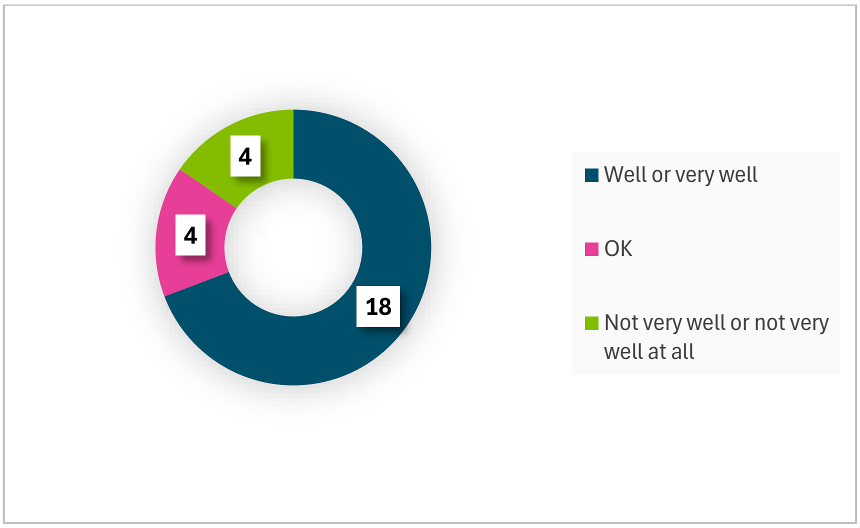

Figure 12: Q12.6 How well did your care home listen to you?

65 respondents to our survey said that they had used a residential care home in the past 18 months. Of these, 26 left a rating for how well the service had listened to them (or their Carer). Most people (18) told us that they were listened to well, or very well, with a further four saying that they were listened to adequately. Four people told us that they were listened to poorly.

In the in-depth interviews, a number of themes emerged about what people valued most in care homes. As with domiciliary care, people mentioned a caring, compassionate and helpful attitude from staff. As one Carer told us,

> Well, for a start there seems to be plenty of staff. They're very kind. They approach him well, I suppose they're all very patient people, they, nothing's too much trouble for them … [My husband]'s always clean and dressed. And in the lounge with others, if somebody spills something, they're there straight away mopping up. They're just very good at caring and I think it's well run by the manager.

The attitude of staff seemed to help some people to feel like a care home was a proper home. One person living in a care home told us that he liked living there because it was like "home from home, and the manager is like a mother for grown-ups".

Carers also valued homes which were welcoming to them, and treated them with care. As one person said, “They’re very kind … Every time I go in, they straight away find me a chair”. They also valued homes where they could visit as much as they liked, and for as long as they liked.

Relatives of people receiving care told us about what a difficult decision it could be to move a family member into a care home, and six people spoke to us of the lengths that they went to, to try to keep them in their own home. Some people simply wanted their relative to be in their own surroundings, but three others were worried about their relatives being neglected if they were to move into a care home funded by NCC.

Related to this, some people we spoke to had found the process of finding a suitable home difficult. This was often because of a limited selection of suitable care homes in their local area, especially because NCC can only fully fund placements up to a certain fee level, after which the family must pay a ‘top-up’ to meet the fees (if a more cost-effective option is available and is not chosen). Some people mentioned their perception that placements fully-funded by NCC would be of lower quality than they would choose themselves. Two people told us that their relatives had been sent to home placements funded by NCC, and had had bad experiences there. One person said they had to “fight” to keep their mother-in-law in her home when she was no longer able to pay for her own care, and feared the quality of care she might have received in an NCC-funded home. Another knew that her mother’s savings were gradually depleting, and was worried about whether she would be able to stay in the care home she was in, where she was happy, once adult social care became involved.

Very important to Carers being happy once they did find a home, was for the home to take their advice seriously, when they were telling them how best to care for their relative. Some people we spoke to found their advice being ignored, at least at the outset. One Carer, whose advice was not heeded at first, said, when aspects of the home’s care did not work:

> In fact, I was almost glad that some things happened there, and I thought, I'm glad you are seeing that for yourself … They have got him under control and they've managed him now very well. But it took several months, and these are the kind of things that I would've been explaining to them were happening at home. I kind of get the impression that they think, ‘Oh, it can't be as bad as she's saying. Surely it can't be as bad as all this’. And it wasn't

> until they got him into the home, and [the manager] did on one occasion say, ‘I can see why you couldn't manage him at home’. So, gradually people came to an understanding of what it was like.

Nine people told us about the aspects of care homes that they were not satisfied with. Three of them mentioned cramped premises as part of the problem, and this could impact on people in different ways. One person told us about how the lack of green outdoor space was depressing for her husband, who had worked outside for his whole career. Another spoke of how the communal spaces in her husband’s home were too small to allow more than eight people to gather, making organising stimulating activities more difficult. This led to her husband staying in his room for longer periods than he would have liked. A third said that her husband had been given a small room, which did not have enough space for him to be able to do the physiotherapy activities that he needed to do to recover from an injury.

Three people told us about how their home was not sufficiently able to cope with people of limited mobility, and that their relatives lacked stimulation and, in one case, the ability to exercise enough to maintain capacity. One person said,

> It's a very good show home. It puts on a really, really good do when you're going round as a visitor. But to anybody who can't move about and do things and join in with all those wonderful ideas that they've got going, the vulnerable are not in the same happy position.

Four others mentioned short-staffing and the underpayment of care staff as problems that they thought impacted on their or their relative’s care.

Experiences with Assistive Technology and home adaptations

The Assistive Technology service of NCC provides a range of electronic gadgets that can help people to live independently in their own home. The service visits people’s homes to do an assessment of what might be useful for them, and then suggests suitable devices. Some of these are provided on a free loan basis, while others which the service does not provide are available commercially.

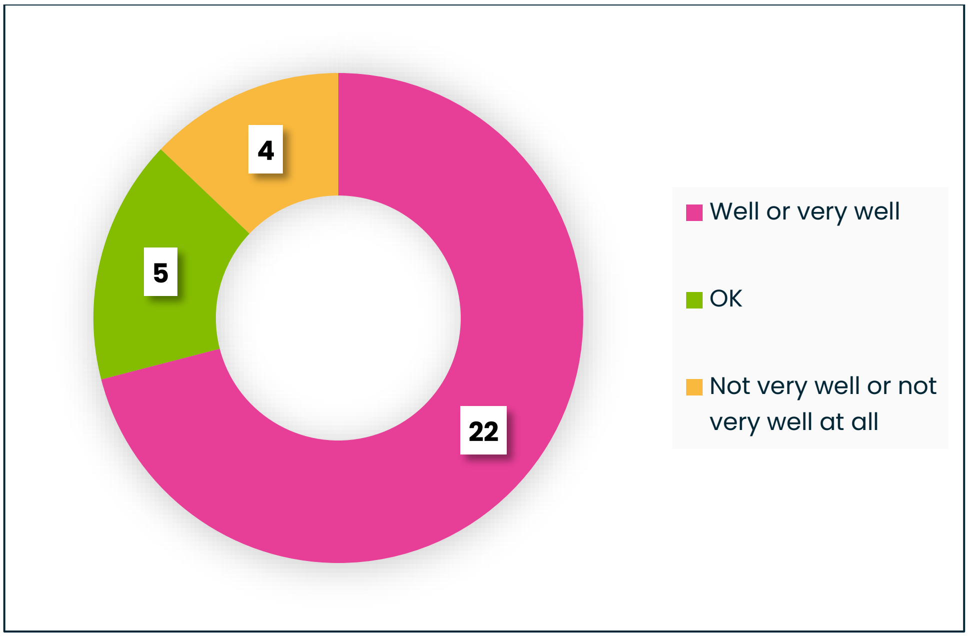

Figure 13: How well did the Assistive Technology department listen to you?

In the survey, 62 people told us that they had used Assistive Technology from NCC, and 31 people provided a listening rating for the service. As shown in the chart above, 22 people said that the service listened to them well or very well, and five more said that it listened to them adequately. Four people mentioned the service in interviews, and they all had positive experiences with it. As one person said:

> [Assistive Technology] have been very useful. Some of it was useful, some of it wasn't, but it's more been a help to me. So, we've both got the press button alarms, we've got the assistive tech for fire alarms and all that sort of thing.

Some people are also eligible to have adaptations made to their home, to help them to stay independent, subject to an assessment by an Occupational Therapist. Adaptations can include equipment to aid mobility and prevent falls, such as grab rails, or changing the level of the toilet. In the survey, 13 people told us that they had received home adaptations. Ten of these said that the service had listened to them well or very well.

Home adaptations were also mentioned by seven people during in-depth interviews. Two of these people spoke about long delays in hearing back from NCC about whether work could go ahead in their homes, and one person told us that they had been refused a wet room in her house, but she did not understand the reason for the refusal. Another person was contesting an NCC rule that they would only fund wire netting fences, on the grounds that her sight impairment made it difficult for her to see where the fence was.

The other three people mentioned the positive aspect that adaptations had had on their lives, and complimented the service. One person told us,

> I had further aids to assist me, and they arrived very promptly indeed … I needed to have my toilet made higher, and that facility came. I needed to have some sort of grab rails, put under my mattress to the side of my bed so that I could more easily get myself out of bed. And that happened immediately. So, I was very impressed by that.

Professionals' views of NCC listening

As part of the listening theme, we also carried out in-depth interviews with professionals in the voluntary sector and district councils who have experience of contacting adult social care on behalf of older people. We spoke to 13 people, and these included staff of:

- Age UK Norfolk
- Age UK Norwich
- The Alzheimer's Society
- Community Action Norfolk
- The Hanseatic League
- POhWER
- West Norfolk Deaf Association
- West Norfolk and King's Lynn Borough Council
- Great Yarmouth Borough Council

There was recognition from some of these professionals that the people they worked with were not necessarily typical of all older people receiving adult social care, but were more likely to be people who were having bad experiences, and so needed help. One person told us:

> I actually spoke to somebody yesterday for example, who had had a very positive experience. They'd had a disabled facilities grant processed within two months, which is very short timeframe for something like that. And actually, we're very satisfied. Equally, we've had an email come in this morning of somebody who's fighting for the bare minimum as a carer for their relative who's an older person and is completely exasperated with the process and feels they're not being listened to. So, we see the extremes here.

Most professionals we spoke to praised the staff in adult social care who they worked with, and recognised that they were under great pressure. One person told us that they worked as an advocate for five years for people accessing adult social care, and could not recall working with anyone who did not share his organisation's values of trying to make sure that people's voices were heard and that their care was person-centred.

Another person praised how social workers and assistant practitioners were “very considered” regarding people’s capacity, and will place the person with dementia at the centre as much as they possibly can, and help them to understand the decisionmaking process. This person also said that social workers are now very focused on people’s wishes, which they welcomed, as they said that this had not always been the case in the past.

However, they did think that “the churn of different practitioners can be difficult for people”. A support person can change four or five times and older people often want to build up a relationship with that person. They can struggle to engage with adult social care when they are not able to do this. Sometimes their organisation would try to help with communications between the older person and adult social care, to try to “bring down the tension a little bit, between the worried service user, and the social worker under the cosh”.

Another person made a similar point about how they help older people with referrals to adult social care, which some people feel anxious about doing themselves. Having a trusted third party make the referral gives reassurance to such people, even though the referral will not get any preferential treatment as a result.

Three professionals thought that the accessibility of services could be improved. Similarly to some of the people we spoke to who were receiving support, they thought that some professional language was used that people did not always understand. One person told us:

> Social services could break down the process for people, and talk to them in layman's language, rather than in statutory and professional-sector language. People are nodding, ‘Oh yes dear, thank you,' but they are not understanding it.

Another person who worked as an advocate talked about the need to make processes understandable, to not use jargon, and to check whether people have understood the process they are using. They also spoke about the need to still use leaflets, since many older people still use them, even in a digital age. They thought that people might be put off when calling the main telephone line, because they do not know which button to press, and which buzzwords to use when they speak to someone. This poses particular problems because, “it’s very hard to measure how many people you might have put off. All you can do is to work to make things more accessible.”

Finally, there seemed to be a difference in the experience of larger and smaller voluntary sector organisations. One person told us that they thought that adult social care “go to the big boys first” (meaning the larger organisations), when, in this person’s opinion, smaller organisations tend to have more day-to-day contact with people, and better knowledge of local communities. People we spoke to in smaller organisations were less satisfied with trying to contact adult social care on behalf of their clients than people from larger organisations. They also seemed to find it harder to get through to the right department, when contacting adult social care on behalf of older people who struggled to navigate the phone system and the website for themselves. One spoke of the difficulty raised by confidentiality concerns, which meant that staff from adult social care would not always speak to them, but at the same time voluntary sector organisations were being called on to support people by adult social care. “There is still a culture of, ‘we are the professionals and you guys ain’t’”, they said.

The role of social care in hospital discharge

As detailed in the section, 'Why We Looked at This' above, NHS is the lead partner in discharging patients from hospital, and acute hospitals identify which patients will require support when they leave hospital. Where hospital staff judge that this is the case, they will complete a Transfer of Care form which is sent to a 'Home First Hub' outside the hospital, where a team of health and social care professionals decide what support the person should be offered. Therefore, conversations that patients have in hospital about post-discharge care mostly happen with hospital staff. Where appropriate, patients may have a Care Act Assessment after discharge, to determine what support they might need to meet their ongoing needs, and these conversations happen with social care staff.

Hospital admission

In the survey, 124 people told us that they had been admitted to hospital in the past 18 months. As mentioned above, we wanted to understand people's whole journey from before their hospital admission, through to exiting the 'discharge pathway', into some kind of long-term residence in a community setting. So, we asked people for the reason for their hospital admission, and whether there might have been some help that they could have received that would have allowed them to avoid admission. The chart below shows that the most common reasons for admission were falls, illness or infections, heart problems and breathing problems.

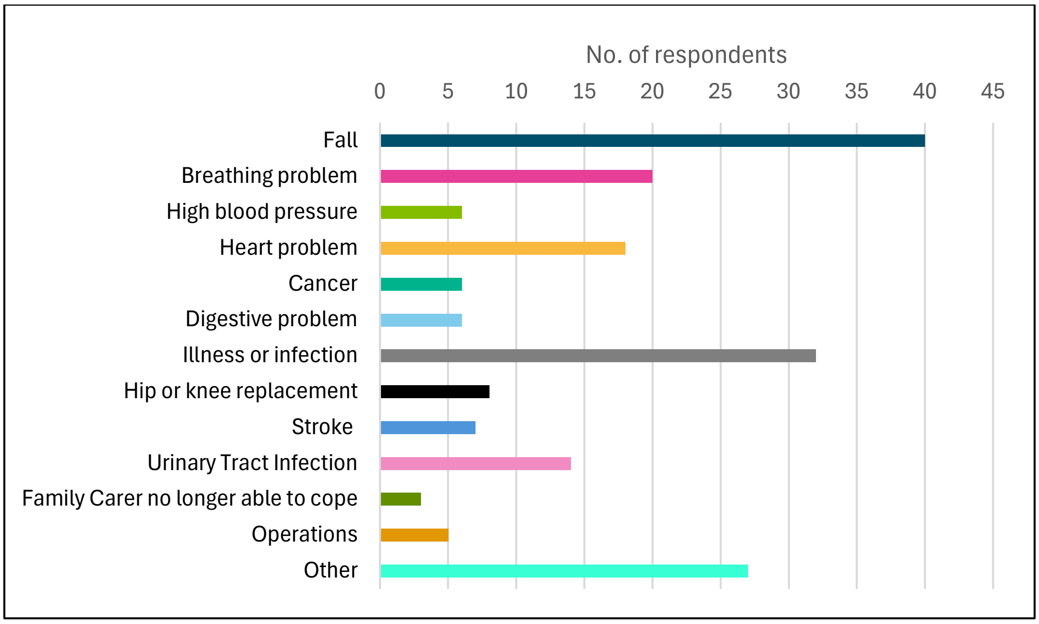

Figure 14: Q14. What was the reason for going to hospital?

68 per cent of respondents (72 people) told us that they thought their admission to hospital could not have been prevented through extra support. For the 33 people (31 per cent) that thought it could have been prevented, the most common support mentioned was falls prevention advice, equipment or home adaptations (18 people, or 55 per cent). Five people (or 15 per cent) mentioned support or respite for a family Carer, and three people (or nine per cent) mentioned assistive technology.

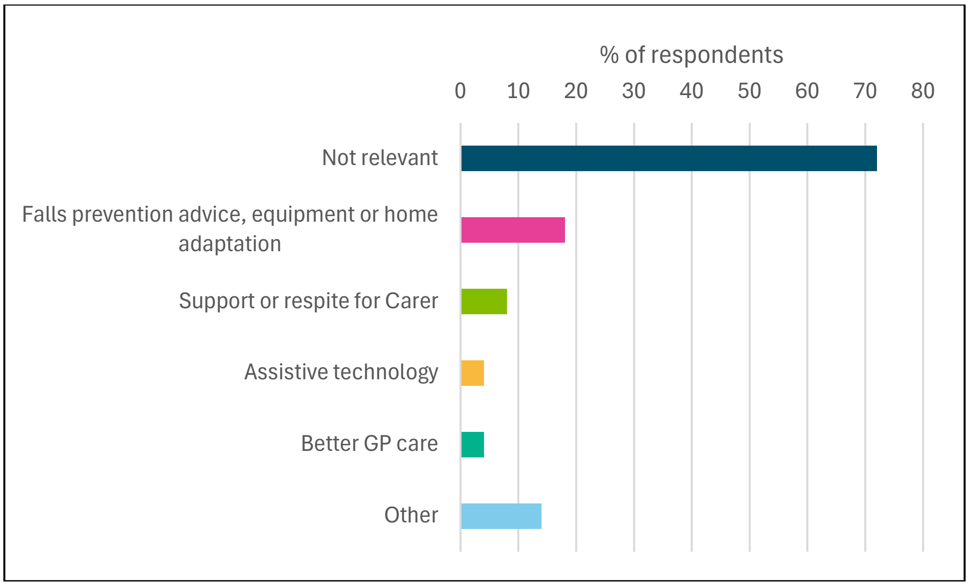

Figure 15: Q15. What could have prevented your admission? (respondents could select more than one option).

Discharge communications

Next, we asked people four questions about discharge communications and decision making during their stay in hospital. This was to try to gauge how well people felt they were listened to during this process, and whether they were getting information about their options.

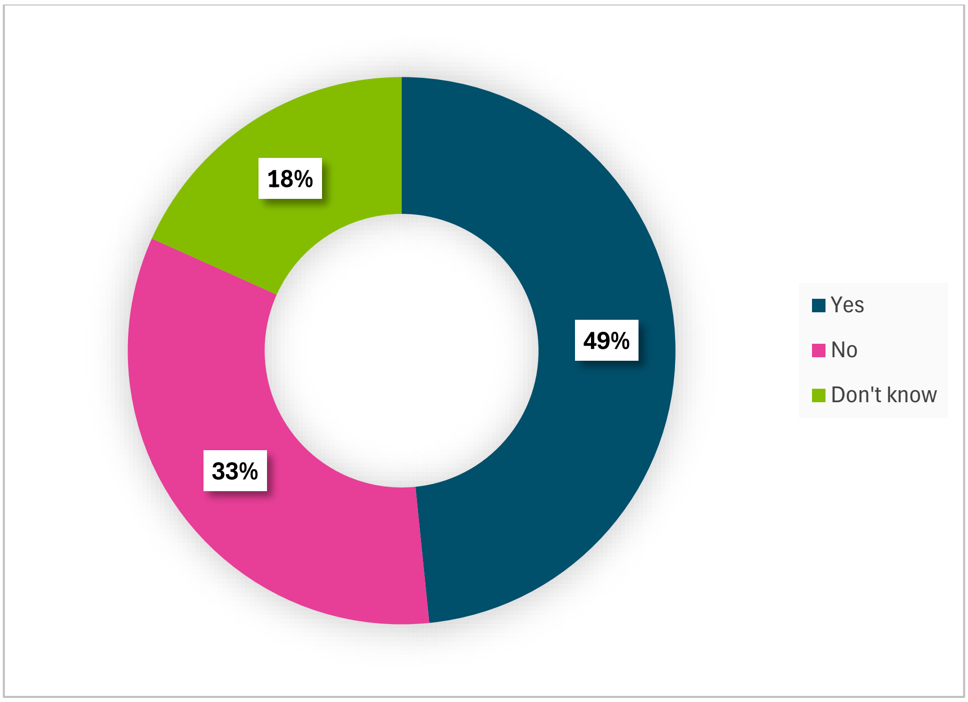

Figure 16: Q16.1 While you were in hospital did anyone ask where you wanted to be discharged to and with what help?

As this chart shows, a third of all respondents said that they were not asked where they wanted to be discharged to, and what help they wanted to receive. It is worth noting that this figure includes respondents who left hospital without any social care support. The figure varied depending on what support people received after they left hospital. The figure was lower, for example, for those receiving social care support after they left hospital, as the table below shows.

Care received after discharge	Yes	No	Don't know/don't remember	No. of respondents
All respondents	49%	33%	18%	93
All people receiving social care	54%	25%	21%	52
Reablement	60%	20%	20%	25
Nursing home*/care home	33%	33%	33%	15
None	36%	36%	27%	22

Table 4: Q16.1 While you were in hospital did anyone ask where you wanted to be discharged to and with what help?

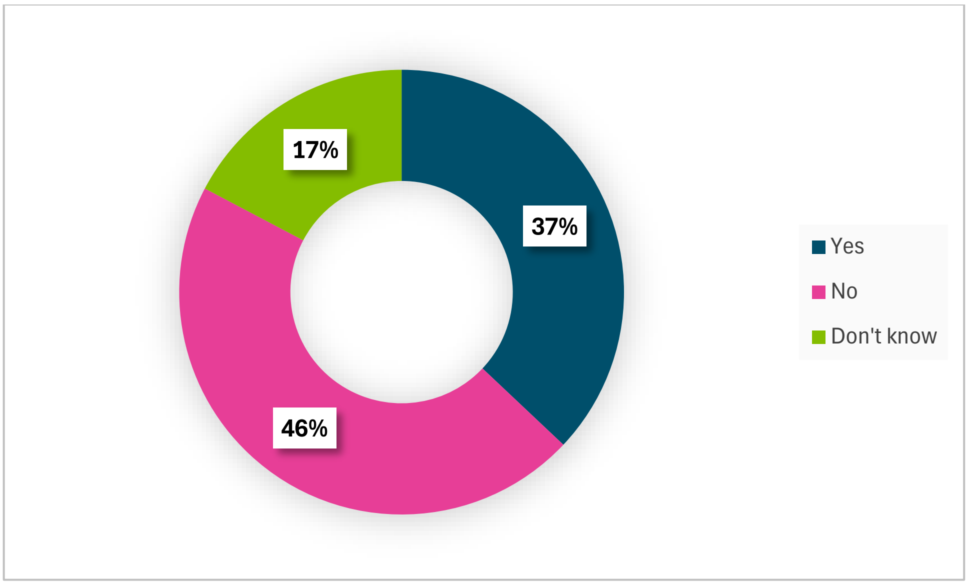

Figure 17: Q16.2 While you were in hospital did anyone ask what your Carer's preferences were?

Even more people reported that their Carer was not asked what their preferences were for discharge (46 per cent, or 37 people). Again, this figure was lower for people leaving hospital with social care support (37 per cent, or 17 people). The next question was about what information people received about the care they would receive after discharge:

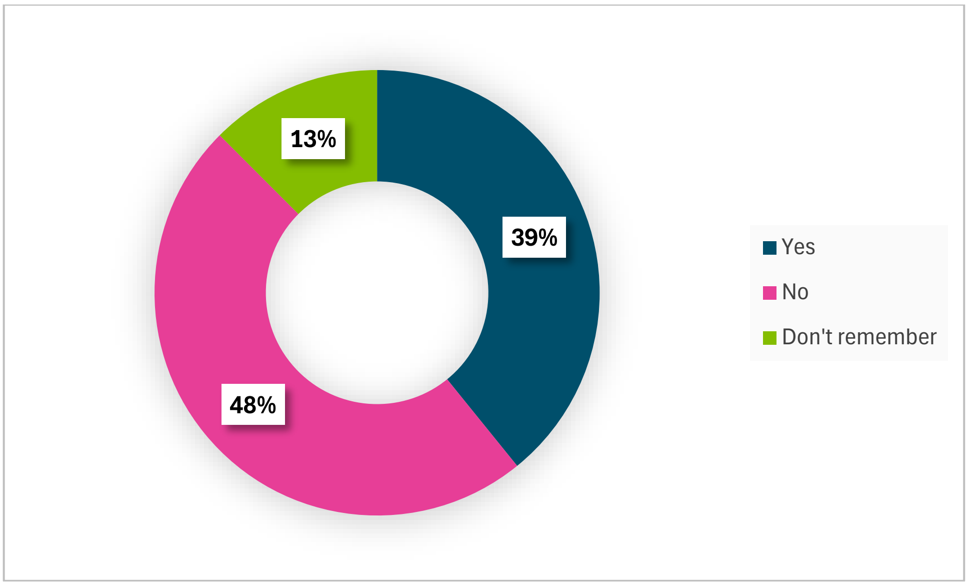

Figure 18: Q17. Were you given information in good time about what care you would get after you left hospital?

Almost half of all respondents did not get timely information about the care they would receive after they were discharged (and 39 per cent of respondents receiving social care after hospital).

The next question we asked was about understanding how decisions were being made about discharge. This understanding is obviously important both for people to know why the care they are being given is thought to be the most suitable option, but also so that they can try to influence the decision should they wish to.

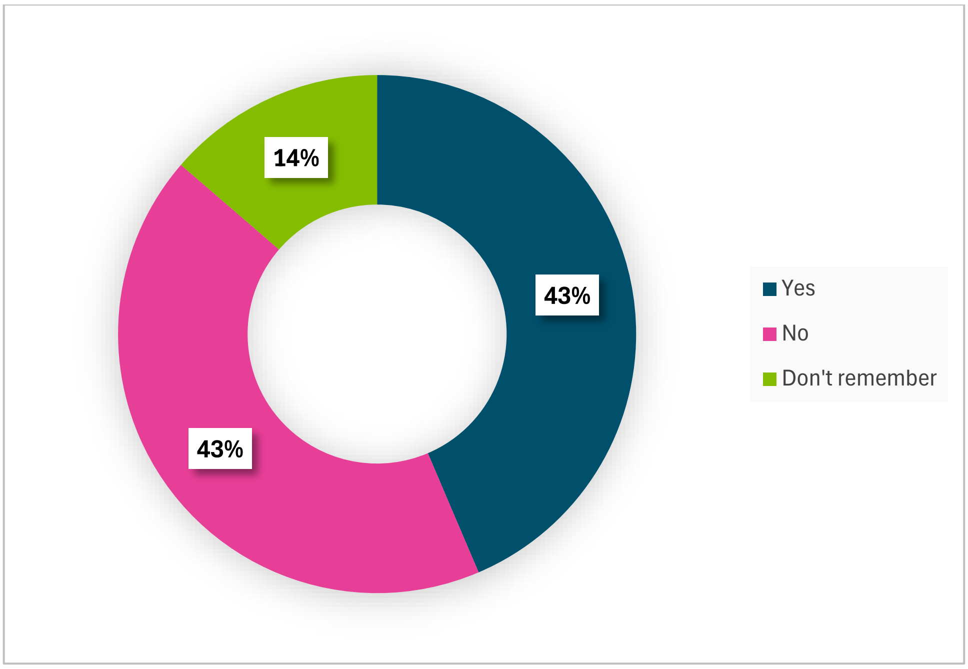

Figure 19: Q18. Did you understand how decisions were made about your hospital discharge?

Half of people who could remember, said that they understood the decision process, and half did not.

The feedback we received in qualitative interviews about this topic was more positive overall than the survey feedback. Most people we spoke to were happy that they had been kept informed about the care package that was going to be in place for them when they came out of hospital, and felt they understood why sometimes this could take some time to put in place.

Some people did mention that when the time for discharge came, this could be at quite short notice, and they would have preferred to have been told earlier. Two people we spoke to were anxious on the day of their discharge, because their Carers did not seem to have been informed, and they were being asked questions that their Carers would normally have answered for them. Two other Carers mentioned that the hospital had communicated about the discharge with the residential home where their relative lived, but not with them, and they felt cut out of the conversation. As one Carer put it:

> Any arrangements for discharge were made between the discharge team at the hospital and the home. I had no say in that at all. And in a way, that's not a bad thing. I hadn't got to worry about it had I? Because it's the home that had got to do the work when he came out. But I couldn't get any real information because they weren't talking to me.

One of the patients in these cases also felt that they were not being communicated with, and that there was a “secret code” between residential homes and hospitals, and that they were going to “slip [him] out the back door”.

Some other people mentioned that they had not been asked about what their care package would be after they left hospital, but were not upset about this, because they felt that the care met their needs well.

Gender disparities in responses on discharge communications

A significant finding in the survey data on discharge communications was that there was a marked difference between women and men’s responses about discharge communications. Women, for all these questions, reported having been asked about their preferences and given information substantially less often than men did, and said that they understood the discharge decision-making process much less often than men did. The charts below demonstrate this difference.

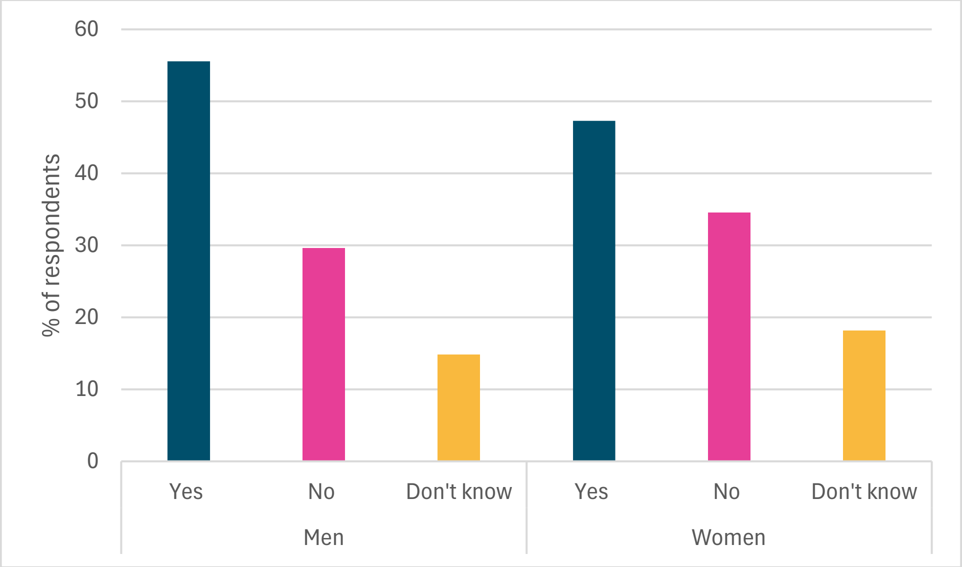

Figure 20: Q16.1. Were you asked where you wanted to be discharged to and with what help? Gender comparison (%)

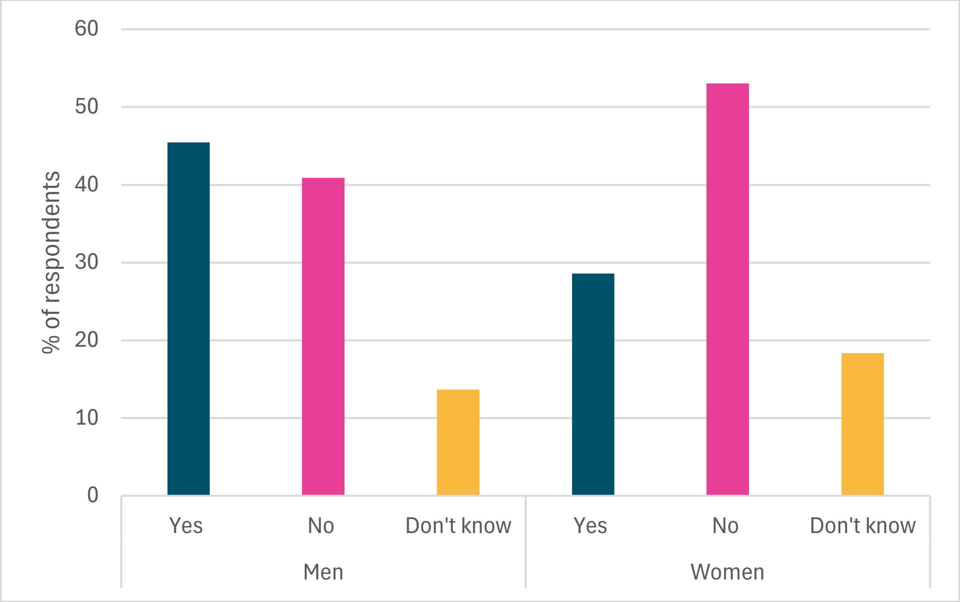

Figure 21: Q16.2. Were you asked what your Carer's preferences were? Gender comparison (%)

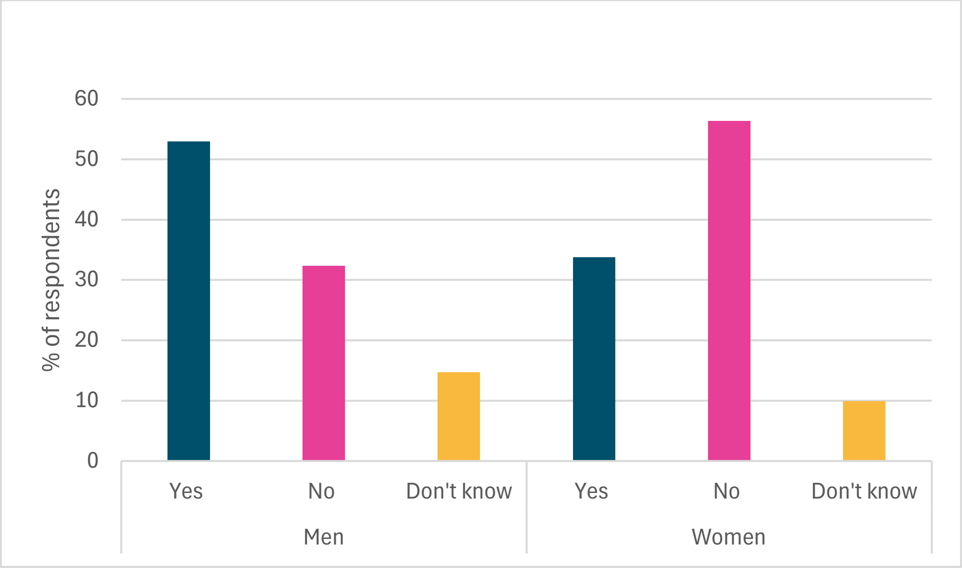

Figure 22: Q17. Were you given information in good time about what care you would get after you left hospital? Gender comparison (%)

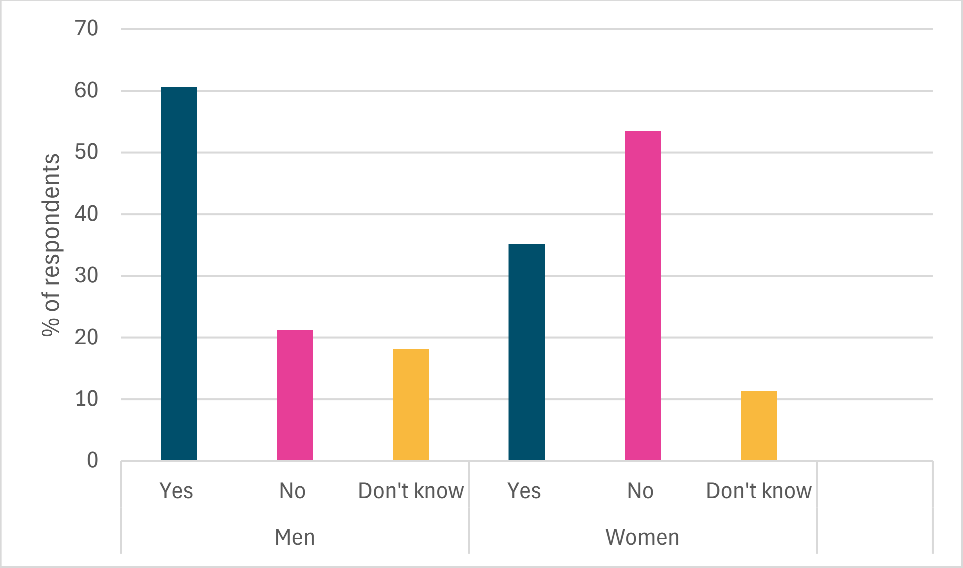

Figure 23: Q18. Did you understand how decisions were made about your hospital discharge? Gender comparison (%)

Differences in patient satisfaction by gender have been found in other studies, in various settings, with women often reporting more negative experiences than men (see, for example Elliott et al., 2012; Chen et al., 2022; Teunissen et al., 2016; Woods & Heidari, 2003). Our findings in Norfolk suggest that it would be valuable to investigate these differences further, in order to discover whether women are being systematically communicated with worse than men are during the discharge process, and how this might be remedied.

Care Act Assessments at home

As mentioned in 'Why We Looked At This', above, and important aim of the discharge theme was to investigate people's experiences of having Care Act Assessments in their home. Since the introduction of the 'Discharge to Assess' model, patients are discharged to their homes or another residential setting in the community, and have their care needs assessed there, rather than in hospital. This is in order to try to help people leave hospital earlier, and also because people are thought to make better decisions when they are away from the stress of being in hospital. These assessments are carried out by social workers in what are called "Follow-on Teams". Assessments may also be carried out for NHS continuing healthcare (an ongoing package of care paid for by the NHS for people with a 'primary health need') and NHS funded nursing care (funding nursing care in a nursing home for those who are not eligible for continuing healthcare funding).

We asked in the survey about people's experiences of having Care Act Assessments and the reports are discussed in the listening section about. The following charts show the results for the same question, but for the subset of people who had their assessments at home after a hospital discharge:

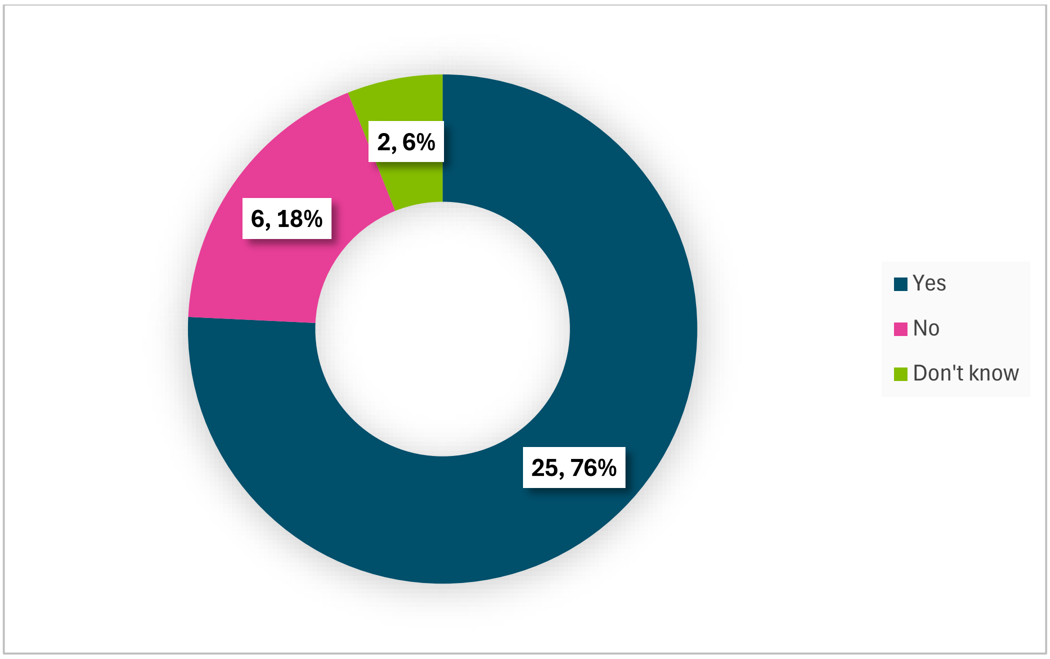

Figure 24: Q9. Were all the people you wanted to be involved in your assessment included? [Follow-on team assessments only]

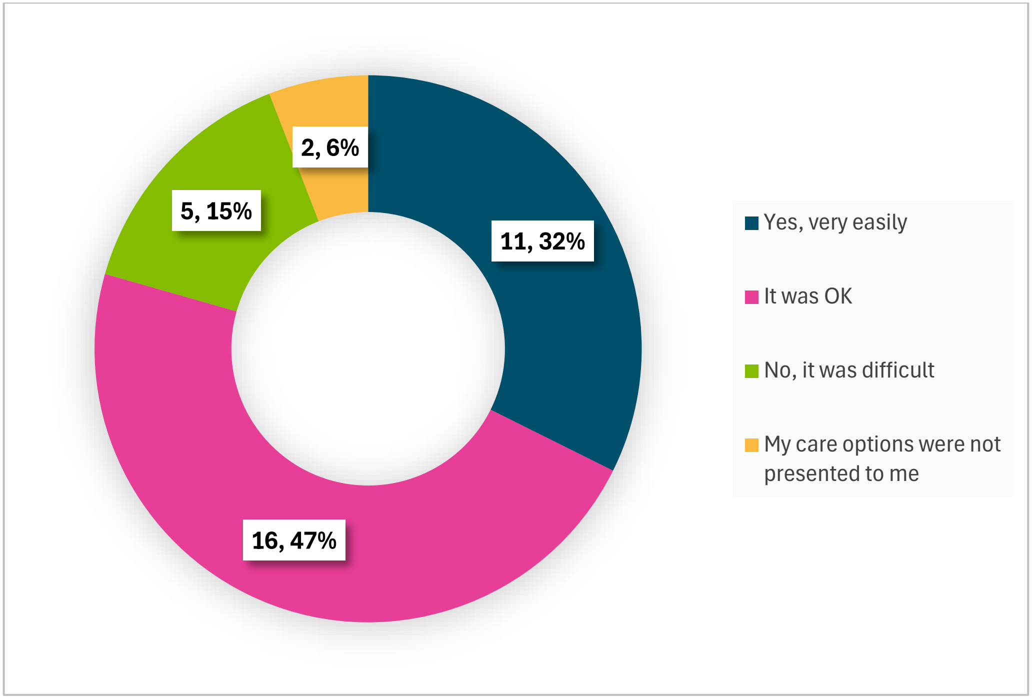

Figure 25: Q10. Were your care options presented to you in a way that you could understand easily? [Follow-on team assessments only]

For question 9, the results are almost identical to the whole sample of people having Care Act Assessments and reviews. For question 10, the proportion of people saying that they could easily understand their options is 7 per cent lower than for the whole sample, although the numbers of people answering this question is relatively small, so it is hard to draw firm conclusions from this.

It seems that most people had the people included in the assessment that they wanted to be, and almost four fifths of people understood their options. However, people also told us about some aspects they were less happy with. Of the 34 people answering this question, 20 left comments about what would have made the process better, and 13 of these were comments that related to social care. Three people mentioned that they would have liked information about the services that adult social care offered, so that they knew what to ask for during the assessment. Another person made the related point that, unless you know what services you might require, it is difficult to answer some of the questions in the assessment.

Four Carers mentioned that they were not communicated with well about their relative's assessment, which ended up hindering the assessment itself. For example, one person said:

> My mum had her care assessment on her own on the day my dad went into hospital with no warning and no communication with her son or daughter as requested. She had no idea what was going on, was confused and worried, and then panicked that she'd let two ladies in the house.

Three people mentioned that an appointment was not set for the assessment, and so they were not prepared for it when it happened. One person wrote,

> Calls come from private number and often I was not prepared for a call and not always had information at hand.

Two people mentioned that they would have preferred an assessment in person, but that it was done over the phone instead. Two other people mentioned that they thought the social worker doing the assessment lacked care and compassion. One person wrote:

> I am aware that this is always going to be a difficult time for us families involved, and totally aware that social workers are not magicians, however you do not need to be a magician to do your job with kindness and compassion and listen, as well as do your job to the best of your ability.

We also carried out in-depth interviews with 20 people about the assessments they had undergone after leaving hospital. Most of these people were happy with the assessment that they received. As such, they did not generally have a lot to say about the process, only that they were happy with it, had been listened to well, and had received a care package that met their needs (or had been assessed as not needing any further support). One person who was particularly happy said:

> She's Dad's social worker and she's part of the discharge to assess team ... And she's brilliant. She's the only continuity we've had and she's the only person who listens, has the time. She's very gentle.

This person also mentioned that the social worker had delayed closing her father's case file, to give a complex home situation time to settle – perhaps underlining the point made in the listening section above, about some people wanting to be signed off later than they are. Two people mentioned that they would have liked to have had the assessment in hospital rather than at home. For one of these, this was because they were expecting discharge to work as it had before discharge to assess was introduced, and commented that it felt like "no-one was in control" of the process under the new system.

However, the most mentioned point that people were not happy with was related to who would pay for the care that they received after they left hospital. Four people we spoke to were surprised and annoyed to hear that they would have to pay for the care they would receive upon discharge, because they had been told in hospital that this care was universally free for everyone. This may partly also be related to some confusion between NHS care, that is free at the point of delivery, and social care services, which are means-tested and often charged-for. One person told us about how they were shocked at how much it would cost, despite being happy with the care itself:

> Apparently, this is another thing at the hospital because the … people who discharge you at the hospital says you get the first six weeks free. And they've been saying that all the time. We've been asking about the cost of care and that is not true. You are paying from the onset and it amounts up to quite a lot of money a week … Apparently it's changed. Now everything's changed. That's all they say. You used to get it free but now you don't. My husband had a stroke before about three years ago, 2019, and the first six weeks of that was free and we didn't need all those six weeks because he recovered so well that we didn't even need the care for so long. But now … you have to fund it yourself. I think it's about something like 24 pound, 12 an hour or something. And then if you've got two people you can work that out.

Another person told us that he had been told his post-discharge care would be free, and did not understand that he was signing up to pay for care when this was put to him by social workers when he was back at home:

> When I left hospital and came home, my house was full of all sorts of people. I was in a bit of a mess, bit of a state, and I signed without really knowing what I was signing, for [a care agency] to come. All I know was that there was two ladies sitting in my lounge and they gave me some paperwork and said, sign that. And eventually for about four days, some really nice people, but male and female came one o'clock past Sunday in the morning who suddenly appeared at my bedroom door and the other one late in the afternoon. I've cancelled them. It been acknowledged that they were cancelled. We were told when I left hospital there'd be no charge for carers for several weeks, I think six weeks, and at the moment I'm having an argument because somebody in Norfolk County Council are trying to tell me they've got to send me an invoice for some money.

Care received after leaving hospital

In the survey, we asked people about the care that they received immediately after leaving hospital.

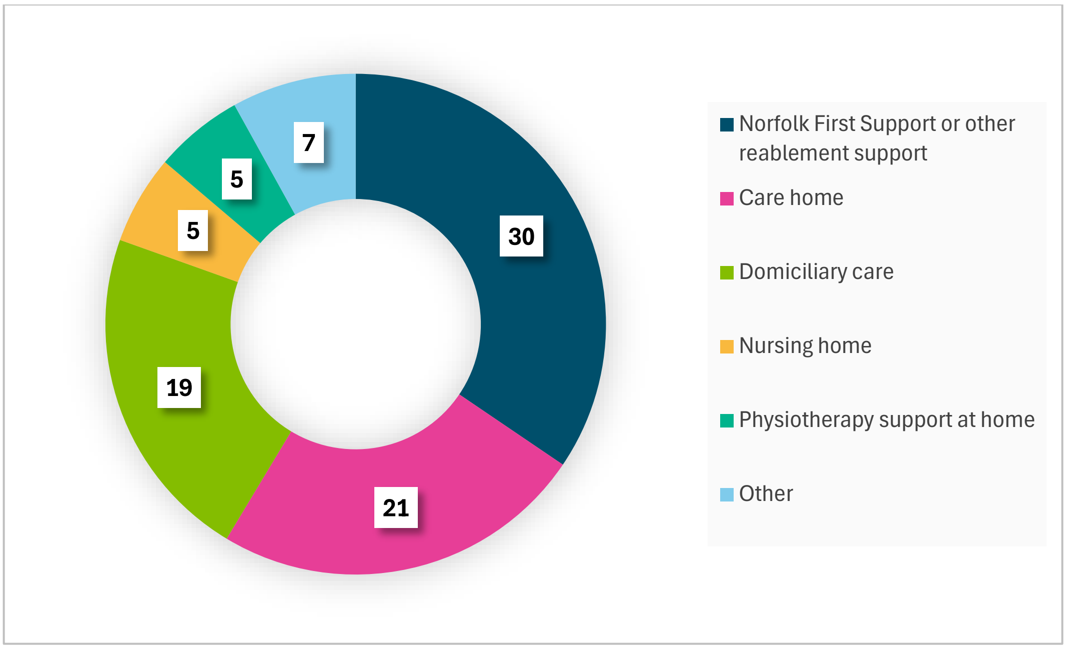

Figure 26: Q20. What care did you receive after you left hospital?

The largest three categories here, as the chart shows, are reablement support, care homes and domiciliary care. Next, we asked people four questions about the care that they received:

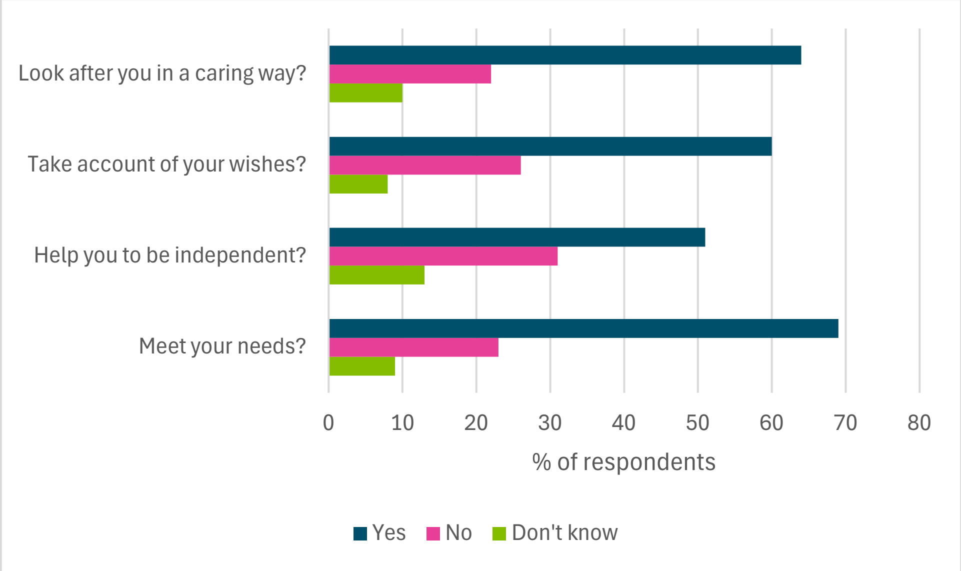

Figure 27: Q21: Did the care you received after discharge do any of the following?

We can see here that most people were happy with the care that they received, at least in the four aspects we asked about. The lowest scoring aspect was that related to promoting independence, with only slightly over half of people agreeing that the care that they received helped them to be more independent.

The charts below break down these scores by the three main services that people received after discharge: reablement support, residential care and domiciliary care.

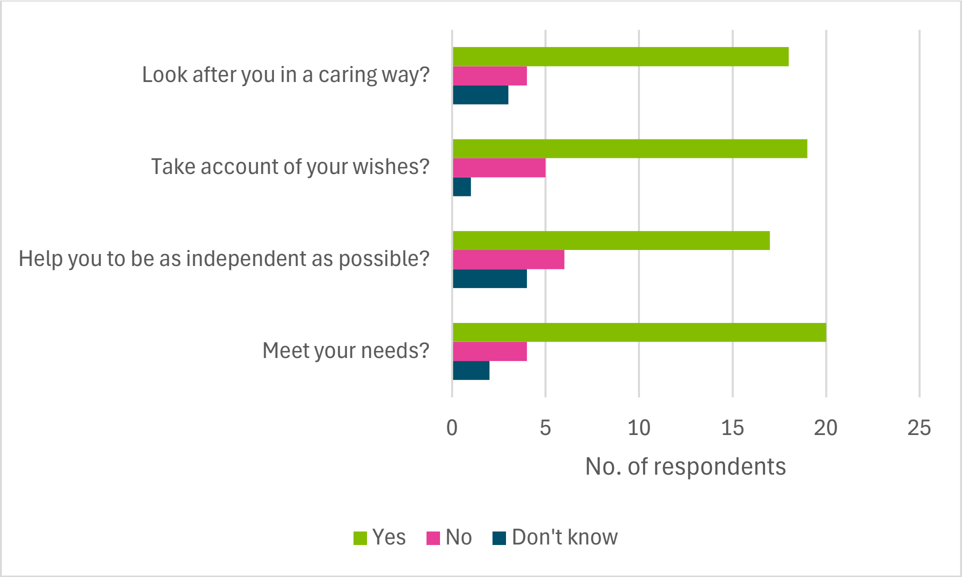

Figure 28: Q21. Reablement after discharge. Did this care do any of the following?

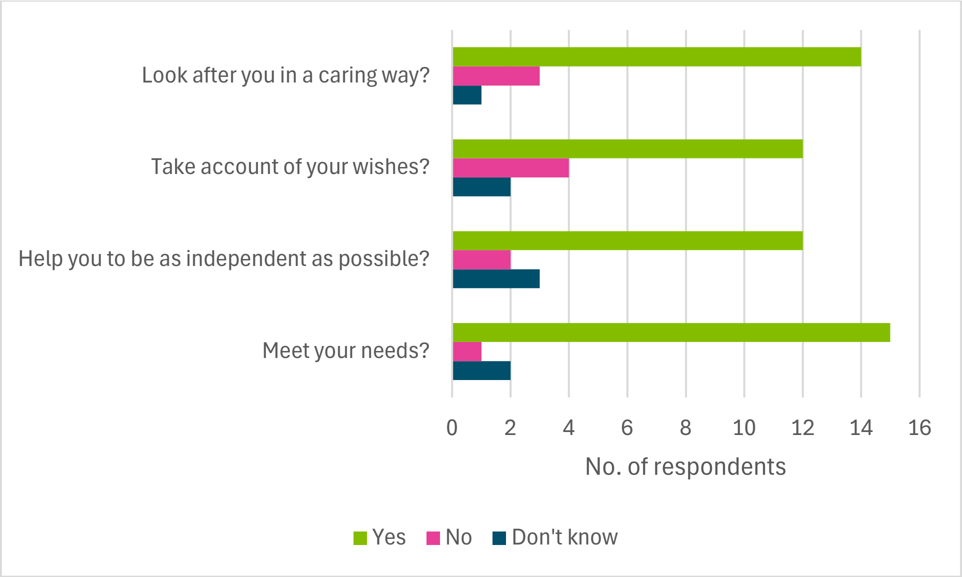

Figure 29: Q21. Residential care after discharge. Did this care do any of the following?

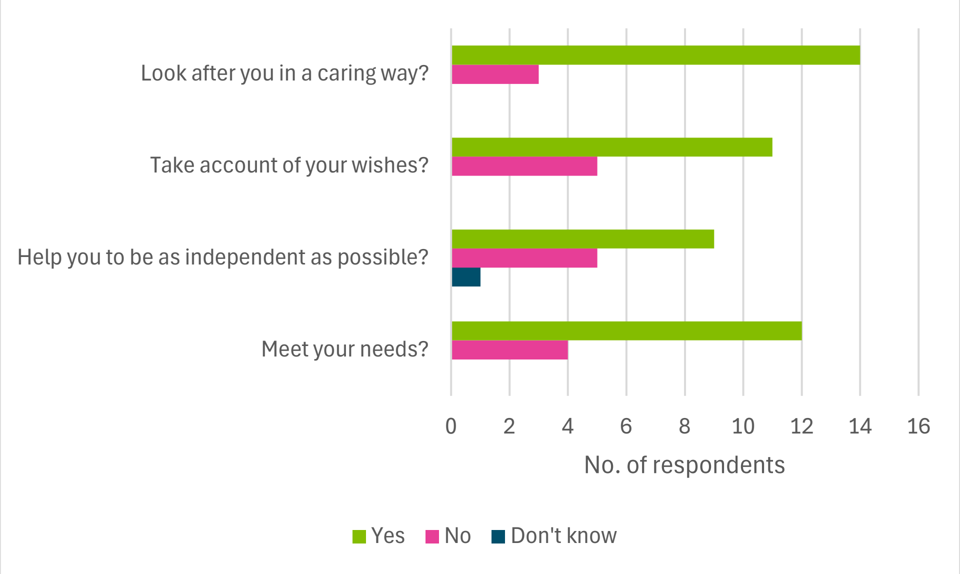

Figure 30: Q21. Domiciliary care after discharge. Did this care do any of the following.

People were then asked to say what this care did well or badly. Sixty-eight people replied to this question, and the most popular answer, given by 19 people (or around a quarter of respondents) was that it quite simply met all of the needs that it was intended to meet. The next most popular response, given by 13 people (or 17 per cent of respondents) referred to the care being, or not being, compassionate and caring. Seven people (or eight per cent) mentioned good or bad communication from services. Three people told us that they had been given an inappropriate care package: two of them told us that they had been given reablement support, when they needed domiciliary care, and one person old us that they needed reablement support, but were given domiciliary care.

The qualitative feedback that we received in the in-depth interviews concentrated mostly on the reablement support for Norfolk First Support (NFS). Almost all the people who mentioned this service said that they were happy with it. They mentioned that they arrived very promptly after their discharge, that they were compassionate and helpful, and that they were good at promoting people’s independence, and that the service would withdraw earlier than planned if the person had already regained their independence. Two people mentioned problems with the service. One Carer told us that the service would ask their mother, who had mild dementia what she wanted when they came to visit. Due to the cognitive impairment of dementia, her mother did not know what to ask for, and found it stressful to be asked a question she did not know how to answer. A different Carer told us that the carers sent by NFS were not qualified to care for their father due to the complexity of his needs and the family situation, but they did not refer him on to a different service that could have been more suitable.

Professionals’ views on discharge and integrated working between different health and social care organisations

One of the objectives for year one of the project was to try to understand how well the discharge to assess process was working from the point of view of professionals. In particular, we wanted to understand how well people thought integrated working between health and social care professionals was functioning, and how well the risks of discharge for patients were being assessed by different categories of professional. To try to understand this, we interviewed 16 professionals about their views on this. These included seven people working for NCC, five people working for the Integrated Care System, two people working for the Norfolk and Norwich University Hospital, and four people working for voluntary sector organisations.

A pivotal document in the integrated discharge of patients is the Transfer of Care form. This is completed by health professionals in the hospital, in consultation with the patient and their relatives and any other key contacts, before being passed to a multidisciplinary discharge hub outside the hospital. This hub includes social care professionals, clinical leads, practice consultants, occupational therapists, physiotherapists, community assistant practitioners and social care assistant practitioners, supported by integrated care coordinators. This hub will decide what support should be in place before the patient can be discharged to a community setting (whether this is their own home, or an existing placement in a residential care home). The form is intended to *describe* the patient’s condition and situation, rather than *prescribing* what care the person needs, which is a decision that will be made by the discharge hub staff, based on the contents of the form along with the other records that are held about the person’s medical and social care history. Once completed, the form should provide considerable detail about the patient, including:

- Whether there has been a discharge planning discussion with the patient and/or their Carer, family member or representative
- The person’s expectations for discharge
- Whether they have given consent for the transfer of care referral
- Whether the patient has someone who can assist with their care post-discharge, and with transporting them back home
- The person’s communication needs
- The person’s mental capacity and any powers of attorney given to others

- Whether they have any dependents
- Their medical history
- Whether they have any cognitive or mental health issues
- What kind of property they live in, whether it has stairs and how entry can be gained
- What their existing care arrangements are (whether formal or informal)
- What everyday tasks they need help with
- What practical help they require (related to the state of their home, including de-cluttering, putting the heating on, home adaptations, buying food and more)
- Their medication
- Their mobility requirements including any risks of falls
- A rating of their clinical frailty
- A rating on the elderly mobility scale
- Questions about a range of different risks they face, including safeguarding issues, clutter at home, malnutrition and infection control
- Questions about any complex needs that they may have (including any palliative diagnosis; any emotional or psychological issues; registered nursing needs; and any cognitive, neurological, emotional or psychological issues).

‘Risk appetite’ and integrated working

Most of the professionals we spoke to thought that integrated working was functioning well, and was working better than before discharge to assess was introduced.

However, most people agreed that there was still a difference in ‘risk appetite’ (meaning how much risk they were willing to tolerate when making discharge decisions) between social care professionals and healthcare professionals. Social workers were said to be more likely to allow someone to be sent back into the community with a risk that they might not have quite enough support, to try to encourage them to develop their independence. This is often called an instance of ‘positive risk taking’. If the care proved to be insufficient, then more support could be given to that person. The reasoning behind this approach was said to be that once care is in place, people are often reluctant to have it withdrawn, even when they do not need it anymore (in the judgment of professionals).

Health professionals, who are used to treating people in hospital where help is available for people 24 hours a day, were said to have more of a focus on making sure that someone was completely safe before they were discharged. However, one person working for Norfolk and Waveney's Integrated Care System (ICS) told us that it is not always as simple as this, and that occasionally the reverse was true. For instance, they would from time to time encounter situations where social care professionals were too focused on the family's wishes – for example because the person's spouse did not want them to come home yet – and could lose sight of what the patient wanted. The importance of consulting the patient and not just Carers, was emphasised by another ICS staff member as well.

Conversely, another professional, with a background in social care, thought that sometimes a reason for healthcare professionals being more worried about someone's discharge could be because they had not asked enough questions about the family support network the person had at home, which could make a residential care placement unnecessary.

One professional told us that they thought that the Norfolk and Waveney system was quite risk-averse compared to some other systems in other areas of the country. They attributed this to a blame culture historically, and "*perhaps not a lot of support from senior management. They say, 'take risks', but when you get it wrong, people are concerned about the ramifications. It's all very well someone sitting at a desk saying 'take risks'*". This history could be difficult to shift, because of a lack of experience in taking risks.

Three professionals told us that the risk conversation was complicated by the limited capacity there is in the Norfolk system to care for people after a hospital stay. One person working in East Norfolk told us that three nursing homes had closed in the past year, and this could make it much more difficult to get someone out of hospital for the final months of their life. Another example was the lack of therapists in community services, meaning that a clinician might keep someone in hospital longer, because they know that the patient would not be able to receive that therapy in the community. Some of the technology that could help to get people out of hospital faster – such as falls pendants, which can help to monitor people and assess their risk of falling – are not really relevant if there are not enough care staff to go and visit regularly when a risk does develop.

As one person told us, "If it was a nice, 'Everybody goes out same day or next day because we've got an abundance of capacity out there for people to go', it'd be a very different picture I think around that appetite for risk". When asked which parts of the county had a particular lack of capacity in the care market, professionals mentioned north, south, east and west Norfolk, with Norwich being the only area not mentioned.

Communication issues with discharge to assess

Despite the overall feeling that discharge to assess had made integrated working better, some people mentioned some disadvantages of the system. Two people told us that they thought the discharge process was now slower. One person said that they thought this was because of "the back and forth" between the hospitals and the wards, which was quicker when there were more social care staff based in hospitals. Another person said it was because management and oversight was harder, now that the team is not all under one roof, and it could be difficult to pinpoint who was in charge of a particular patient's case.

Two other people said that they thought that some of the team camaraderie had been lost now that more social care staff were out of the hospitals. One health professional said that contacts are now at arm's length and rely on email, which is problematic because, "*social care professionals are human beings, and you need to be able to eyeball them*", to communicate well with them. Also, it was quicker when "you could just grab someone", rather than having to wait for a reply to an email.

Problems filling in the transfer of care form

Three professionals mentioned that the risks of a 'failed discharge' (meaning a situation when someone was discharged from hospital but had to be immediately re-admitted because of a lack of care at home) were increased by a failure to fill in the transfer of care form in properly. This could be caused by several different factors. One person told us that sometimes people are desperate to get out of hospital, and so try to give hospital staff the impression that they can cope by themselves, when in fact they cannot.

Another person told us that the problem can sometimes be that a clinician in the hospital who does not know the patient well enough, has filled in the transfer of care form, leading to inaccuracies. A related problem was that information about a patient's home situation and discharge preferences could get lost if they were moved from ward to ward several times for reasons of infection control. This could mean that a member of staff on their new ward might fill in the form, even though the patient had only arrived there recently.

Two people told us that healthcare professionals in hospitals sometimes used the form to prescribe what they thought the person needed upon leaving hospital, rather than filling in all of the details and letting the discharge team decide what care the person needed.

Finally, one of the professionals we spoke to raised the problem of staff in acute hospitals continuing to tell patients that they would receive six weeks of free care when they left hospital, whereas this is now subject to a financial assessment, and some people will have to pay some or all of the costs of their care.

Disagreements between health and social care professionals

We asked the professionals what disagreements might arise between health and social care professionals during the discharge process, and the most common answer was that disagreements would arise about who would pay for someone’s care. “No-one enjoys this part of their job, on either side of the fence”, one person commented. Another person said:

> “We have a lot of patients where social care will say, ‘No, they're on a health pathway. Health will fund that’. And then we'll say, ‘No, they're not on a social’, and back and forth, back and forth, and you've got this poor individual in the middle whilst people are arguing. And it'd be so much simpler if we're an I C S [Integrated Care System], this is our population so it shouldn't really matter. Our funds are our funds. Why can't we bring our funds together and do things jointly? … It doesn't feel like as a system we’re anywhere near that at the moment.

The extent of the integration of budgets for post-discharge care does vary across the county, however. One person we spoke to in east Norfolk, told us that they thought that discharges in this part of the county were more integrated than in other parts of the county. An important part of that integration was that this person’s role allowed them to direct the activity of various teams as it related to an individual’s discharge, whether that team was the Integrated Care Board, East Coast Community Healthcare, Norfolk County Council or Suffolk County Council. ‘Digital maturity’ and well-resourced, fully substantive staffing also made things easier in the East.

Another person working in the East summed up how they thought integrated working should function:

> I don't necessarily think we harness and connect the dots early enough, that all of us [health, social care and district councils] are wrapping around the needs of the person and trying to respond to what they want, what would make life better for them. So rather than a clinical response, what is it an individual wants, and some of that needs to be delivered in partnership and how can we do that really effectively? So, the integrated way of working, I think is not at the mature level that we need it to be to really benefit people and help drive things like the prevention agenda and drive different ways of working and what matters to communities. You think you'd be able to do that without the money discussion, but in reality you can't.

Experience of adult social care after a dementia diagnosis

In this part of the project, we were trying to understand the experiences of people who had received a dementia diagnosis in the past three years. We asked about people’s experiences over three years (rather than over 18 months as in the rest of the project) because many people do not seek help from adult social care until their dementia symptoms worsen, and symptoms are often still mild at the point of diagnosis. We were interested in aspects of people’s general experience of services in Norfolk, whether they be health or social care services, to try to determine what gaps there are in services and how adult social care could help to support people better.

As with the hospital discharge theme, we were interested in understanding people’s experiences over time, which in this case meant gathering information on their experiences from just before diagnosis, up to three years post-diagnosis.

Thirty of the people we carried out in-depth interviews with had dementia, and we heard about a range of experiences of diagnosis. Most people had been diagnosed at an NSFT (Norfolk and Suffolk Foundation Trust) clinic or hospital.

Two people had been diagnosed by NSFT staff visiting them at home, four people had been diagnosed by their GPs, one person had been diagnosed by an Admiral nurse and one person was diagnosed in an acute hospital after they had been admitted for a hip problem. People's experience of diagnosis was mixed, with five people having to push for a diagnosis, with services, usually GPs, being reluctant to refer people on for a diagnosis.

For three Carers the situation was complicated by their relative being unwilling to undergo a diagnosis. As one Carer told us, *"getting her to go back to discuss something that she's terrified about is not the easiest thing in the world"*. One Carer mentioned how this affected willingness to provide support from adult social care. It took a long time to convince his wife to have a dementia assessment, so that by the time the diagnosis was received, she had been exhibiting symptoms for around two years. However, as far as the person he spoke to on the phone was concerned, the diagnosis was dated only two months before their conversation.

In the survey, 71 people told us that they had dementia, or were caring for someone with dementia. We asked people whether they had been supported to learn more about their condition after their diagnosis. Just over half of people said that they had received information, but a third had not:

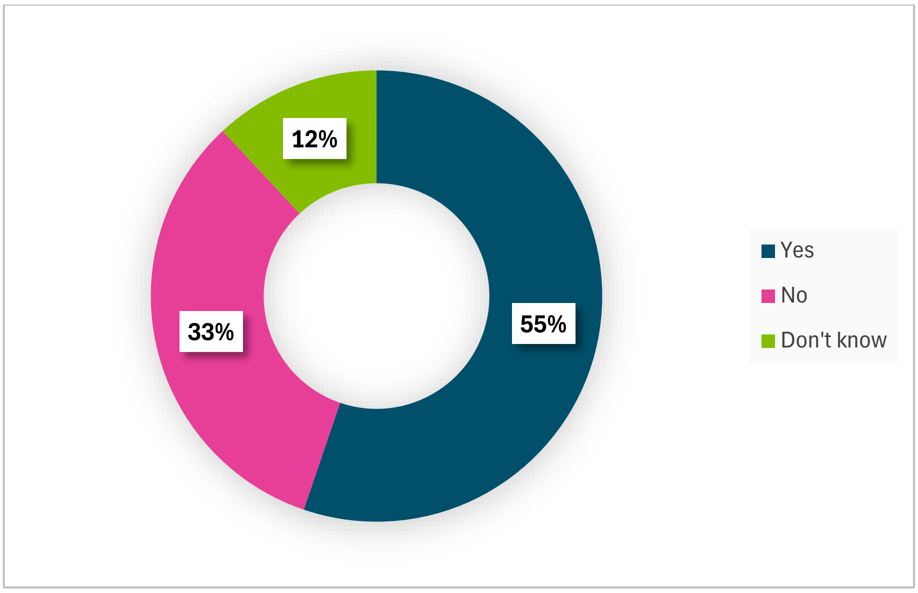

Figure 31: Q23. When you received a diagnosis, did you get support to learn more about the condition?

In the in-depth interviews, people reported having received varying amounts of information upon diagnosis. Around a quarter of the interviewees reported being happy with the amount of information that they received, and those who were happy had often received face-to-face guidance from a professional. In some cases, signposting was provided including information on support groups, the frailty elderly team, support with finances and the Alzheimer's Society. The focus was primarily on supporting the person with dementia, with less information on support for Carers. Some people mentioned that they had received a lot of information ("such a heck of a lot to read though"), that they struggled to process without assistance.

Some people reported having received no information at all, and spoke vividly about how difficult they found navigating the new condition without information and advice. One Carer commented:

> The nurse explained it, but I didn't understand it. I still don't. I had to ask, last year I asked for the psychiatrist to come out and explain it. That whole process was diabolical because they do, I felt I let my husband down with this because I really thought that once we got to the memory clinic that they would help us, and they didn't.

Another Carer told us what information would have been helpful, as well as how the workload of being a Carer made it difficult to seek help:

> We didn't know how to approach everything, do anything to look after Mum because we hadn't had any training or anything. It's just, 'Right. Your mother's got vascular dementia', and we were dropped, right? We felt like we were just dropped straight into a cauldron of boiling water. Where do we turn? Where do we go? How do we look after Mum? So really, everything that we've done for my mother has been on the job. We've really taught ourselves on what we need to do.
>
> We haven't had any support from anyone to say, 'This is how you should answer these questions. This is how you should help your mum with the dementia. These are the things that will come up with her dementia. She will have issues with this, this and this'. We've had none of that at all. So, everything that we do with Mum and help with Mum is what we've taught ourselves really.

> The person from the Julian Centre said that there were places we could get support from. I think the biggest problem is you have is when you're helping someone with dementia, it's just a full-time job. And if you aren't there looking after that person, you're at home. You just need a break from it all. And you're so involved that you don't tend to look for help from anyone else. You just want to get through the next 24 hours really.

The next question in the survey was a related one, about whether people had received support to plan for the future, after their diagnosis.

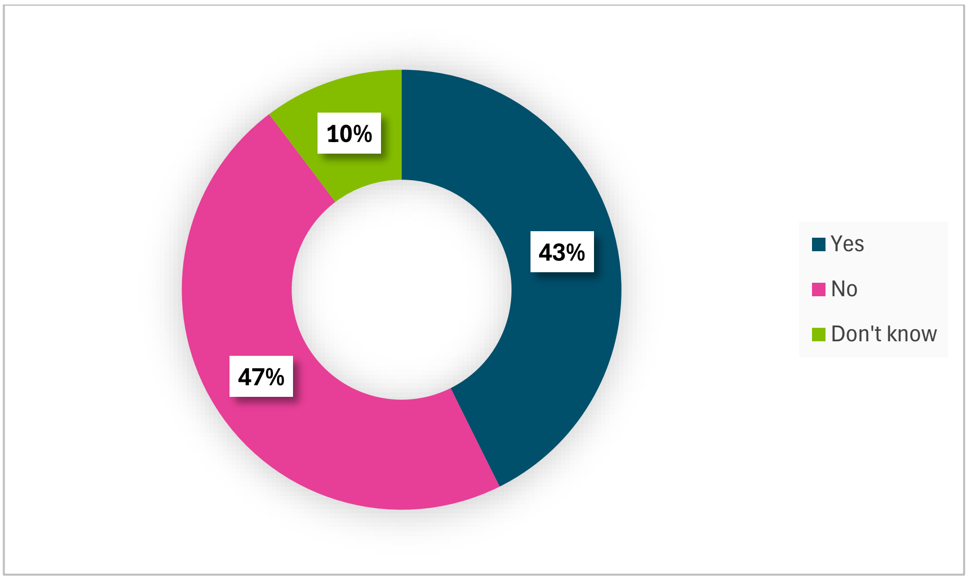

Figure 32: Q24. Have you received any support to plan for the future?

As this chart shows, almost half of people told us that they had not received any help to plan for the future. People mentioned a wide range of different kinds of assistance that had helped them prepare for the future, with no one category predominating (25 responses), including a care home or nursing home placement, advice from an Assistant Practitioner, information and signposting, equipment, and being referred to an assessment (people mentioned Care Act Assessment, incontinence assessment and Occupational Therapist assessment).

We also asked people what kind of help would have helped them to plan for the future better, and received 67 responses. The most common answers are shown in the chart below:

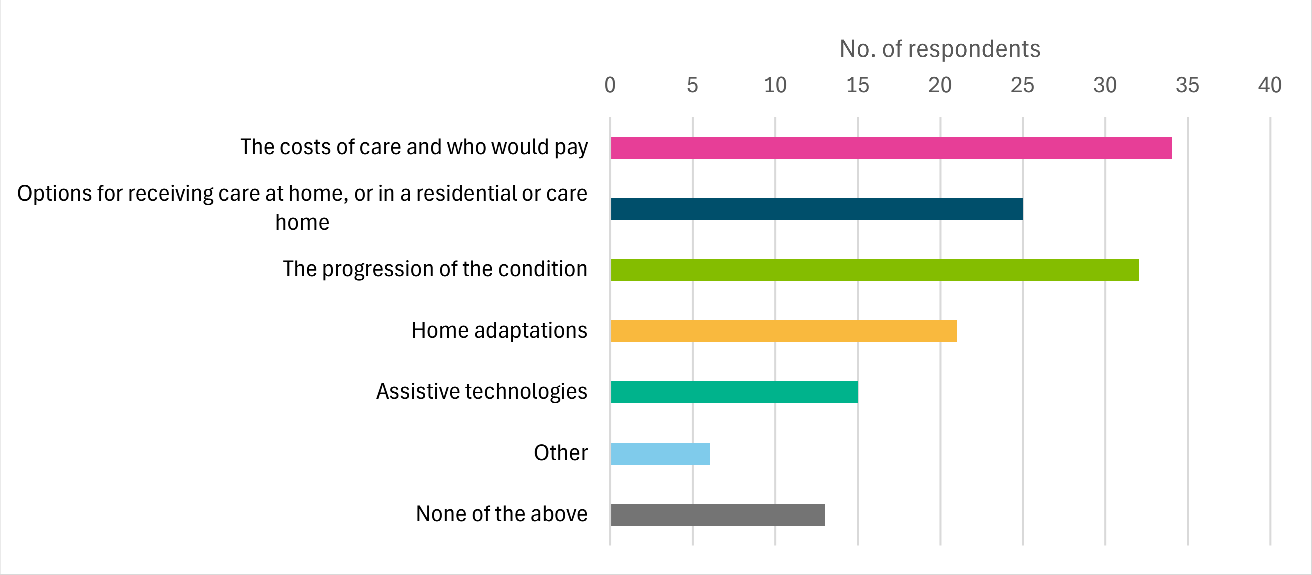

Figure 33: Q25. What support would have helped you to plan for the future better? Information or advice about:

The most popular answer was about the costs of care and who would pay, which is similar to what people told us about financial assessments (discussed in the section on 'Listening', above), that people wanted to know what their financial situation would be in the future. The next most popular options were information on the progression of the condition the person was suffering from, and about options for domiciliary and residential care.

Fourteen people in the qualitative interviews told us that they had not received any significant help to plan for the future, and mentioned similar categories of information as people in the survey, especially information about payment for care, and about the progression of the condition. On the latter, someone said to us:

> Because you don't know, because nobody's told me what could happen, what the stages are and what I've got to look forward to with him. And I think that would help if somebody could come and explain and say, 'Well look, these are the stages and this is what could happen' … I mean, I know everybody's going to be different, but you could still be sort of prepared.

One Carer said that they were worried about what would happen to their relative if they were to die and could no longer look after them, and would have liked more information on that.

Three people talked about how the workload and unpredictability of caring for someone with dementia, and the emotional toll it took, made it very difficult to plan for the future. As one Carer put it,

> So, I'm just doing the best that I think he would want and just the best I can do. But I am literally just going day to day. I can't think ahead to what might happen next. I think if you took it all on at once, it's just too much to take on, isn't it? I just feel my whole life is a learning curve … Nobody's mentioned the future and I haven't mentioned it. I wish I knew. This is why I think I must be, this is why I'm so stressed because I must be somebody who always wanted order and to know what I was doing next and not say be in charge and in control. But now I've got no control over anything anymore. And I would like to know the future, but no one can tell me that. Or they just say he's on the predicted pathway, which is going to be different for everybody.

It seems likely that Carers having these sorts of experiences would benefit from receiving support to think ahead and plan for future challenges, as it would provide both practical preparation, as well as helping to reduce stress and uncertainty in the present.

A more general point that people raised in the in-depth interviews was that they often experienced a long gap between the initial diagnosis, and receiving any contact from services. "*It's like the minute you get diagnosed, you are told to get on with it*". People spoke of feeling abandoned, and wanted services to check in with them periodically to see whether they were getting the support that they needed, and some Carers wanted reassurance that they were "*doing the right thing*" in how they provided care. Several Carers we spoke to told us that they had to chase up support, and thought that services should be more proactive in responding to requests, and even offering support before it was requested.

Finally, we also asked people about the domiciliary and residential care that they had received, and how well it met the needs of someone with dementia.

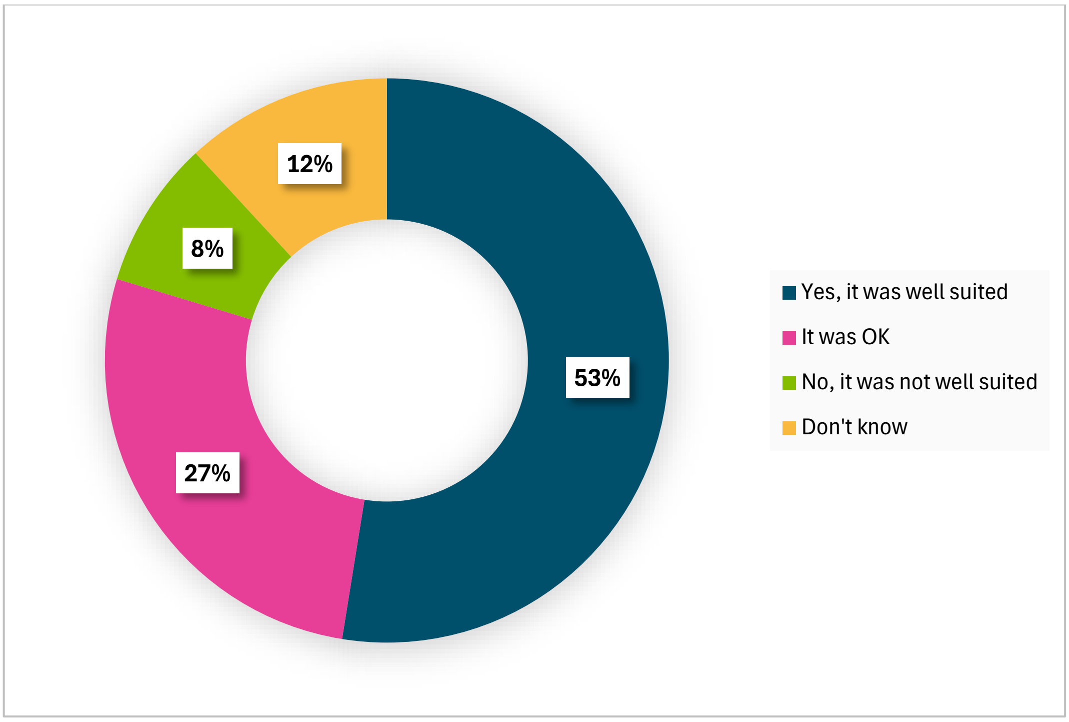

Figure 34: Q26. If you have received care in your home, or care in a care home, was this well suited to meet the needs of someone with dementia?

Eighty per cent of respondents thought that the care was either 'well-suited' or 'OK' for someone with dementia. We also asked people what would have improved this care.

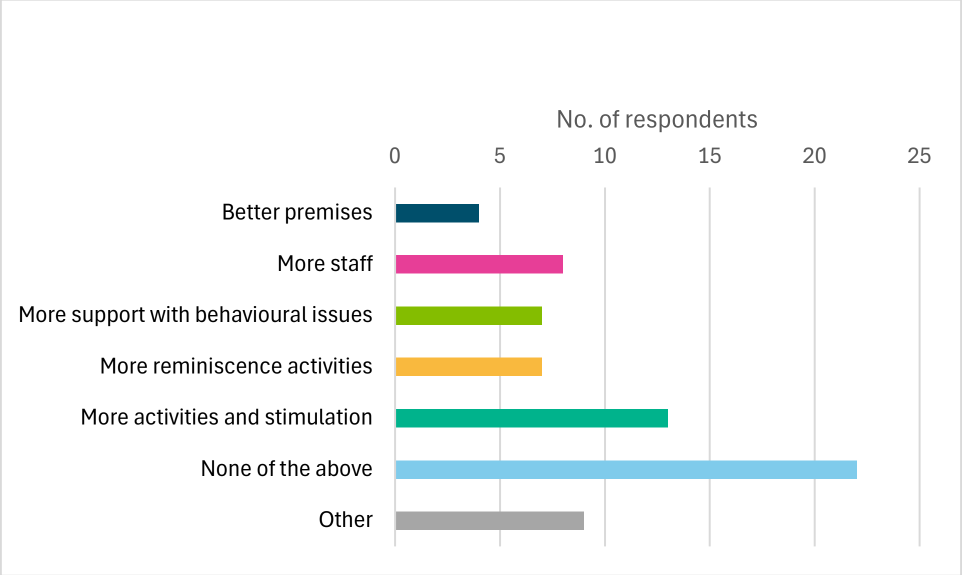

Figure 35: Q.27 What would have improved this care?

The most popular responses were more activities and stimulation, and more staff. See the section on 'Listening' above for more details on qualitative and quantitative feedback about domiciliary care and residential care.

Domiciliary care for people with dementia and a mental health condition

One theme that emerged in the in-depth interviews was about problems some people experienced with domiciliary care for people with dementia and a mental health condition. Four people spoke to us about these problems in the in-depth interviews. While this is a small number of people, the consequences for people were severe, and the problems that they encountered were similar in each case.

In these four cases, we interviewed Carers, who wanted to talk to us about how some of the care provided through ASSD had made their relative's condition worse. These people had all been diagnosed with dementia, and also had mental health conditions characterised by significant anxiety.

In all of these cases, the people receiving support became very anxious if they were receiving care from people that they did not already know, and needed a degree of predictability from their care in order to stay mentally well. A particular problem was domiciliary care agencies sending in a large number of different paid carers, which did not allow the person receiving support to get used to them. For instance, one person told us:

> They started September, I think by Christmas we'd had 22 carers through the door, which was the whole team, apparently. So that didn't help, and it is very crucial bearing in mind, Mum was waiting for a dementia diagnosis, but has got mental health, chronic anxiety and addiction problems … With Mum's mental health, we can't have a lot of people because she don't like it. She can't cope with it mentally. She finds it far too much. Even over the years, even me and my brother have been turned away and, 'You can't visit today, Mum's not in the mood'. So, she'd literally locked down with Dad.

These agencies also did not listen to other requests that Carers were making to protect their relative's mental health. One Carer gave us two examples of this, related to the timing of the visits, and giving notice of visits:

> Can you make this person-centred? Me and my brother had to go, 'I'm sorry … but 9:40 on Saturday's too late'. Mum, I've said from the beginning,

> needs it to be 9, 9:15. She can push 9:20. She can't cope with anything after that because she's awake from four o'clock onwards in the morning and her anxiety builds, so all that goes on. So, they just haven't got it.
>
> Initially, they would ring to say, 'I'm at the pharmacy, Constance'[*]. Then they'd ring and go, 'I'm now leaving the pharmacy, Constance, I'm on the way to you'. Because that just kept her anxiety low. And that's been a nightmare because they haven't been able to do it right.
>
> [*]Not her real name

These people told us about the heavy workload of trying to make sure that their relatives were properly cared for. One person said that, "*it's like a full-time job … Seriously, I'm so sick of moaning, I get on my own nerves*".

We also heard how these people felt that adult social care did not take their relative's mental health problems seriously enough, and were reluctant to provide the person-centred care that their conditions needed.

One person spoke to us of arranging a care agency independently for their mother, who suffers from severe anxiety, which was able to provide the same staff members coming in regularly to care for her. An assessment from a senior mental health nurse stated that her mother needed consistency of care, to protect her mental wellbeing. However, when adult social care started to pay for their mother's care, the allocated social worker said that the existing agency was too expensive, and an agency was appointed which sent in a large number of different people into their mother's home. Also, rather than introducing the new agency gradually, taking over one visit at a time as requested by the Carer, they took over all of the visits from one day to the next, with severe consequences for this person's wellbeing. As this Carer told us,

> I know it sounds dramatic. I genuinely didn't think my mum would live much longer if they carried on, and that was because no consistency in carers, all different people all times. That terror got to the point where Mum was refusing help, refusing food, refusing medication, and utterly, utterly traumatised … She was in trouble. She'd lost more weight. So, my

> Mum had gone down from probably what was a good healthy 10, 11 stone in her normal lifetime to six stone.

The Carer told us that she felt that adult social care staff were reluctant to believe the extent of the impact on her mother's wellbeing. Another Carer commented on her interactions with a social worker about her mother's care:

> She then questioned the fact why she got a morning call, as she's not having to wash. Mental health, mental health, what else do I need to say? Addictive mental health, anxiety, depression, has tried to commit suicide numerous times and luckily hasn't made it. But what more do I need to say? She's taken herself to bed for seven years, that's not bloody normal.

Two of these people also mentioned the added complexity of their relative's spouse's care needs, and wanted services to take better account of both people's needs while providing care. One person told us about how community nurses were often visiting the house to look after their father, but not paying any attention to the impact that was having on their mother's mental health. Another person spoke to us about how a domiciliary care agency they were using for their father was not willing to even consider also providing care for their mother when she developed care needs, which made their situation considerably more complicated.

The stress of having to cope with these problems also had serious impacts on the wellbeing of the Carers. Carers told us that they had reached 'breaking point', and one person told us that they had considered taking their own life. One person told us about the burden of having to constantly make sure that her parents are being cared for properly:

> I'm working six days a week with my job and then when I do have a day off, I'm so tired … I have no social life. [My brother] has got no social life. We are now falling out with each other because things are getting very stretched now. Mum's calling me all through the night. Sometimes she has a bad night. So, I'm getting that and then I have to ring every morning and just prep her for the medication … And we get that every week and nobody's supporting us.

Carers' Experiences

The first question that we asked Carers in the survey was about Carer's assessments. Carer's Assessments are an opportunity for a Carer to speak to a professional about what support they need. It involves discussing how caring affects the Carer's physical, emotional and mental wellbeing, and whether they are able or willing to continue to provide care for someone. A number of services can be offered to support Carers, including information and advice; respite care to give them a break from caring; counselling and mental health support; benefits advice and more.

Carer's assessments are carried out directly by the local authority in some areas in England, but Norfolk County Council and Norfolk and Waveney Integrated Care Board currently commission Carers Matter Norfolk to carry out Carer's assessments. Carers Matter is run by a partnership of Caring Together, Voluntary Norfolk and Norfolk & Suffolk Care Support.

As shown in the chart below, around a third of the 117 people who answered the question, said that they had received a Carer's assessment, a third would like an assessment but have not had one, and a third would not like an assessment. Out of the 36 people who would like an assessment, 16 people said that they were unaware of the Carer's Assessment, 16 people said that they would like an assessment but had not been offered one (though it is possible that some of these people were not eligible for an assessment), and 4 people were on a waiting list for an assessment.

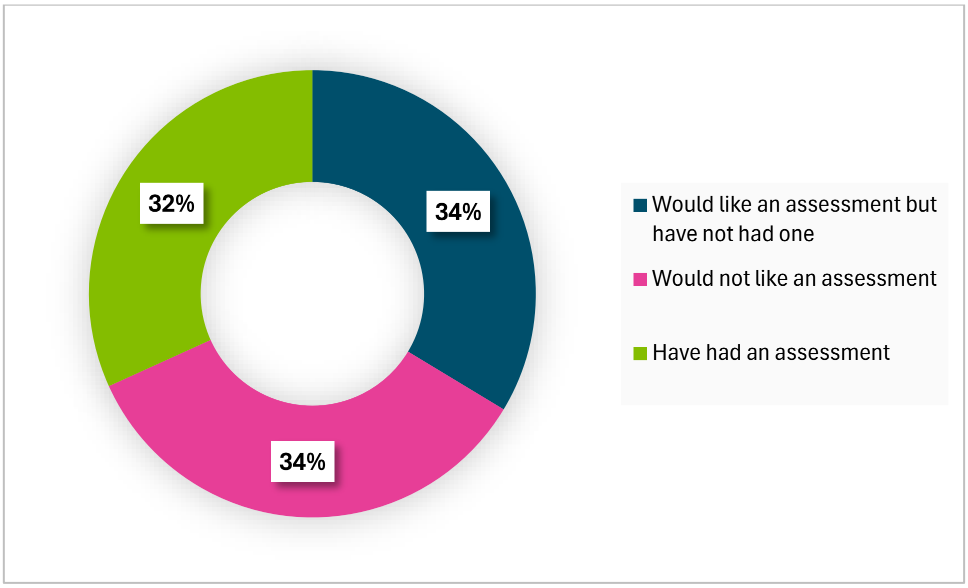

Figure 36: Q28. Carer's assessments

Next, we asked people what support they had received as Carers:

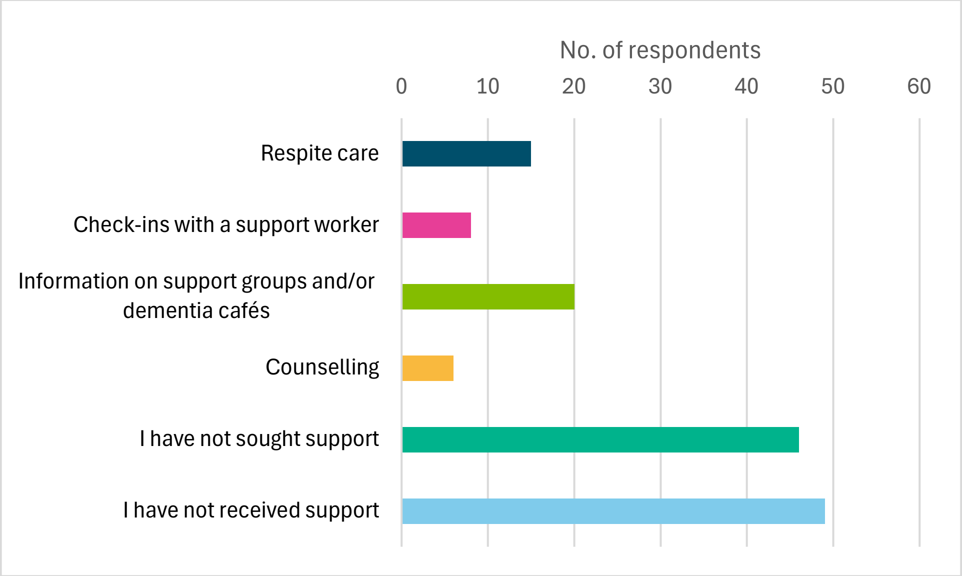

Figure 37: Q.29 What support have you received as a Carer?

The most popular responses were that people had not sought support (36 per cent or 46 people) or had not received support (43 per cent or 55 people). The next most popular answers were information on support groups or dementia cafés (16 per cent or 20 people) and respite care (12 per cent or 15 people). We also asked people who had received support, how helpful it was for them:

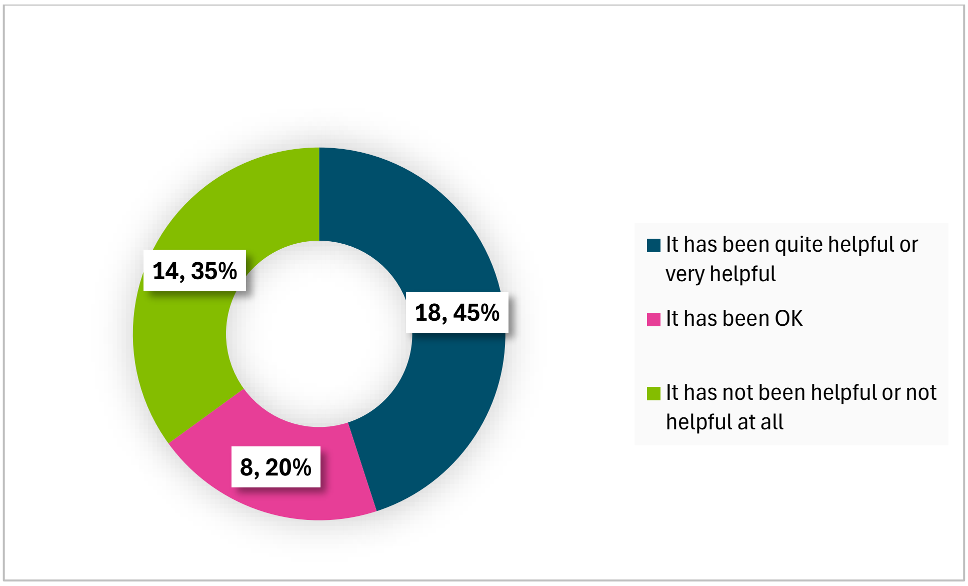

Figure 38: Q30. How much has this support helped you?

Most respondents found the help that they did receive to be either helpful or OK (26 people or 65 per cent).

In the interviews with Carers, six people told us about the positive impact that Carers Matter had had on their situations. Four people told us that they had received counselling sessions, and three of these said how helpful they had found these. For example, one person said:

> I had a few sessions with the counsellor, which was absolutely brilliant, and I wish I could have it endless. It really helped having somebody to talk to each week.

People also told us that, as well as helping them to access useful services, the Carers Matter staff were helpful and empathetic. One staff member was described as “a friendly person you can really talk to”, and a Carer told us that “it was lovely” to get their phone calls and advice. People also told us that Carers Matter had helped them to access befriending services, sitting services and respite care, as well as giving them advice on benefits, and helping them to make plans for the future.

Three people told us that their contacts with Carers Matter staff was more mixed. Two people told us that they formerly had staff at the service who were very good, but that they had left and been replaced by someone who was not as good. For another person, the opposite had happened. Three people mentioned that they had been signed off after a year, and they found it inconvenient to have to get a new referral. One person questioned why they were being signed off, when they were caring for someone with a long-term condition.

Four people said that they had contacted the service, but that they had been unable to offer them any meaningful help. For one person, this was partly due to broader failures in the system, and the seeming impossibility of finding domiciliary carers who would be able to look after her parents well enough to ease the pressure on her. She asked:

> What are they going to offer me? What are they going to offer me when all we need is carers to come in and do what they need to do in the right way at the right time so we can step back. I don't need counselling. I don't need a spa day to be honest. I don't want the feet done. I'm not bothered about nails, and I've got to go to work.

Another Carer said that the sitting service they were offered was for too short a period to offer a meaningful break for her, and another said that they were unable to offer her the one visit a day from a carer that she asked for. Another person was frustrated that “it was all advice and pathways”, and felt that she wanted more practical help, and someone else said that, while they did receive information, “it was a big bump of information … which was too long to be any good”.

Services and carer breakdown

Of the 32 Carers we interviewed, 13 people told us about times that they felt overwhelmed and unable to cope with their caring responsibilities. Some typical comments were:

> I've got to the point now where my GP is so worried about me that I might just disappear, because I can't take anymore.
>
> We are coming to a point where something's got to give. It's kind of, I'm getting so tired now. Things get on top of you. It just takes one little thing and then the little pack of cards begins to collapse.
>
> I’ve just got so much to think about.
>
> Everyone’s sort of relying on me, so if I collapsed, then the whole caboodle falls down.
>
> All we are doing is we're going over there constantly, running around working and we don't stop. We don't have a drink, we don't have food and we don't have a life. And now we've started to fall apart, me and my brother.

In this context, getting services right for Carers is vital, particularly because, as several Carers pointed out, the cost to services of Carers no longer being able to cope is substantial, as is the damage to the cared-for person’s wellbeing.

Two Carers we spoke to mentioned that being overwhelmed had affected their interaction with services. One person told us how they accepted a respite placement for their mother that they thought might not be suitable, because they were too tired to say ‘no’:

> Well, to be honest with you, the mixture of me being so tired and exhausted and them saying that, “This is what you must do and this will be better for your Mum and this will be better for you, and this is all we've got to offer”. I just bent. I just bent.

Another person spoke to us about the difficulty of understanding what was happening in a multi-disciplinary discharge meeting in a community hospital when they were exhausted, which stopped them from having a meaningful influence on it:

> I'll just say one thing in their defence, that if one is so tired and overwhelmed, I don’t know how they could help more. Maybe they did explain it and it didn't go in, I don’t know … but maybe there would be a mechanism of giving them a bit of information over a drip feed rather than just going to this meeting.

This indicates the importance of professionals always taking account of the wellbeing of the Carer, and not just the patient, as several Carers were keen to emphasise. One Carer spoke eloquently of her experience of caring for her husband:

> And nobody seemed to be saying, ‘Well, Lucy* is not well herself. What are the stresses and strains that she's been under? And should we be looking a little bit at the whole family situation?’ What they did was to look at Michael*, who they saw as their client, and dismissed anything that I was saying about my own health problems.
>
> And they've been lifelong problems. I've got [a range of mental and physical health problems], for which I'm under treatment with hospitals. So, my energy levels and my stress levels have to be controlled in some way too. And of course, this is what I was kind of feeling was being ignored.
>
> There was one conversation I had with the nurse for the frail and elderly, a very capable nurse. She was a very good nurse. And I remember saying to her, she had come to visit, and I said to her, ‘It's not so much Michael now’, I said, ‘it's me’. ‘Oh, don't be silly’, she said, ‘of course you can cope. Maybe

> you just need a little bit more help'. It was like a smack in the face. I can't explain it more than that.
>
> [*]Not their real names

For many of the services we asked people about, most people said that they were happy overall, but it was also common to hear thatnot all services had not worked well for them. Our findings suggest that, for Carers who are already overwhelmed with their caring workload, failures and delays in services could be the factors that lead to Carer breakdowns, because they start to feel that there is no help available for them.

For example, one person told us that someone from ASSD had called her once, but then had never got back to her, and the domiciliary care agency's support was not working well for her cared-for person. She told us how this affected her:

> From my point of view, I felt abandoned. I can remember just crying and just think at that point, thinking, feeling quite despairing that you really can't get help.

Another Carer said, after asking what help they were entitled to and not receiving a response for several months:

> I get very frustrated with it. That's basically the situation we're in: asked for help, nothing has come.

This seems to be why many people we spoke to were keen to have a single point of contact, and to have professionals proactively checking in with them: it would help them to feel that they were not alone, that people cared about what they were going through, and would provide reassurance that if they do need help, it is available for them.

Support with behavioural challenges

In the survey, we asked Carers whether they felt they had received enough support to manage behaviours that may challenge others. Forty-eight people (or just over two thirds) said that they had not:

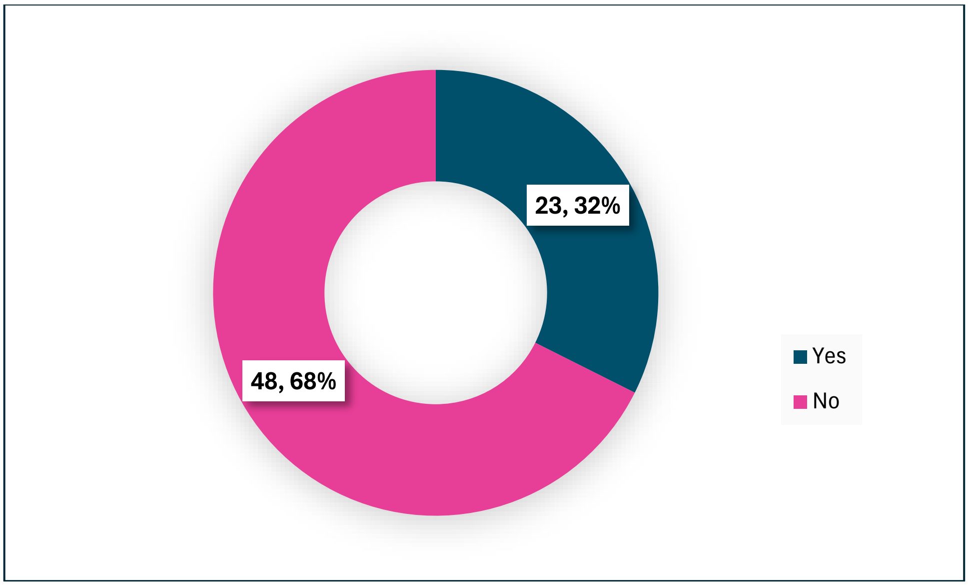

Figure 39: Q.32 Have you received enough support to manage behaviours that may challenge others?

We also asked people what kind of support would have helped them to cope better with behavioural issues. People gave a wide range of different answers, which are summarised in the table below:

Table 5: What support would have helped you to cope better with behavioural issues?

Suggestion	Number of people
Funded respite care	5
Care home placement	3
Mental health support	2
Domiciliary care given earlier	2
Better social life	2
Support groups	1
Dedicated case worker	1
More recognition for Carers	1
Help with mobility	1
Carers Assessment	1

In the in-depth interviews, 14 people we spoke to told us that they had not had any help to deal with challenging behaviour. Five of these people felt that they did not need this assistance, but nine people did. One person told us about her struggle with her husband's behaviour and what she wished someone had told her earlier on in her struggles with her husband's behaviour:

> Once they get this diagnosis it's, "Off you go". They don't want to know. I wish to goodness I'd been able to keep him at home ... I was literally terrified of my husband and trying to keep him safe, keep both of us safe ... I found that I couldn't trust him to be on his own. He needed constant supervision. So, I had to stop work ... I just couldn't cope anymore. He didn't strike me, but he'd just fling me away. And I was learning, I didn't know the best way to be with him, it's such a learning curve. And at this stage of the illness, nobody tells you. Three years on, I've realised how traumatic it was for him at the time. But over time, well, he's survived the crisis, so the trauma is lessened.

For some people, like this Carer, they were looking for guidance, information, and perhaps training in how to understand what was happening to their relative, and how to cope with behaviour themselves.

Three other people identified a lack of capacity from care providers to manage behavioural issues. Two people said that care homes had refused to take their relative on, because of what they saw as quite minor incidents. For example, one person had shouted at night because they were stuck in their bathroom, and when a prospective new home heard about this, they refused to take that person on. Another person told us about what they saw as a lack of capacity in domiciliary care agencies to cope with behavioural issues:

> I don't think [care agency] had it, okay, [another care agency] haven't got it. And they look after old people. They all look after old people. If you go through that provider's list, I can have Timbuktu Healthcare and I can write a whole list of what they do, but if you go, "Oh, dementia, so do you manage behaviour? Do you manage dysphasia, continence?" "No". And I'll lay money that you can do that as a questionnaire and they will not. They'll say, "No, we don't, but we do dementia". What *do* you do then?

Maintaining relationships and connections to the local community

Finally, we asked Carers whether they, and the person they look after was able to maintain relationships, and links to their local community.

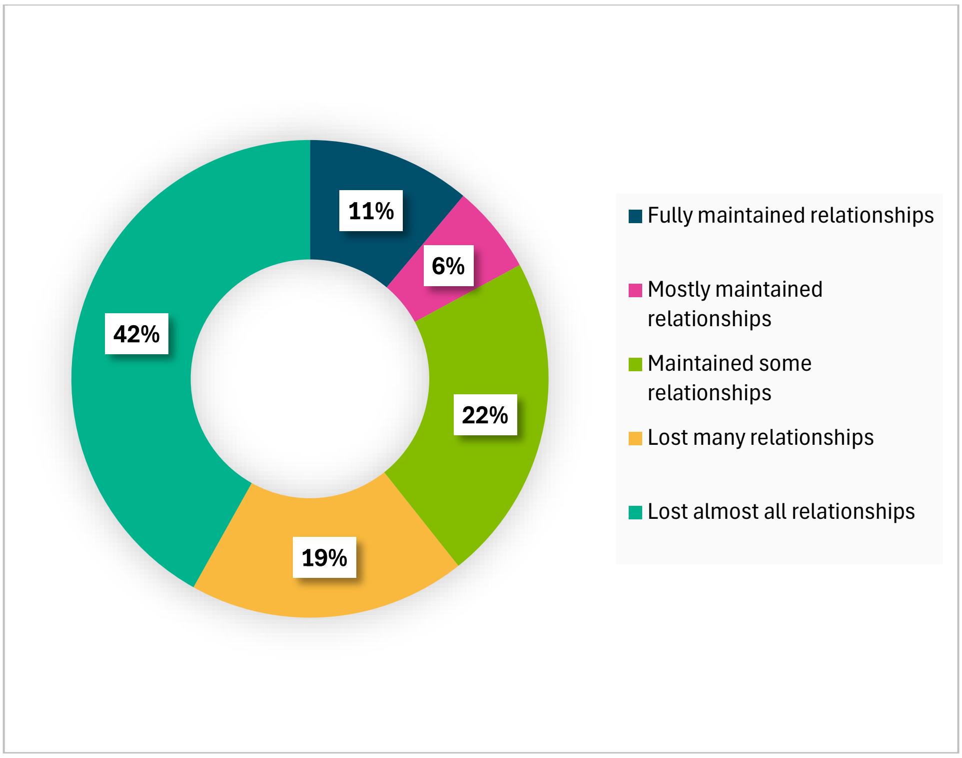

Figure 40: Q31. To what extent have you and the person you care for been able to maintain relationships, and connections with your local community?

As this chart shows, 61% of people told us that they had lost many or almost all of their relationships. This clearly seems to be an area of great need for older people with care needs in Norfolk. The people we spoke to in the in-depth interviews also told us about problems with socialising. Some people managed to maintain relationships, often with the help of family, who would make a point of visiting regularly. Some people were involved with local churches, and a few others made use of day centres and befriending services.

People who did not have this help often told us that people withdrew from them socially, because they were uncomfortable speaking to someone with dementia, or did not know what to say. A Carer spoke vividly of the effect of this on her:

> I was always a very active person. As I said, I worked part-time until I was 70. I was involved with the church. I've got lots of friends, but I'm finding that people, friends aren't inviting us anymore. People don't think we want to come to the house. I think they don't know how to deal with him. And

> what I find is that when I do meet up with my friends, all I seem to talk about is him, I've got no other, I haven't got anything. It's difficult to maintain other interests. So, I am finding it hard because I've always been such an outgoing and involved person and my life is getting smaller by the minute.

Part of the problem for this person is how all-consuming looking after someone can be. Some people told us that it can be very confining, and leaves very little spare time to be able to pursue interests or maintain relationships. One Carer gave us a practical example of this:

> I can't even get to the garden. I'm standing here. I've got one eye on him in the lounge and one eye looking at a blessed deer running across my garden and I can't get out there to shoo it away because the furthest I go is to my bins outside the back door except on a Wednesday or a Friday as there's a carer here.

A further difficulty was that people with dementia often became unable to engage in the activities in the community that they used to, for reasons of capacity. One Carer gave us the example of this happening to her mother:

> Right at the point where she was volunteering in an RSPCA shop for a good 15 years, and she was coming home quite stressed … I think they were realising that she was getting a little bit forgetful … and then they decided to ask my Mum in a nice sort of way to leave. So therefore, my Mum then become just this lady in a bungalow on her own, and the only person that was visiting her was me and my family.

Some other Carers told us of the value of persuading people to engage in new kinds of social activities, but also spoke of the difficulty to persuade people to try new things:

> I think we're getting more isolated now. Mum used to go out and see friends and the husband who lives in Norwich and all that kind of thing. But she is very much at home now. And to be fair, a lot of her friends actually died off. But she has said that she's bored, stuck at home by herself. And

> we've tried to get her to go out to maybe a little group at the library and stuff, but way she's kind of not interested, but they're new people and it's kind of frightening to see new people.

While some people did manage to persuade their family member to do new things, and people mentioned Church activities, befriending groups, day centres and peer support groups, in some areas these were not available. Some Carers told us that peer support groups had recently closed in their area (particularly in West Norfolk, with the closure of West Norfolk Carers), and one Carer told us that she had looked for any kind of social activity for her cared-for person, but that she had "just drawn blanks everywhere" she had looked.

What this means

Year one of this project has sought to answer a wide range of questions about different areas of older people's experiences of adult social care in Norfolk. On the three main project themes we draw the following conclusions.

Most people feel well listened to by social care services, but the feedback we received suggest that some people find interacting with services challenging. This is partly related to information and knowledge. Some people who are newcomers to the sector struggle to know how to navigate it. There are many organisations and services, which these people said they find overwhelming and difficult to navigate alone, particularly as they often struggle to understand the jargon used in the sector. People also mentioned across all project themes that they were unsure of what services social care can offer them, and so did not always know what to ask for.

This suggests that people need more information about their options and entitlements, but people also said that they wanted professionals to guide them through the information, rather than being left to do so themselves. Related to this is the problem that some people raised of not being given information about how much they would have to pay once their savings dip below £23,250, but having to wait until their savings reach this level. This is creating significant uncertainty and worry for these people.

A key point for many people in receiving information and accessing support is their Care Act Assessment. Again, most people were happy with their assessments. However, a significant proportion of people (19 per cent, or 26 people) had not had all of the people involved in their assessment that they wanted to be. NCC have been putting an increased focus on making sure that everyone that should be is involved in assessments over the past year, or so. It is not clear from our data if some of the people that we were talking to had had assessments before this period (because we asked about experiences in the last 18 months). Nevertheless, our findings suggest that this might still be a problem area.

A common finding across themes in the in-depth interviews was that some people thought that they had been signed off too early by social workers, and would have liked professionals to check in with them after their care package had begun to see whether it was working well. They found that the hassle of starting a new referral when a problem arose was a significant barrier to getting the care that they needed.

Most people we spoke to said that they were happy with how domiciliary care (58 per cent, or 36 people) and residential care services (69 per cent, or 18 people) listen to them. However, workforce problems continue to affect capacity in the Norfolk care market, making it difficult for people to find suitable providers, and affecting how flexible, timely and person-centred this care can be. NCC has been taking a range of measures to improve this situation for some time, as detailed in the workforce strategy: https://www.norfolk.gov.uk/article/38964/Adult-social-care-workforce-strategy. However, this is partly a national level problem, and only so much can be done at a county level.

On hospital discharge, 31 per cent or 33 people told us that falls prevention advice, equipment and home adaptations could have prevented their admission to hospital. This is an area in which work has been ongoing across the health and social care system in Norfolk, but it may be that it is not well known enough across all organisations.

Communications around discharge seem to be a particular area where improvements could be made. Significant numbers of people reported not having been consulted about their (33 per cent, or 31 people) or their Carer's (46 per cent or 37 people) discharge preferences, not being given information in good time about their care package and not understanding how discharge decisions were being made. This suggests a concerning degree of uncertainty for people, and this problem seems to be especially pronounced for women. It is not clear what the causes of this gender disparity might be, but it could be investigated further.

Some people also told us that they were annoyed that they had been told that they would receive six weeks of free care after they left hospital, only to find that they would have to pay for this care once they arrived home.

Most professionals told us that they thought that the discharge to assess system was working well and had improved integrated working. However, much work remains to be done in this respect, and it seems that more integrated budgets and spending powers would allow professionals to orient support to the needs of individual patients, rather than having protracted debates about who should pay for what support. Differences in ‘risk appetite’ seem to persist, but these are often complicated by the lack of capacity in the care provider market, which often prevent positive risks being taken in the community.

We asked people about their experiences of receiving support after they had been diagnosed with a condition. We found that significant proportions of respondents felt that there was insufficient support to learn more about their future (33 per cent or 22 people), or support to plan for the future (47 per cent or 32 people).. People said that they would like more information after the diagnosis, specifically about the nature and progression of their condition, and information about who will pay for care when the time comes and what their care options are. Carers are often overwhelmed by their caring workload and want professionals to guide them through the information, as well as checking in with them periodically, especially in the period between diagnosis and when they start to reach crisis point as the condition worsens.

In terms of care providers’ performance in caring for people with dementia, most people (80 per cent, or 47 people) told us that they were satisfied. There were issues raised, again, about staff shortages, however, and about unsuitable premises and insufficient stimulation through activities. A particularly severe problem was raised by a small number of people about how domiciliary care services work with people with mental health problems and dementia, with the care provided in a way that can worsen their condition, and these people also thought that social workers underestimated the complexity of these situations.

Finally, Carers told us that they were often overwhelmed by their responsibilities, which makes it especially important that services support them well, to avoid Carers burning out. This suggests a need for professionals to always consider Carers’ wellbeing at the same time as the person receiving support. Carers Matter received positive feedback in terms of the support it provided to help with Carer’s wellbeing, however, a thirdof Carers who spoke to us had not received help from them and would like to. Part of the problem for the people we spoke to was that they had not heard about the service. As in the other sections above, Carers wanted professionals to proactively check in with them to see if they were coping since they often felt abandoned and alone, and some did not understand why they were signed off from the Carers Matter service after a year and would have preferred a check-in to see whether they still needed support.

Finally, there seems to be a very significant problem with social isolation for older people with social care needs and their Carers, with people’s social lives deteriorating dramatically as they have lost their independence.

Recommendations and response

We make a number of suggestions for action, which are divided into **recommendations** that can inform social care strategies now, **engagement and research actions** that the project itself will take up in the remaining two years, and **longer-term goals** for Adult Social Care. Responses from NCC are included under the recommendations.

Listening

Recommendations

- Information on the social care 'offer' is already available online, yet some older people we spoke to told us that they did not know how to access it, and were not always confident accessing online information. New ways of providing older people with information on the adult social care ‘offer’ should be considered, including hard copy materials. Information could be printed in the Your Norfolk magazine, which is distributed to over 400,000 households in Norfolk. Information could also be published in Parish newsletters.
- Some people who were new to the social care sector told us that they found the number of options and organisations confusing, and found information hard to decipher by themselves. Such people could gain considerable confidence with a short guidance session from a knowledgeable professional. Age UK Norfolk and the Norfolk Community Advice Network both provide telephone advice services, and signposting people to these services when they first develop a social care need could reduce confusion considerably. Such signposting is already happening, but could be increased in settings such as:
  - GP surgeries after someone develops a new health condition or frailty.
  - Acute and community hospitals when older people are admitted.

Response from Adult Social Care:

We will:

- Identify what information could be provided in hard copy, recognising that we need to ensure it doesn't become out of date.
- Make better use of existing hard copy publications to share information.
- Review the information and signposting that is available in GP surgeries and raise this will colleagues in health organisations to see how further information could be provided at key times by health professionals.

Engagement and research actions

- In Year two of the project, we will explore how information about adult social care can be better communicated to older people in a way that they find easy to access and understand.
- Recently-implemented measures to ensure that everyone is included in needs assessments that people want included should be reviewed to verify whether they have been successful. These measures began to be implemented during the period people were asked about in Year 1, and so the results were unclear on this point. The project could revisit this topic in future years.

Longer-term goals

- Subject to available resources in the future, check-ins with professionals should be scheduled for people who have recently had a Care Act Assessment to see whether a care package is meeting their needs. Adult Social Care should consider delaying signing people off until a check-in has taken place.

Hospital discharge

Recommendations

- As detailed above, a significant proportion of patients reported not being asked about their discharge preferences, not being given information in good time about their discharge destination, and not understanding how discharge decisions were made. To begin to remedy this we would recommend that:
    - When staff are filling in a transfer of care form or making a referral for patients who will need social care support after leaving hospital, all patients and Carers should be explicitly consulted about their

    discharge preferences, and see that their preference has been recorded.
    - When staff judge that a patient will not need support after discharge, they should nevertheless check this decision with patients and Carers and ask what their preferences are.
- Communications with patients in hospital about how social care after discharge will be paid for should be improved. We recommend that information be provided in a range of formats for people who are still in hospital and their carers, or at the earliest opportunity thereafter.

Response from Adult Social Care

We will:

- Target Year 2 research to better understand available information and best practice to meet people's needs.
- Liaise with partner organisations as part of ongoing hospital discharge process improvement to share the findings of this report and recommendations and in particular focus on information available to patients in hospital about social care choices.

Engagement and research actions

- The gender disparity in satisfaction with discharge communications is concerning. Its causes are unclear from the feedback we gathered, however, and more in-depth information is needed before recommendations can be made. In year 2 of the project we will therefore consult older women patients about their experiences, as well as gathering hospital staff's views on this topic.
- In year two of the project, we will consult ward staff in acute and community hospitals on how communications with patients and Carers about their preferences for support after leaving hospital can be improved. We will seek ways to provide more accurate information about post-discharge care and funding, managing expectations and preventing potential frustration, and test this information with patients.

Longer-term goals

- Further pooling of health and social care budgets and spending powers should be considered, to reduce delays caused by budget disputes, and to ensure that person-centred care is not hampered by organisational barriers.

Support after a dementia diagnosis

Recommendations

- The North Norfolk Dementia working group has recently started taking actions which address two of the most prominent findings from Year 1 about dementia services, and we recommend that these are rolled out to other areas of the county. These are that:
    - More learning support should be given to people upon diagnosis, and more help to guide people through their options, including on social care and who will pay for it. Information resources have been developed in North Norfolk showing people the process they will go through with services before and after diagnosis, and what support is available to them.
    - More check-ins from professionals should be considered and a mechanism for adult social care to be in contact with people earlier in their journey - these are due to be carried out by Protect Now with all people in North Norfolk with a dementia flag on their records, and the Dementia Support Service are contacting everyone awaiting a memory assessment with NSFT.
- In addition, measures could be taken in the short-term to reduce the social isolation of some people with dementia. Some of the feedback we received suggests that services providing some dementia peer-support groups were recently recommissioned, putting some local groups under threat of closure. ASSD should verify whether existing groups have been replaced by the new providers, and explore options to replace them if they have not been.

Response from Adult Social Care

We will:

- Share the findings of this report with all Integrated Care System organisations reviewing dementia care in Norfolk.

Engagement and research actions

- Norfolk and Waveney ICB is currently formulating a county-wide dementia strategy. In year 3 of the project we will consider how to collect people's feedback on their experience of the roll-out of the new strategy.

Longer-term goals

- More activities and stimulation in care homes for people with dementia should be considered and enabled where necessary.
- Domiciliary care options for people with mental health conditions and dementia should be reviewed, with a view to raising awareness amongst providers of how to care well for people with these conditions.

Carers

Recommendations

- The feedback that we received suggests that Carers Matter Norfolk’s services are invaluable to many older people, but could be promoted to more people, with around one third of respondents saying that they would like a Carer's assessment but had not received one. While some of these people may not be eligible for an assessment, we recommend that NCC investigates where the service is being promoted, and whether it could be promoted more widely, especially in settings such as GP surgeries, where people may discover for the first time that they have a social care need.
- Carers Matter Norfolk could consider checking in with people after a year, rather than signing them off, where someone is suffering from a chronic or progressive condition.

Response from Adult Social Care

We will:

- Review how Carers assessments are referred and opportunities to increase the number of people accessing these.
- Share the findings of this report with commissioners who are in the process of reviewing the existing contract for Carers support.

Engagement and research actions

- We will also engage with people in more detail in year 2 about what help they would like to help them to stay socially connected as they get older.

Longer-term goals

- More help could be provided to Carers for dealing with behaviours that challenge – and most people told us that more respite care would help them most in this respect.

References

ADASS. (2023). *Adult Social Care Budgets & Waiting Times: Autumn Survey Report 2023*. Association of Directors of Adult Social Services. https://www.adass.org.uk/media/9897/autumn-survey-report-2023-adult-social-care-budgets-waiting-times.pdf

Alarm over number of care vacancies as county faces surging dementia numbers. (2024, April 29). Eastern Daily Press. https://www.edp24.co.uk/news/24275185.norfolk-care-vacancies-sparks-alarm-dementia-cases-rise/

British Geriatrics Society. (2023). *Protecting the rights of older people to health and social care*. British Geriatrics Society. https://www.bgs.org.uk/policy-and-media/protecting-the-rights-of-older-people-to-health-and-social-care

Buch, E. D. (2015). Anthropology of Aging and Care. *Annual Review of Anthropology*, *44*(1), 277–293. https://doi.org/10.1146/annurev-anthro-102214-014254

Chen, P. G., Tolpadi, A., Elliott, M. N., Hays, R. D., Lehrman, W. G., Stark, D. S., & Parast, L. (2022). Gender Differences in Patients' Experience of Care in the Emergency Department. *Journal of General Internal Medicine*, *37*(3), 676–679. https://doi.org/10.1007/s11606-021-06862-x

Elliott, M. N., Lehrman, W. G., Beckett, M. K., Goldstein, E., Hambarsoomian, K., & Giordano, L. A. (2012). Gender differences in patients' perceptions of inpatient care. *Health Services Research*, *47*(4), 1482–1501. https://doi.org/10.1111/j.1475-6773.2012.01389.x

Healthwatch England. (2023, December 20). *NHS urged to do more to help patients leave hospital safely*. https://www.healthwatch.co.uk/blog/2023-11-20/nhs-urged-do-more-help-patients-leave-hospital-safely

Healthwatch England, & British Red Cross. (2020). *590 people's stories of leaving hospital during COVID-19*. Healthwatch England.

https://www.healthwatch.co.uk/sites/healthwatch.co.uk/files/20201026%20Peoples%20experiences%20of%20leaving%20hospital%20during%20COVID-19_0.pdf

Landeiro, F., Roberts, K., Gray, A. M., & Leal, J. (2019). Delayed hospital discharges of older patients: A systematic review on prevalence and costs. *The Gerontologist*, *59*(2), e86–e97.

Luengo-Fernandez, R., & Landeiro, F. (Forthcoming). *The economic burden of dementia in the UK*.

Reeves, C., Islam, A., & Gentry, T. (2023). *The State of Health and Care of Older People in England 2023*. Age UK. https://www.ageuk.org.uk/globalassets/age-uk/documents/reports-and-publications/reports-and-briefings/health--wellbeing/age_uk_briefing_state_of_health_and_care_of_older_people_july2023.pdf

Teunissen, T. A. M., Rotink, M. E., & Lagro-Janssen, A. L. M. (2016). Gender differences in quality of care experiences during hospital stay: A contribution to patient-centered healthcare for both men and women. *Patient Education and Counseling*, *99*(4), 631–637. https://doi.org/10.1016/j.pec.2015.10.033

Turnpenny, A., & Hussein, S. (2022). Migrant Home Care Workers in the UK: A Scoping Review of Outcomes and Sustainability and Implications in the Context of Brexit. *Journal of International Migration and Integration*, *23*(1), 23–42. https://doi.org/10.1007/s12134-021-00807-3

Willett, K., Winn, M., Roughton, R., & Skinner, A. (2020). *COVID-19 hospital discharge service requirements*. https://mg.salisbury.nhs.uk/media/2175/19032020-nhse-i-hmg-letter-hospital-discharge-guidance.pdf

Wittenberg, R., Hu, B., Barraza-Araiza, L., & Rehill, A. (2019). Projections of older people living with dementia and costs of dementia care in the United Kingdom, 2019–2040. *London*: *Care Policy and Evaluation Centre, London School of Economics and Political Science*, *79*. https://www.infocoponline.es/pdf/Working-paper-5-Wittenberg-et-al-dementia.pdf

Woods, S. E., & Heidari, Z. (2003). The influence of gender on patient satisfaction. *The Journal of Gender-Specific Medicine: JGSM: The Official Journal of the Partnership for Women's Health at Columbia*, *6*(4), 30–35.

World Health Organization. (2021). *Global status report on the public health response to dementia*. https://digitalcommons.fiu.edu/srhreports/health/health/65/

Appendix

Experiences of Adult Social Services from people supporting someone with dementia

Carers Voice Norfolk & Waveney – interviews report

April 2024

Carers Voice Norfolk and Waveney conducted 21 interviews with Carers of people with dementia who were diagnosed within the previous 36 months and one Carer of a person who was diagnosed more than 36 months ago who is currently in receipt of services from Adult Social Care.This is part of a three-year engagement project which Norfolk County Council commissioned Healthwatch Norfolk to undertake about the experiences of people over 65, and their Carers, of Adult Social Services.

This project is looking at areas of current and predicted high demand for social services support for older people, including dementia services. The dementia theme of this project is exploring the challenges people living with dementia and their Carers face, including:

- Knowing more about their dementia
- Planning for the future
- Being supported to be involved in decisions about their lives
- Maintaining relationships and connections to their local community
- Support to Carers
- Managing behaviours that may challenge others
- Living positively with risk

Seven Carers were supporting a parent, one Carer was supporting a grandparent and thirteen Carers were supporting a partner including spouse. Carers were located across Norfolk including Broadland, Breckland, South Norfolk, North Norfolk, West Norfolk, Central Norfolk and Norwich. The interviews took place from November 2023 to April 2024. The interviews took place via telephone or Zoom depending on the preference of the Carer. One Carer shared their feedback via email.

The report begins with an overview of the key overaching themes identified by Carers. This is followed by a summary of feedback on specific project themes, and the final section summarises recommendations from Carers.

Key themes about experiences of Adult Social Services from people supporting someone with dementia

Communication and trust

Several Carers reported difficulties with communication with Social Workers. In some cases, multiple Social Workers were involved. Some Carers felt contact and support is only offered when they reach out and there is no regular follow up. Difficulties were reported when a specific Social Worker was off work because of sickness, with Carers having to chase for support. A lack of trust was identified, particularly when Social Services were commissioning a care agency or facility that meets the needs of the person they are caring for. Carers often feel they must do their own research.

Two experiences were reported of a lack of communication regarding payment for services including respite and Norfolk First Support, where people assumed 6 weeks free support would be provided. This support is now means-tested according to people’s income and has not been free for everyone for some time.

Some Carers reported the number of people and organisations being involved in people’s care which can be overwhelming and difficult to manage and that a single point of contact would be helpful. Multiple Carers reported lack of communication and involvement in hospital discharge planning resulting in the person they care for being placed in a setting that they felt did not meet their needs. However, when there is clear communication and time to understand individual needs, Carers reported feeling supported.

Lack of available care

Carers told us there is a lack of available support from domiciliary care agencies and other services within the community that meet the needs of people with a dementia diagnosis. This seems to be particularly prevalent in rural areas of Norfolk. Carers said that this results in a lack of support available to access and the absence of choice. Carers reported needs being identified by Social Services but support not offered due to shortages of care staff and lack of support in the local area. Multiple instances were shared, including an experience from one Carer who was left without support for 6 weeks following discharge from hospital, and the person they care for was subsequently readmitted.

Carers having to initiate support

Carers often told us that they have to be the ones to initiate or push for support for the people they are caring for and for themselves. Overall, Carers did not feel supported to plan for the future or manage challenging behaviours. Carers fed back about the need for someone to offer reoccurring check-ins to provide reassurance that they are ‘*doing the right thing*.’ Some Carers felt they have been ‘*left to fend for themselves*’. A gap in support was reported from when a person is diagnosed with Dementia to when more intensive support is needed. Carers mentioned that there is a lack of follow up after the diagnosis has been made. *“It’s like the minute you get diagnosed, you are told to get on with it’.*

Lack of person-centred care

Generally, Carers told us care is frequently not tailored to meet the individual needs of a person. There are concerns about the training and support provided to new domicilary care staff. Carers told us that inconsistency of support provided by care agencies can be very problematic for people with dementia and systems are rigid with a lack of flexibility around, for example, the timing and length of visits.

Carers reported that activities offered within care homes are usually generic and not based on individual interests. Carers that sourced and privately funded care reported more flexibility and continuity of care.

Limited support for Carers of self-funders

Carers of people with dementia who are self-funders shared that they do not feel supported by Social Services. They feel they are left to research and organise services with little or no support.

Break from caring

Carers told us that having access to a break from caring is really important. However, the support offered needs to be suitable to meet the needs of the person with dementia so they can feel assured the person they care for is being looked after. Carers shared that there is a lack of choice and availability of appropriate respite that meets individual needs.

Discharge

Carers reported a lack of involvement from when the person they care for was admitted to hospital through to when they were discharged. There were also difficulties with the care facility people were discharged into. Specific issues were highlighted about the care home not being suitable for their needs or located a long distance from their home.

Lack of mobility support

A few Carers reported initial contact or sessions with a physiotherapist or occupational therapist, but these had not continued, which had impacted on the person they care for's mobility. It felt as if services 'gave up' on rehabilitating them. Some Carers raised questions about whether these staff have experience or training to support someone with dementia.

Positive experiences with Adult Social Services

The following instances were highlighted by Carers as examples of good practice:

- Practical support from Occupational Therapists, Assistive Technology and 'Care and Repair' such as equipment (stair rails, shower seat, etc) and technology (alarms, sensors ring doorbell) were mentioned by several Carers as being helpful. One Carer said the service had been '*marvellous'.*
- Some Carers have received support from Norfolk First Response, Swifts and Night Owls. Norfolk First Response stepped in when no other care locally could be found. However, one Carer shared they did not have the best experience with Swifts.
- The social worker within Julian Hospital was helpful.
- Emergency Duty Team: – One Carer contacted them in a crisis and could not fault the team. They were good at coming back to them, following up and keeping the Carer updated.
- Good conversations were reported with services but for some this was due to internal knowledge about how systems worked.
- Crisis point- felt heard and supported wishes. Did not push for anything they didn't want and were patient when things changed due to wishes around respite.
- Social worker that came to meetings about a longer-term placement was helpful.

- A social worker suggested to suspend lunch time care visits until further notice instead of cancelling the service, so that the Carer would not have to go through the process of finding a provider again.
- After a Carer contacted Social Servies about respite care, they quickly arranged the support needed.

Specific Project Themes

Diagnosis of dementia

Most dementia diagnoses were the result of contact with the GP after Carers noticed the person they care for becoming more forgetful, losing things, having trouble with directions and difficulties keeping track. Some contact with the GP was initiated after incidents at work. From the GPs, referrals were made to Chatterton House in King's Lynn, the Julian Hospital in Norwich and West Suffolk Hospital Memory Clinic. Some Carers mentioned visits from the Community Matron, Mental Health Nurse or Alzheimer's Nurse to complete an assessment or support with medication. One diagnosis was made during an admission to hospital although this process was gradual and not always clear.

Carers reported difficulties getting the person they care for to go to appointments about their memory. Some Carers described having to push for referrals to be made. Many Carers told us about a lack of support after a diagnosis had been made with little or no follow up being offered, resulting in Carers feeling alone. Some diagnoses were made over the period of the Covid pandemic, which Carers felt could have affected their experience.

Some Carers reported that the diagnosis was empathetic and respectful. One Carer said they were called to be given the diagnosis but the person they care for was sent a letter. Several Carers mentioned issues with medication and asked whether more can be done to assess the needs of the whole person, rather than only those needs covered by medical services.

Were you given any information and support and where was this from?

There were varying levels of information and support given following a diagnosis. Several Carers reported no support being provided from the GP as well as no follow-up. In some cases, signposting was provided including information on support groups, the frailty elderly team, support with finances and the Alzheimer's Society. The focus was primarily on supporting the person with dementia, with less consideration given to Carers.

Carers mentioned support was received from the Julian Hospital, Chatterton House and Alzheimer's Nurses but some Carers reported this stopped after or shortly after the diagnosis.

Support from Adult Social Services

The support received from Adult Social Services varied between each Carer from little/no support to arranging a care home placement.

Events leading to Carers receiving support from Social Services

Five Carers stated they initiated contact with Social Services themselves as the care needs for the person they support increased. Some Carers felt they were the ones who had to seek and push for support, with one Carer stating that '*it can be a complete minefield*', if you do not have prior knowledge of social care and how the system works.

Six Carers had contact with Social Services after the person they care for was admitted to hospital or had a fall. Additionally, two referrals were made to Social Services by healthcare practitioners due to Carer breakdown or the Carer's health conditions.

Two Carers of people who are self-funders were not aware of, or were advised that they could get support from, Social Services as they perceived they had too much money in savings to qualify for help.

Some Carers were already in touch with Social Services before the diagnosis of dementia was made due to other health conditions.

Care Act assessments and annual reviews:

Thirteen Carers were aware that an assessment had taken place or were in the process of arranging one. Two Carers were unsure whether a Care Act Assessment or Annual Review had taken place but have received support for Adult Social Services.

Experiences with the assessment were mixed with some leading to support being put into place. However, despite the outcome, some Carers told us support was not always forthcoming due to lack of availability which led to Carers feeling on their own.

Some people Carers support have not had a Care Act assessment and were not aware of what this entailed. This was particularly prevalent for Carers who arranged and paid for care privately.

People being supported to be involved and listened to in decisions about their care

Five Carers felt they were involved in decisions. Two Carers stated they were initially involved but this changed due to a hospital admission and lack of communication from Social Services. The Carers that felt involved tended to be the Carers who were supporting a self-funder and felt the responsibility to make the decisions fell on them. One Carer said they were involved and listened to and were able to have good conversations with services but that this could be due to their internal knowledge.

Over half of the Carers who took part in an interview said they did not feel listened to. Specific instances were mentioned about not feeling listened to in regard to finding domiciliary care staff who have the expertise to care for someone with dementia, about the care required and the needs of the person with dementia. A few Carers mentioned that the person they are caring for with dementia did not seem to be included in conversations.

Three Carers shared their experiences about the difficulties of staying involved when the person they care for was in hospital, with two Carers saying they had to 'battle' with Norfolk County Council. One Carer reported feeling a 'loss of control' when the person they care for was admitted into hospital.

A few Carers have reported that they have had to appeal or complain to get the right support. Some Carers mentioned initial involvement but no follow up unless Social Services was contacted directly.

Two Carers mentioned the Carers Identity Passport as supporting them to be included in conversations in health settings.

Feedback about domiciliary, residential or care home care funded by Norfolk County Council

Domiciliary Care Agencies

When people were happy with domiciliary care agencies, they would mention that staff are often kind. The quality of relationships with care staff were also important for people. Where there has been continuity of care from the same care staff, this has allowed relationships to be built up, and people who were happy also sometimes mentioned that agencies had managed to match staff well to the personality and needs of the person they were supporting. People wanted companionship from staff, and it was also mentioned that the early phase of the relationship can be important, with one person mentioning staff who were patient at the beginning, and built up trust before doing more around the home.

More broadly, people mentioned the importance of an agency being helpful and ready to take on tasks, including help with hygiene, in particular. Carers were particularly happy when the person they looked-after received the right support, and could be confident that they were being looked after well. They were also happy when they received support that allowed them to have some time to rest and recuperate, so that they can continue to manage in their caring role.

On the other hand, Carers also often mentioned aspects which they were less happy with, and would like to change.

Where people were not happy, a number of issues were raised including factors limiting people’s choices, poor listening practices, problems with inexperienced and poor quality care staff, and issues with the timing and length of visits.

A key factor limiting people’s choices was the limited supply of care agencies to choose from due to shortages in the sector in Norfolk, and one person reported an attitude from social services that they would just have to ‘get what you are given’. Another person said that they felt that social services did not have the time to help people to find suitable care agencies, and others spoke of the difficulty of finding suitable care without assistance.

Another Carer mentioned that they felt that they had to stick with the care agency they were with, despite not being satisfied with it, to keep consistency of care for the person they look after. Others mentioned the lack of flexibility of some agencies, for instance one agency refused to provide only one visit per day because it was not cost effective for them, and cancelled the person’s contract.

Some Carers told us that their wishes were not listened to by care agencies. The limited supply of care agencies contributed to people feeling worried about complaining, however, because they did not want to ‘rock the boat’ and disrupt the care that they were receiving, or potentially have to look for a new agency.

The short supply of care agencies is partly related to shortages of qualified care staff in the market in Norfolk. Carers spoke about how the agencies that they used were sometimes short staffed, and/or were staffed by people who were inexperienced. One person spoke to us of occasions when two care staff with no experience would come into their home. This left some Carers having to closely supervise care staff, meaning that the care did not reduce the burden on them as much as it should. Some staff were also found by Carers to be patronising and not empathetic, and some staff were unwilling to provide help with personal hygiene.

Carers felt that some staff were not qualified to support people with dementia. For example, one Carer told us that staff did not check the fridge to see if the meal had really been eaten, when a cared-for person said it had been.

There were also problems with visit timing and length. Sometimes visits came too close together to be fully useful – especially if support with mealtimes was being provided. Some people also spoke about visits being shorter than they were meant to be, with staff completing the allocated tasks and then leaving, rather than staying and providing company to the person they were supporting. They also sometimes arrived late and exhausted, because agencies did not pay them for travel time, making travel particularly stressful. These problems with visit timings made caring well for people with dementia difficult, as they often particularly need consistency, predictability and structure in their day.

Carers mentioned several improvements that they would like to see:

- Increased availability of care particularly in rural and border areas
- Person-centred care that is tailored to an individual's needs
- Flexible support and being able to make a choice. Not just having to ‘get what they are given’
- Consistency of care staff
- Improved training for new staff

Care homes

When people were happy with care homes, they often spoke about the good qualities the staff showed. Kind, well-meaning staff was a common theme, and staff showing kindness to Carers as well as the people they were supporting was also important. People also wanted staff who seemed to know what they were doing, and were able to look after people well.

People also wanted managers to be kind and open, and people were happy when managers were available to chat to Carers, made efforts to respond to all requests and kept them informed about their cared-for person’s condition. Carers liked to receive a warm welcome when they arrived in a care home, and to be free to drop in when they wanted to, and to stay as long as they wanted to.

Carers felt a great deal of relief when they could be confident that the person they cared for was being well looked after. When people found that their cared-for person was always cleaned, dressed and was in communal areas with other people, this helped to give people confidence in their care.

When people had done their own research and found homes with good reputations, good Care Quality Commission ratings and which were suitable for the person they cared for, they were more likely to be happy.

We found that there was a wide range of different experiences with residential care, some of which were very positive, and some significantly negative. People told us that they thought that good managers made a big difference to how good a care home was.

As with domiciliary care, people were concerned about the impact of staff shortages, and these had an impact on Carers’ trust that the right care was being provided. Some people also mentioned that there was sometimes a lack of person-centred care, and some staff did not read information provided by Carers about the person’s likes and dislikes.

Two people raised concerns about how active their cared-for person was, one saying that activities were generic and not based on individual interests. The other said that the person they cared for spent too much time in bed, as there were not enough staff to get them up.

People also mentioned their concerns about the supply of suitable care homes in the market. One person told us that there was a limited supply of care homes that would take on someone with dementia after a hospital stay, and others mentioned that the care homes people had been discharged to after a hospital stay were unsuitable, due to the location and the standard of care provided.

Some Carers were also concerned about the standard of the home that social services would allocate their cared-for person to, with a perception that if you could afford to fund your own care you would get a better home.

Carers' suggested improvements:

- Involvement and communication about plans, particularly when a person is being discharged from hospital
- Homes that meet needs in their local area
- Person-centred care based on individual needs and likes
- Engaging activities in care homes, based on individual preferences and not assuming what people like
- Staff need to treat people as people. This includes spending time to talk to them and encouraging people to talk about themselves and their interests, which staff then respond to
- Intergenerational work and activities
- Cultural understanding of staff
- Align approaches with up-to-date research

Respite care

Carers who had received respite care spoke of how it was extremely valuable for them, as it allowed them to take a break from caring. However, some people experienced problems with arranging respite. These problems were related to a lack of suitable provision and difficulty finding a placement, and two people were not provided with clear information about who would pay for their placement. One person mentioned problems with communication about the placement with their social worker, meaning respite care had to be arranged in a crisis.

Some people said that the care provided did not meet the needs of their cared-for person. In particular, two people spoke to us about the negative effects of respite for people, one because he was not kept active, and another because he slept in a recliner chair for the duration of his stay, which gave him swollen feet. Two other people talked about the limited mental stimulation in the home, which led to declines in their cognitive abilities while in respite care.

Carers' suggested improvements:

- Respite facility closer to Carer
- More help to arrange respite

Sitting services:

Carers using sitting services mentioned how useful it was for them to have a break, and to access local groups and to get out into the community. They also spoke of the kindness of the people providing the sitting service, and said that introductions to the person being cared for had gone well.

Some people spoke to us about a lack of flexibility in these services. For example, one Carer shared that they had to go out while the sitter was there, but they would have preferred to stay in and do bits around the house. Another Carer said that if the sitter is off sick, they hold the hours so that she can use them another time. However, if the Carer is ill and/or doesn't need the hours, they lose them and still must pay for them. One person said that they thought that their sitting service did not provide much stimulation, and another mentioned that some sitting services had closed due to staff shortages and lack of funding.

Carers' suggested improvements:

- Increased availability and flexibility of services

Daycare

People using daycare services mentioned that these were very valuable in giving Carers a break from their caring responsibilities, and that people using the service often enjoyed them.

On the other hand, people told us about waiting lists to access these services, and that there were a lack of available options in people's local area. It was also mentioned that although these services provide respite for Carers, it could be a lot of work to get people ready in the morning.

Support for Carers

Carers Matter Norfolk (CMN):

Most of the feedback received about CMN was positive, and people told us it had made a significant and positive difference to their lives. Carers either found out about the service through their own research, or had a referral made by a professional in social services, or a social prescriber.

People spoke of how valuable Carers Breaks were for them, and those who had received counselling sessions mostly found these very helpful, describing them as "wonderful" and "absolutely brilliant". People also received support to access food vouchers and peer support.

A positive point for most people using the service were the helpful CMN staff who gave them advice and carried out the Carer's Assessment with them. People especially appreciated receiving visits from CMN staff. However, changes in staff had impacted some people's experiences, with staff they were very happy with leaving, and being replaced by people they did not find as helpful. There was also some mixed feedback about signposting – some people found this very helpful, but others thought that there was too much information all at once, and found it overwhelming.

Several Carers commented on the length of support available from CMN. Since Dementia is a progressive disease, they did not understand why they were signed off from the service after a year. Some Carers also mentioned that they had experienced some communication difficulties with CMN.

Other support mentioned:

- Good friends and family
- Carers Voice, including newsletter
- Admiral nurses
- Caring Together Befriending Service

- Alzheimer's UK, (including Facebook page which was good to view other people's lived experiences)
- Dementia UK
- Carers Cuppa
- Red Cross support with equipment
- Alzheimer's nurse and workers
- Independence Matters
- Dementia Club
- Julian Clinic workshops
- Social Prescribers
- Duncans Club
- Tapping House Hospice
- Monument Project
- Age UK
- Alzheimer's Society

Carers experiences with support to plan with the future

A large majority of Carers we spoke to had not received support to plan for the future. Some Carers had been given information for future reference, but felt it was up to them to organise support. Two Carers mentioned knowing there are people they can call if they need support such as Norfolk County Council and the Dementia Helpline. Carers are worried about the future but do not often have time to think about this as they are dealing with challenges in the present.

An example was shared by a Carer about a time future planning was mentioned to them. Following the use of the Carer Identity Passport for identification, a surgeon mentioned about a yellow folder (the 'My Care Wishes folder') and resuscitation. This was the first real time that they had considered the future and this support hadn't been provided by any other organisations before.

Carers experiences with support to manage behaviours that may challenge others

Again, a large majority of Carers we spoke to had received little or no support to manage behaviours that may challenge others. Carers mentioned having to do their own research or learn from their own past experiences. Carers reported feeling out of their depth and concerned as to whether they are doing the right thing with little guidance. Requests for support had been made by some to their GPs but was not forthcoming. A few Carers mentioned receiving behavioural support and information including from an Admiral Nurse, speech therapist and Alzheimer's Facebook page.

Impact of dementia on relationships, connections to their local community, and Carers' time for themselves

The majority of Carers stated that they do not have time for themselves. They said that even when they are not with the person they care for, they are always doing something in the background, whether this be shopping, arranging appointments or picking up medication. Additionally, a few Carers reported that they are consistently contacted when they are away from the person they care for, including being called by the person they care for, relatives visiting or organisations such as Careline, meaning they can never switch off. Some Carers reported they are mentally and physically tired. Carers of people with dementia in a care home reported spending significant time visiting, in one case five or more times a week. Some Carers reported being worried to leave the person they were caring for as this creates an element of risk.

Five Carers specifically mentioned that it can be isolating and lonely. They used to go out with friends and family, but a lot of their time now is taken up with caring. Carers reported having *'a smaller life'* and feeling '*alone*'.

Some Carers felt like they had been able to maintain relationships and connections as well as time for themselves and their hobbies. This may be dependent on the level of support needed by the person they are caring for, the care being received and proximity to relatives.

A large number of Carers reported that there has been a strain or change in relationships since the person they care was diagnosed with dementia. Behaviours can cause difficulties with people coming to visit or being invited to visit. Carers stated that relationships with friends and family are important and they can be supportive but sometimes they do not understand the position the Carer is in, and some Carers mentioned that they do not feel they can contact them with issues. Some Carers mentioned they are worried about 'burdening' their family members and friends. This was particularly apparent for Carers with children.

Some Carers have multiple responsibilities to juggle, working Carers in particular. Carers stated that they feel they are being pulled in lots of different directions.

Carers also often reported a lack of services available in their local area, especially those that meet the needs of the person they are supporting. It can also be difficult for the person with dementia to want to engage with activities and groups in the community. Covid and the cost of living has affected access and availability of activities in the local community.

Recommendations from Carers

Services to support people with dementia:

- Support with care, particularly morning and night
- Support to leave the house
- Resources available in the local community
- Befriending services
- Reminiscence and life story work
- Help to stay in contact with family and friends
- Support with letter writing
- Volunteers to help with activities e.g. baking
- Support with physiotherapy for movement including giving Carers advice about different exercises
- Support with accessing blue badges and evidence required
- Support available in border areas

Support for Carers:

- More regular proactive contact from Social Services and/or GP
- Single point of contact for support from multiple agencies
- Regular check-ins from professionals, including support with making decisions and reassurance that they are doing the right thing. '*How do Carers know if they have asked the right questions or asked for the right support?'*
- A listening ear
- More breaks for Carers, and support to spend more time with family

- More financial support. Not all Carers are eligible to receive Carers Allowance. Concerns for self-funders about cost of care and funds depleting. Many Carers have had to pay for equipment out of their own finances including stair lift, continence products and medical support
- Support received at an earlier point, to close the gap between diagnosis and contact with services
- More timely responses to questions raised with social services
- Support needed to ensure availability and the continuation of peer support groups
- Flexibility of appointments particularly for Carers who are working so they can attend appointments.
- List of dementia and wheelchair friendly places in Norfolk and activities for people with dementia
- Go to guide for Carers
- More compassion and understanding from professionals about Carers and the other roles they have
- More role models in the media for people supporting a partner
- Help navigating and arranging support

Carers expressed their gratitude for the opportunity to share their experiences, have their voices heard and help towards improving support.

Support that was signposted to after the interview included:

- Carers Voice
- Carers Matter Norfolk
- Carers Cuppas
- Groups page on Carers Matter Norfolk Website
- Dementia Support Service
- Emergency in my place
- Norfolk County Council website- information about Care Act Assessments
- Carers UK
- Independent Age- paying for care information

Experiences of people over 65 of Adult Social Services -survey

This survey is aimed at people over 65 and those who care for them, who have accessed Adult Social Services in the past 18 months.

Who is Healthwatch Norfolk?

Healthwatch Norfolk is the independent voice for patients, service users and Carers 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 currently working with Norfolk County Council (NCC) to understand the experiences of people over 65, and their Carers/family members, of adult social services. Hearing directly from people who are using or have used services will allow NCC to gain a better understanding of people's experiences.

Using Adult Social Services could mean accessing any of the following:

- Day centres
- Support to live in a residential or nursing home
- Carers coming to your own home (domiciliary care)
- Direct payments or personal budgets to meet your care needs
- Help to make your home safe and comfortable to return to after hospital
- Carers helping you to become independent again after a stay in hospital (including Norfolk First Support)
- Welfare or money advice from Norfolk County Council
- Assistive technology to help you live independently
- Home adaptations for people with reduced mobility or risk of falling

- A service to help you to communicate with Norfolk County Council such as POhWER advocacy services, Age UK welfare advice, or Citizen's Advice

Not everyone sees themselves as a Carer and some people may not be sure whether or not they are a Carer. The Carers Trust defines a Carer as "*anyone who cares, unpaid for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support*".
The survey will take around 20 minutes to complete. Some questions are optional.

If you would prefer to do this survey with us over the phone, 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 to receive the survey in alternative formats, including Easy Read or large print.

How the survey results will be used

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

All responses will be anonymous. The survey results will be used to make recommendations to NCC on how people's experiences can be improved, as part of a project report. The report will also be publicly available on our website and may be used in other Healthwatch Norfolk communications.

Survey closing date: 29th May 2024

Please note that questions marked with an asterisk (*) require responses.

1. Please tick to confirm *

☐ I have read and understood the above statement

2. Please tick to confirm *

☐ I live in Norfolk. I am aged 65+ and have accessed social services in the past 18 months

OR

☐ I live in Norfolk, and am a Carer/family member of someone aged 65+ who has accessed social services in the past 18 months

Communicating with adult social services

3. Have you contacted adult social services using the main telephone line on 0344 800 8020 in the past 18 months?

- ➢ <u>If not, or you don't know, please skip to question 7.</u>

☐ Yes
☐ No
☐ Don't know

4. How easy was it to get through to the service you wanted to speak to?

☐ Easy
☐ Neither difficult nor easy
☐ Difficult
☐ Don't know

5. Did you feel the person you spoke to understood what you were trying to tell them?

☐ They understood me well
☐ They understood me adequately
☐ They did not understand me well
☐ Don't know

Please use the space below to explain the reasons for your response:

6. How long did you wait for someone to get back to you, after your initial contact with social services?

☐ 1-6 days
☐ 1-3 weeks
☐ 4 weeks or more
☐ Not relevant
☐ Don't know

If you waited a long time for a response, what were the consequences of this for you?

Having a needs assessment

7. Has a social worker or assistant practitioner spoken with you to assess your (or your family member's/the person you look after's) care needs in the past 18 months?

☐ Yes
☐ No
☐ Don't know

➢ <u>If you answered 'No', please skip to question 12.</u>

8. Why did you have your needs assessed? Tick all that apply for your most recent assessment.

☐ A new medical condition
☐ An existing medical condition deteriorated
☐ My family Carer could no longer cope
☐ Due to being discharged from hospital with help from social services
☐ It was a review of my care needs
☐ Don't know
☐ Other (please specify):

9. Were all the people you wanted to be involved in your assessment (such as a Carer, relatives or friends) included?

☐ Yes
☐ No
☐ Don't know

10. Were your care options presented to you in a way that you could understand easily?

☐ Yes, very easily
☐ It was OK
☐ No, it was difficult
☐ My care options were not presented to me
☐ Don't know

11. What would have improved your experience of your assessment?

Receiving Services

12. Which of the following services have you (or your family member/the person you look after) received in the past 18 months? Tick all that apply.

☐ Carers coming into my home (domiciliary care)
☐ Care home
☐ Assistive technology (electronic gadgets to help you live independently at home, such as sensors, pendants or GPS trackers)
☐ Sensory support (for people with either sight loss or hearing loss)
☐ Day centre
☐ Other (please specify):

How well did this service(s) listen to you?

Leaving hospital (hospital discharge)

Have you (or your family member/the person you look after) been admitted to one of Norfolk's acute hospitals or community hospitals in the past 18 months?

The acute hospitals are: the Norfolk and Norwich University Hospital, the James Paget University Hospital and the Queen Elizabeth Hospital.

The community hospitals are: Norwich Community Hospital, North Walsham Hospital, Ogden Court, Kelling Hospital, Dereham Hospital, Swaffham Hospital.

➢ If you haven't been admitted to hospital, please skip to question 21.

13. What was the reason for going to hospital?

☐ Fall
☐ Breathing problem
☐ High blood pressure
☐ Heart problem
☐ Cancer
☐ Digestive problem
☐ An illness or infection
☐ Arthritis
☐ Hip or knee replacement
☐ Stroke
☐ Urinary Tract Infection (UTI)
☐ Family carer no longer able to cope
☐ Other (please specify):

14. Could the admission to hospital have been avoided? If so, what support could have helped to avoid it?

☐ Falls prevention advice or equipment
☐ Support or respite for Carer
☐ Assistive technology such as sensors, cameras or lights
☐ Home adaptations to prevent falls or aid mobility
☐ Not relevant
☐ Other (please specify):

15. While you were in hospital did anyone ask:

	Yes	No	Not applicable	Don't remember
Where you wanted to be discharged to and with what help?	☐	☐	☐	☐
What your Carer's preferences were?	☐	☐	☐	☐

16. Were you given information in good time about what care you (or your family member/the person you look after) would get after you left hospital?

☐ Yes
☐ No
☐ Don't remember

17. Did you understand how decisions were made about your (or your family member's/the person you look after's) hospital discharge?

☐ Yes
☐ No
☐ Don't remember

18. Do you think you could have left hospital earlier if some extra support had been offered?

☐ Yes
☐ No
☐ Don't know

If yes, what would that support have been?

19. What care did you receive after you left hospital?

Definition of reablement: ***Reablement is a type of care that helps you relearn how to do daily activities, like cooking meals and washing.***

☐ Norfolk First Support (or reablement support from a different organisation)
☐ Residential care home
☐ Other (please specify):

20. Did this care (tick all that apply):

	Yes	No	Don't know
Meet your needs?	☐	☐	☐
Help you to be as independent as possible?	☐	☐	☐
Take account of your wishes?	☐	☐	☐
Look after you in a compassionate and caring way?	☐	☐	☐

What did this care do well (or badly)?

Services received after a dementia diagnosis

If you, or the person you look after, has had a dementia diagnosis in the past 36 months, please answer the following questions.

- ➢ **<u>If not, please skip to question 26.</u>**

21. When you (or your family member/the person you look after) received a diagnosis, did you get support to learn more about the condition?

☐ Yes

☐ No
☐ Don’t know

Who provided this support?

22. Have you (and your family member/the person you look after) received any support to plan for the future?

☐ Yes
☐ No
☐ Don’t know

If yes, what did this support involve?

23. What support would have helped you to plan for the future better? Tick all that apply.

Information or advice about:

☐ The costs of care and who would pay
☐ Options for receiving care at home, or in a residential or care home
☐ The progression of the condition
☐ Home adaptations
☐ Assistive technologies to help you cope with the condition
☐ None of the above
☐ Other (please specify):

24. If you (or your family member/the person you look after) have received care in your home, or care in a care home, was this well suited to meets the needs of someone with dementia?

☐ Yes, it was well suited

☐ It was OK
☐ No, it was not well suited
☐ Don’t know

Please use this space to tell us why you have chosen this answer:

25. What would have improved this care? Tick all that apply.

☐ Better premises
☐ More staff
☐ More support with behavioural issues
☐ More reminiscence activities
☐ More activities and stimulation
☐ None of the above
☐ Other (please specify):

Carer Health and Wellbeing

- **<u>If you are not a Carer, please skip to question 31.</u>**

26. Carer's Assessments

If you are a Carer, you are entitled to a Carer's Assessment.

Definition of a Carers Assessment: "*It’s a chance to let your local council or trust know how your caring responsibilities affect you physically and emotionally. They will use the assessment to find out what support you need, whether you’re willing or able to carry on caring, what you want to achieve in your daily life and whether you qualify for help.*"- CarersUK

Which of these statements applies to you?

☐ I **have** had a Carer's Assessment **within the last 12 months**
☐ I **have** had a Carer's Assessment but it **was more than 12 months ago**
☐ I am on a waiting list for a Carers Assessment
☐ I have **been offered** a Carer's Assessment but **did not want one**
☐ I have **never been offered** a Carer's Assessment, but **would like one**
☐ I have **never been offered** a Carer's Assessment, but **do not want one**
☐ I am not aware of Carer's Assessments, but would like one
☐ Not sure

27. What support have you received as a Carer? Tick all that apply.

☐ Respite care
☐ Check-ins with a support worker
☐ Information on support groups and/or dementia cafés
☐ Counselling
☐ I have not received support
☐ I have not sought support

28. How much has this support helped you?

☐ It has been very helpful
☐ It has been quite helpful
☐ It has been OK
☐ It has not been very helpful
☐ It has not been helpful at all

29. To what extent have you and the person you care for been able to maintain relationships, and connections with your local community?

We have:

☐ Fully maintained relationships and participate in our local community
☐ Mostly maintained relationships and participate in our local community
☐ Maintained some relationships and participate in our local community

☐ Lost many of our relationships and struggle to participate in our local community
☐ Lost almost all of our relationships and do not participate in our local community

30. Have you received enough support to help you to manage behaviours that may challenge others?

☐ Yes
☐ No
☐ Not relevant

If not, what support would be helpful to you?

Demographics

In this next section we will be asking you some questions about yourself and your life. If you are completing this survey on behalf of someone you care for, please answer these questions for your cared-for person. **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.

31. Do you (or the person you care for) have any of the following conditions? Please select all that apply

☐ Dementia
☐ Mobility problems
☐ Mental health condition

☐ Brain injury
☐ Physical disability
☐ Heart condition
☐ Prefer not to say
☐ Other (please specify):

32. 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:

33. How old are you?

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

35. What is your gender?

☐ Man
☐ Woman
☐ Non-binary
☐ Genderfluid
☐ Questioning
☐ Prefer not to say
☐ Prefer to self-describe:

36. Where did you hear about this survey?

☐ GP website
☐ Healthwatch Norfolk Event
☐ Healthwatch Norfolk Newsletter
☐ Healthwatch Norfolk Website
☐ News (website / radio / local newspaper)

☐ Search Engine (e.g. Google)
☐ Social Media (e.g. Facebook / Instagram / Twitter)
☐ Through a friend or co-worker
☐ YouTube
☐ Other (please specify):

Want to keep in touch?

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

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 like to be contacted about future Healthwatch Norfolk social care related projects, please leave your email here:

If you would like to enter the prize draw to receive a £10 shopping voucher, but would not like to be contacted for any other purpose, please leave your email or telephone number here:

Thank you for completing this survey

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